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The Electronic Patient Record

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Oral and written evidence

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The Health Committee

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Footnotes

In the footnotes of this Report, references to oral evidence are indicated by 'Q' followed by the question number, and these can be found in HC 422–III. Written evidence is cited by reference in the form 'Ev' followed by the page number; Ev x for evidence published in HC 422–II on 25 April 2007, and Ev x (HC 422–III) for evidence published in HC 422–III on 13 September 2007.

Witnesses

Thursday 26 April 2007 *Page*

Thursday 10 May 2007

Thursday 7 June 2007

Thursday 14 June 2007

List of written evidence (HC 422–III)

List of written evidence (HC 422–II)

List of unprinted written evidence

Additional papers have been received from the following and have been reported to the House but to save printing costs they have not been printed and copies have been placed in the House of Commons Library where they may be inspected by Members. Other copies are in the Record Office, House of Lords and are available to the public for inspection. Requests for inspection should be addressed to the Record Office, House of Lords, London SW1. (Tel 020 7219 3074). Hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

Breakthrough Breast Cancer (EPR 32A)

Computer Sciences Corporation (CSC) (EPR 46A)

Dr Thornton (EPR 50A)

Dr Thornton (EPR 50B)

Robert Erskine (EPR 68)

Rachel Gould (EPR 72)

Sufferers of Iatrogenic Neglect (EPR 77)

Action on Rights for Children (EPR 80)

Patient Information Advisory Group (EPR 81)

Oral evidence

Taken before the Health Committee

on Thursday 26 April 2007

Members present:

Mr Kevin Barron, in the Chair

Charlotte Atkins	Mr Stewart Jackson
Jim Dowd	Dr Doug Naysmith
Sandra Gidley	Dr Richard Taylor

Witnesses: **Mr Richard Granger,** Director General of IT for the NHS and **Mr Harry Cayton,** National Director for Patients and the Public, Department of Health; and **Dr Gillian Braunold,** National Clinical Lead for GPs, Connecting for Health, gave evidence.

Q1 Chairman: Good morning. Could I first apologise for the few minutes' lateness of the Committee. It looks a bit thin around this side of the table but you are probably aware we have a Mental Health Bill in standing committee at the moment and members of this Committee have been heavily involved in it, in different forms, for the last eight years now. We have got some members up there who are currently doing standing committee work, but I suspect we will be joined at some stage this morning by one or two members. For the sake of the record, would you introduce yourselves and the positions you hold. Could I start with you, Dr Braunold?
Dr Braunold: I am Gillian Braunold. I am a GP in Kilburn, and I hold the position of GP National Clinical Lead.
Mr Granger: I am Richard Granger. I run national IT systems for the NHS in England.
Mr Cayton: I am Harry Cayton, I was the Chair of the Care Record Development Board and I am Chair of the Ministerial Taskforce on the Summary Care Record.

Q2 Chairman: Welcome back again. I think I said last time you were sat there you were better attended than some members of the Committee and it is absolutely the case this morning! I understand you want to make a short statement to us before we start this morning's evidence session.
Mr Granger: I want to cover three things: firstly, the general progress we are making; secondly, to give you a snapshot of the typical transaction volumes that benefit patients every day in the NHS in England today; and, thirdly, I want to finish with a comment on the general environment around the introduction of new technology into health care. When the Government announced its investment programme in IT in the NHS in England in 2002 there was already a considerable quantity of computers in use in the NHS, and almost all of them were characterised by being nothing more than glorified electronic filing cabinets. If you wanted to move any information between buildings you typically had to move it using word of mouth or paper; there was very, very little movement of information between buildings. Of course patients generally do not just get cared for in one place. There are a number of people who would say that there have been enormous successes in the 1990s in investment in IT in the NHS. I would say, having come from a background of having worked in social security computerisation, the progress that had been made was lamentable—and yet at very significant cost of about a billion pounds a year at 2002. The revisionists are busy at work now trying to make out the progress that had been achieved before 2002 was extremely good and has somehow been retarded by the introduction of national systems; but the evidence does not substantiate that viewpoint. Where you have 33,000 or so GPs in nearly 9,000 locations, and you have none of them able to move patient records electronically between sites and yet over three million patients a year change the GP they are registered with, I do not see how that mess could be described as a success; and yet some eminent GP IT advisers have described it as a success. One of the other things I found extremely quaint when I started delivering this programme was most of the people working in the delivery of clinical systems in the NHS have what would generally be considered to be serious conflicts of interest. They are the owners of software companies, have a financial interest in them, or advise them whilst also undertaking clinical practice. It has the benefit of them being closely associated with the solutions they deliver, and the disbenefits of them having certain conflicts they have to manage. We introduced a process as part of the procurement which was Civil Service standard stuff that we required people to declare these conflicts of interest, and we would not allow them to work on procurement activities if they had involvement with any of the potential bidders. That caused some distress for some of the so-called experts in this domain. It is what has been described by many as "a bit of an alligators' playground". In the last four years we have doubled the availability of network connectivity to the NHS. We now have 19,000 places connected up, so we have one of the biggest virtual private networks on the planet and people take that for granted. In some locations it does not work as quickly as the end users would like—usually because their equipment is badly configured when we go to

investigate. We are now computerising, to deliver prescriptions safely, 200 GP practices a week with the relevant software. We typically move 120,000 prescriptions electronically now on any given day. About every ten seconds a patient gets a booking completed electronically, not at the target we would like it to be at but, nevertheless, a significant volume. I think you heard in your audiology hearing how Choose and Book is being used regularly now to enable accelerated patient flows, and is also introducing a greater degree of transparency about where the bottlenecks are in the system. We have about 50,000 people go onto our national demographic database every day and access two million patient records. That is something that did not exist three years ago; something that most major organisations and most government departments in the UK have had since the early 1990s—an online customer index so that you can send letters to the right place. In fact we see a reduction, as a consequence of that, from about three-quarters of a million patients having a letter sent to the wrong place down to probably around a couple of hundred thousand. The hospitals that are hooked up to this system say the number of letters returned, having been sent to the wrong place, has come down massively, which is a significant concern around confidentiality with a paper-based set of letters going out to patients, and inefficiency where an appointment gets sent out to them, for example, and they do not even get notification of it. We have got an e-mail service that has: a quarter of a million users; sends over a million messages a day; is encrypted; and over a third of those contain patient identifiable information. We have a system which has very efficiently paid GPs money under a "pay for quality mechanism" under their new contact. There were a few problems for a couple of days at the beginning of the new financial year as they stampeded into submitting their returns to get their money quickly. However, that system (apart from a couple of days) has worked very well since it was introduced. We have a major secondary uses database working as well. In closing I just want to reflect on how difficult it is to introduce new technology into health, because it is personal for all of us; we care about it; and a lot of people have anxieties. In the North-West we are about to introduce the Summary Care Record which will provide information about patients outside of the GP setting in which the best information is currently held. Around 0.2% of the public, where we have sent information leaflets to their homes addressed to them in person, have concerns about this. You might not think that is the case if you spend a lot of time in this part of London, but that is the kind of data that comes from other areas of the UK, and the North-West where we are bringing this system in. However, there are a lot of people very concerned. In 1834 *The Times* said, regarding a significant piece of medical technology, that, "it will never come into general use notwithstanding its value. It is extremely doubtful because its beneficial application requires much time and gives a good bit of trouble to both the patient and the practitioner; and because its hue and character are foreign and opposed to all our habits and associations. It is just not going to get used". That was *The Times* writing about an invention from 1816 which I do not think we generally consider to be adverse to medical practice now. They were writing about the stethoscope. I think the adoption of IT systems that move information between care settings and serve patients as they move around the NHS is in a similar position, of a great deal of anxiety because of the introduction of the new technology. People will look back on this in a couple of hundred years' time and wonder what all the fuss was about.

Q3 Chairman: Thank you for that. Many of the issues that you have highlighted, Mr Granger, we will obviously be pursuing in the course of this investigation, this being the first evidence session of the investigation. Could I welcome you and your colleagues as well. Going back 12 months or more now, most of the debate in the media (without the detailed things you have pointed out there) was people thought what was going to happen was that their patient record (and we assume by that, and I assume by that, it was one patient record) was going to go on the national spine and be accessible for people who wanted to know about my medical history. Actually we have got both a separate national and local electronic patient record now in front of us. Does this represent a failed compromise between the two different approaches? After all the talk about having one national record that was going to be all-singing and all-dancing for us, why have we ended up with two? Why is that?

Mr Granger: That is not a change of direction; that is the details of plans which were documented in Spring 2002 in a document published by the NHS Information Authority, which I am sure one of your advisers is familiar with, which was called the *NCRS, National Care Record Service*. That document set out very clearly that there needed to be more widely accessible summary information and detailed local information; and the reasons for that relate to the ability of computer equipment to move large quantities of information around, and concerns about the need or absence of need for detailed information to be available outside of an individual care setting. We are trying to strike a balance between having nothing available everywhere, and everything available everywhere. Over the past three years my colleagues have undertaken a very extensive consultation exercise with clinicians and patients to strike what we think is the right balance there and to introduce that through a staged early adoption process. The delays we have had in doing that are a mixture of software complexity and an extended consultation period about how to do that.

Q4 Chairman: Presumably the bulk of mine will be on the Detailed Care Record, and that will be what my GP and anybody in the South Yorkshire locality where I live most of the time will have. What added value will the national Summary Care Record add?

Mr Granger: I think it would have specific value to you as you shuttle up and down the country between South Yorkshire and London. For example, your key allergies and current medication will be available if you need treating down south during the week or, conversely, when you are up in Yorkshire at the weekend.

Q5 Chairman: What would be the difference then?
Mr Granger: At the moment that information is not available.

Q6 Chairman: It is not available down here, yes, I accept that. What will be the difference in the record? That record can follow me from South Yorkshire to London and back again; one record can follow from South Yorkshire to London; but I am trying to tease out of you, what is the added value of having a national Summary Care Record in addition to the Detailed Care Record which will be about me and my potential needs?
Mr Granger: Quite a lot of the record about you will not be coded in a manner that would be safe for other people to use. It will be meaningful to the people who collected it, and it may be voluminous. It may not be particularly relevant to the care that you need on a spontaneous basis when you are away from home.
Dr Braunold: I think it may help to try and differentiate between the Summary Care Record and the Detailed Care Record, because they have different business functions and are intended to serve different purposes. The Summary Care Record is intended to be a first cut of information to help clinicians who have no access to any other records in the first instance who are unfamiliar with the patient, to help them to get started so they are not working in an absence of information. What we know is the first things that will go up will be the medications of the patients, the allergies and then it will be joined by significant medical history, but in a summarised way. We have left the content of the Summary Care Record of what will be uploaded in the first instance from the general practitioner to be customisable at a local level. The reason we have done that is because there is a different timescale in which the Detailed Care Record is being delivered around the country; and it is not coming in at the same time. There is the potential for the Summary Care Record to actually contain information that will serve local business requirements while they are waiting for the Detailed Care Record. If I take the example of a diabetic care pathway, one of our early adopter PCTs in the country is planning to use the Summary Care Record to help the people who are looking after patients with diabetes in the community, as well as in hospital and general practice; and they want to ensure that the content of the Summary Care Record will help to manage that care, and will have in it the recent results and the recent visits to the various members of the team. That will be enabled if that data is sent up from the general practitioner record. What is very important is that people in the locality where it is being used understand the use to which it is being put and the data set that is going in. My personal belief is that the amount of information in the Summary Care Record will start growing bigger and then go smaller again as the Detailed Care Records become the actual way that in the locality people start to share information; but, because this is a system in evolution, we have to start somewhere. We have started with the Summary Care Record in areas where there is not any other data-sharing quite often because those are the Primary Care Trusts that have said, "Yes, please, we want to be part of the early adopters process for the Summary Care Record". They are very keen and eager to do some data-sharing in their areas. It enables us to test very slowly some of the concerns people have had around confidentiality and access controls *et cetera*, which I am sure we will be discussing, and test them slowly and incrementally, as well as what information was most helpful.

Q7 Chairman: It has been put to us that the exact content of Summary Care Records is not yet known. Is this an evolving situation?
Dr Braunold: There are some things that are absolute. I can very firmly take people through what we are doing with the Summary Care Record in its first iteration. The first thing that happens is a leaflet goes out to the population in the area; and then eight weeks later there is initiation of the repeat prescriptions and the acute prescriptions which are put up as well as the allergies and adverse reactions. That is followed by significant medical history, and we are starting with the core data set the GP has put into their Summary, and they are discussing that with their patients and asking them if they are comfortable with that data set going up in addition to the drugs and allergies. That is in discussion with the patient about what else should join the drugs and allergies. We have not been definitive about what should go in that part, as I said before, to feed the pathways; but also because there has not been guidance previously as to what is in an ideal Summary. Harry will be able to talk about the recommendations from the Ministerial Taskforce about advice as to what should be in an ideal Summary.
Mr Cayton: Perhaps I could say a bit about this, and perhaps I could go back, first, and just think about some of the benefits as I see them from a patient perspective. You are right in a way to question this concept of people travelling around the country. Of course, people do travel around the country a great deal more than they did, but that is not really, I think, the most important reason why this is important. I spent a day recently shadowing an emergency care practitioner with the London Ambulance Service and we spent most of our time visiting frail, older people whose carers or relatives had rung up with that most common of conditions of frail, elderly people which is "had a funny turn". "Had a funny turn" is not a very helpful diagnosis for a paramedic or an emergency care practitioner. Seeing what they have to do in practice, the complications of identifying which medicines a person is on, especially if that person is confused or not very well at all; trying to identify what conditions

they have; the huge benefit to them of having access just to this very small data set initially of medications, allergies and adverse reactions; plus, of course, the administrative benefit of having a computerised system that they can use instead of very large amounts of filling-in of paper forms, with all the introduction of errors that often brings; I think there are some real benefits. One of the myths now is that we still have a profoundly long-term personal relationship with an individual GP. Many of us do up to a point, but GP practices no longer provide services in the evening and at weekends; so everyone who uses a GP service is inevitably using GPs who do not know them very well if they are inconveniently ill out of the hours in which GP offices are open. It is not just the situation around people who are travelling, or people who are unconscious in A&E; it is a situation for a vast swathe of frail, older people, and for every single one of us who might happen to be ill at an evening or weekend. In the Taskforce, to go back to the issue of what is initially in the Summary, we had a very extensive discussion. We had on the Taskforce representatives of the BMA, RCN, the College of Emergency Medicine, the Terrence Higgins Trust, nursing and so on; so we had a wide range of interests. We felt that the most appropriate way to go forward was cautiously and sensibly. We recognise that there are concerns; we recognise that there are doubts; and there seems to be quite a clear consensus, certainly around clinical people, that this small data set that Dr Braunold has described is a significantly useful data set in clinical terms and does not raise as many questions as might be raised by more sensitive information such as diagnoses or medical history. This is a step forward as we build a consensus around what works and what does not work.

Q8 Chairman: That could be interpreted as being a compromise because the ideal is a national patient record, and what we have got now is that there are going to be two national patient records. It sounds to me as if this is as far as you can get. Was this a political compromise in terms of what you wanted in the first place and what we have at this stage?
Mr Cayton: I do not know that you can use the word "political".

Q9 Chairman: It is a compromise then?
Mr Cayton: You might say it is a "professional agreement" around what is acceptable to conflicting interests within the system. Interestingly, as the patient or independent person on this, many of the conflicts are between clinicians; they are not between clinicians and patients on these issues; they are actually between different groups of clinicians who have different conceptions of their role within the Health Service; different conceptions of the balance of power within the Health Service; and who are trying to protect the interests of certain clinical groups, sometimes I have to say, under the disguise of protecting the interests of patients.

Chairman: I have personal experience of the same group of medical people in my constituency who have different attitudes towards some of these matters.

Q10 Dr Taylor: I want to move on to the Detailed Care Record. I can see how feasible the Summary Care Record is; I just cannot see how feasible the Detailed Care Record is. We gather it is going to be made up of different records from different hospital departments, from the GPs. The only information we have got in the Department of Health's submission about Detailed Care Records is under paragraph 29 where it says: "The Detailed Care Record component of the NHS CRS will support the care process and will typically contain: the name; address; date of birth; NHS number; past and current health conditions; allergies; assessment *et cetera*; care plans *et cetera*; treatments, including operations and medication; care reviews; and discharge information". I am very, very concerned about the amount of information that is in hospital notes, and please do not think I am denigrating GPs, because obviously they have got the shorthand type notes worked out to a high degree, and it is going to be relatively easy to computerise GP notes. It is going to be extremely difficult to computerise hospital notes, which are going to be needed in the Detailed Care Records. I would like some ideas, some guidance on how you are going to approach this and make this even possible. I have got lots of specific points to pick up.
Mr Granger: If I could start on this and if Gillian could follow. I think there are two problems. The first is that the computer systems that have existed before this programme have typically only served doctors in one care setting. It has either been a hospital system or a GP system. The market was very firmly orientated in that manner. We have the challenge of getting suppliers of GP systems, and give you for example EMIS and TPP as two suppliers based in Leeds, both of whom are pushing upwards into community and ambulatory care settings with increasingly rich products. At the same time as you see the supplier for the South and London in the acute sector, Cerner, who run the systems that support a third of the hospitals in the US, you see them pushing downwards into what they would term "physician offices", into GP practices. That was a problem that existed before we started this programme, and it is still work in progress. The second problem is that, whilst GPs use Read codes and localised variations of them (and the variations are one of the greatest problems to information liquidity between practices), in secondary care a lot of the information is only coded up after the actual interaction between the clinician and patient. Our challenge is to introduce systems where people are coding information at the point of care; and some of the codification of those systems will be better supported by something we have been working on for some time, which is a proper international standards body called SNOMED CT, which is a much more detailed structured nomenclature to support secondary care, because

obviously Read codes are inadequate in that setting. We have had to take the lead in launching an international body to do that and wresting that from the College of American Pathologists into an international body, and that will be announced later today. It is going to be a long and difficult process to get the complexities of secondary care to code information in a way that it can be used outside of the location in which it was originally created. We are going through some of those difficulties at the moment in the south of England with the implementation of the Cerner system, which is requiring much more data to be collected at the point of care, rather than it being coded up subsequently; which is introducing problems of efficiency in the way the NHS is currently organised in terms of rapid clerking of patients, followed by retrospective tidying up of records and production of billing information and so on. It is a challenge at the moment but we are working through that.

Dr Braunold: I totally understand the question, and I suppose it is important to have a goal. I will try and describe the picture very quickly and then look at the steps we need to go through to get there. As a GP I get something like 125 letters a week from my colleagues in secondary care about my patients and those are structured usually most about the history of that patient—that has always been there; and occasionally there may be some recent results and the medication that has been used; and then there may occasionally be a sentence asking me to do something. I have to read that letter very carefully in case there is an action and I need to file it in my records. In order for me to do that, that has come from a hospital usually dictated by a consultant such as yourself, and it is then typed up by the secretary onto a computer; it is then printed out; and it is then sent by snail mail to me; and I then have somebody who receives it, scans it, then puts it into my computer and somebody codes it back into the computer and checks there are no results or anything I need to do; and then, finally, I check for any actions. For me it is not only a saving of all the scanning and the obvious things that an electronic message could do, but I want to save some of the coding issues so that instead of me receiving stuff for information, which we should share in a Detailed Care Record, that we would change the way we work; that we would only need to send each other actions, instead of sending each other information that we share on a Detailed Care Record. That for me is the Holy Grail of what we are about. It is about really changing the effectiveness and the efficiency of how we work. To get there is not going to be quick. It has taken general practitioners a decade or more to learn how to code carefully and accurately. We have worked through a data quality exercise that we are doing at the moment, on actually saying only GPs who pass the data quality accreditation can submit to the spine, because we want data that is fit for sharing. There is an enormous amount of work to do with secondary care. I understand your concerns. One of the things which my colleagues as the National Clinical Leads for hospital doctors are very keen to do is to really look at incremental ways of delivery of product. This is not a shiny spaceship going to land on secondary care where suddenly everybody has got to do this. I went to visit the Homerton Hospital where Simon Eccles one of my colleagues is based and I said, "I've heard the Homerton is great and it's running this great system". I came from general practice and I am used to flying with my machine and, I have to say, from a general practitioner's perspective I was very disappointed. The reason I was disappointed is because I am used to a very functionally rich system. What gets secondary care colleagues excited is a particular product delivery of particular issues. They have got Order Comms (Order Communications). Order Comms means if they send off 15 blood results they can see at a glance if 12 of them have come back, click on it and see them. They have got bar coding so they know where the results are on the system and they can track them, and that is great. It is the equivalent for me of where we were when we got repeat prescribing. We knew what to do with prescriptions and waves of GPs started to use computers because there was a business benefit to them. I see the secondary care delivery of products as Cerner and Lorenzo and all the others going through their various iterations delivering more and more functionality, year by year. People start saying, "What's coming next? That was quite good". The challenge for us really is to make sure that we do not make that challenge too painful; because you cannot ever get gain without pain. You cannot take on a new laptop without having to learn something. It is always painful gaining new functionality. We have to make sure that we do not challenge the NHS too greatly in the delivery of these extra functionalities. I hope that explains what the Detailed Care Record is for, because I really think it is worth having and it is a challenge worth taking up; but it is not going to be speedy.

Q11 Dr Taylor: I am not saying it is not worth having, I am just wondering if it is a possible dream in the long term. I can quite see how it is easy to put on X-rays; it is easy to put on path results; it is easy to put codes and prescriptions. There is an awful lot of importance in narrative text in hospital notes. How are you going to cope with that? I am thinking particularly that the complaints we get as MPs largely are associated with lack of communication between staff and patients. The basic defence you have got as a doctor is that you have recorded what you have said to the patient or the family. How is that sort of narrative text going to be in the Detailed Care Record; or are we still going to have a paper record in the background? The idea is to get rid of paper altogether.

Mr Granger: One of the feedbacks we had from the new system we put in in Winchester was that the nurses were delighted with the noting functionality. We are looking at trying to increase the quantity of information which is codified so it can be used safely in multiple locations, even within an individual institution; and we are providing a facility which allows people to put the notes in free text format onto a computer system, so that they carry forward

as well. I recognise a lot of people like to use free text because it can be easier for them than codifying things but it has a systemic inefficiency for the NHS unless they are the only person caring for that patient.

Q12 Dr Taylor: But you cannot codify a unique conversation between a doctor and a relative?
Mr Granger: No, but one of the things we generally do not codify, for example, is causation. We will codify that somebody has broken various bones but we will not codify the fact that is because they fell over; so we discharge them from hospital and they trip on the carpet and come back. What we need to get to is the root cause of lots of people falling over as they get older and their housing conditions. You start to collect coded information about a fall which does exist in SNOMED; you start to get some very useful information about the root cause of the admission; whereas just typing that in free text, "Had conversation with patient; she told me she fell over again", is not very helpful.

Q13 Dr Taylor: You are not taking my point. What I am really bothered about is the conversation between staff and a family, explaining what is going on with the patient.
Dr Braunold: I think that is absolutely right. For me that still has to be recorded. There is no reason why it cannot be recorded on the computer in free text format.

Q14 Dr Taylor: How is that actually done? The doctor writes down in the notes in longhand?
Dr Braunold: That will be subject to the local business processes in that Trust. It takes a while for people to move forward. When we went, for instance, to the States (because I went to have a look at how it was working there) quite often the consultants were dictating, and other people were entering the data; and they may have written in long form and somebody would then take it and put in the computer; whereas in other places people are putting it directly into the computer. What some of the software is able to do, however, is as you type in it is able to suggest codes for part of the text you are typing in so that you are not losing the opportunity to have the coding happen simultaneously. It will offer you a code for part of that. Some of the pain we have gone through in general practice is that, frankly, if I look at some of my colleagues' records the most frequently used code in general practices is "had a chat to patient", and then everything is underneath. The move to a richer coding set came with the input of the quality and outcome framework, as people started to realise if they did not code peak flow measurement properly as a code, rather than somewhere in that text as they had done previously, they were not going to get acknowledged for the work they were doing in looking after people with asthma properly. It is around getting people to understand payment by results and your actual peer audit are things that will encourage people to code properly; but that should not take away the text that we have to still write.

Q15 Dr Taylor: Has there been any attempt to get agreement from hospital doctors on what goes in the Detailed Care Record?
Mr Granger: There has been a process that has been going on since the early 1990s around that. I am sure you are more familiar with that than I am in fact. The specifications we have produced software against have their most recent origin in work that was done between 1998 and 2002—electronic record pilots; and in communities around England that were in the process of buying local systems which were generally unaffordable when they got through their procurement process in the South-West, the West Midlands, for example, the Shires procurement and Blackbird procurement. Those were specifications that had been produced by local clinicians, lots of hospital doctor input; and that is then iterated and refined continuously around the country as we take early versions of systems and refine them. It is an uncomfortable process because the requirement changes with time, as people become familiar with systems; so to start with people may want lots of free text input and they may want to do that via a Dictaphone or manuscript, then they want to move to typing some of it. One of the challenges that exists in the hospital sector is that it is only now, in fact a couple of months ago, that the first computer that might actually be really useful for a doctor on a ward round was launched. It is a device which has been developed between the NHS and Intel. Before that you had, at best, a laptop, which is a very nice repository for clinically-acquired infections; or you had a computer on wheels, known as a "cow" generally, dragged around a ward with batteries or wires hanging out the back of it—completely useless for somebody moving through a hospital on a ward round. The hardware is only now catching up with the way that hospital doctors work. We have had the same challenge with rolling out PACS (Picture Archiving and Communications Systems). It is very easy to put a light box in lots of places; they are not very expensive; you move to putting in computers and you need very high resolution screens that are £10,000-£15,000; they need a power supply; they are heavy; they need hanging on walls in theatres; people who might have had screens on three sides with their light boxes and now you have got a problem putting the IT in with the same information availability.

Q16 Dr Taylor: So when is this marvellous equipment going to be available? Is it something you speak into and it automatically gets it on?
Mr Granger: We have that running already. Voice recognition is being used.

Q17 Dr Taylor: Is it now reliable?
Mr Granger: It is getting reliable. It is being used in several hospitals for reporting in picture archiving. These are emerging technologies. They have been around for a long time but they have generally been designed to work in office settings. Most computers that work in hospitals at the moment are office equipment; they are not hospital equipment. Their portability; their cleanability; the ability to make

them hygienic; has been very poor. We have been developing the specifications for washable keyboards, wipeable computers that do not have lots of ports that are uncleanable and so on. The first batch of that equipment was trialled in Salford over the past few months and will come onto the market over the next few months.

Q18 Dr Taylor: Will that allow, for example, the detail of the houseman's history, the detail of the houseman's examination to be recorded on the system?
Mr Granger: Yes. Those tablets that are the size of a notebook, they will do handwriting recognition, voice recording or allow typing either by touching or tapping; and they will allow images to be displayed with a reasonable degree of resolution as well.

Q19 Dr Taylor: Is this going to delay the system further?
Mr Granger: No, but this is something we have to do. From 2002 in the strategy to introduce these systems we found a number of barriers. One barrier was there was not nationally available broadband. We have had Telco (Telecommunications) companies digging roads up and putting cable down in the South-West, for example. Another barrier is the computer equipment that has traditionally been used in clinical settings, certainly in acute settings, is not optimal, and we have had to work with industry to develop that. This is the NHS doing things in a world-leading setting and it has been difficult and it is time-consuming.

Q20 Dr Taylor: Is the main reason for getting the Summary Care Record out first really because it is much easier and practical?
Mr Granger: I think developing a couple of thousand work year software products to a schedule we stood up 18 months ago, that we hit the dates on, has not been easy. I think it delivers significant value out of our investment in a security framework, a central demographic database, a network, and now 102 different end-user systems that are compatible with that central infrastructure. It was always part of the plan. The sequencing of this programme that was stood up in 2002 and what we have now is different. We did not have picture archiving in 2002 at all and we will complete its roll-out during the current financial year.

Q21 Dr Taylor: Do you think you really can answer a GP who has written to us saying the Detailed Care Record can never provide the level of detailed data sharing which would be necessary for shared care?
Dr Braunold: I find that one difficult, because shared care we do at the moment as best we can; so I do not really know what standard that GP is talking about. Improved information will improve our care. I know how often I would like to have information, or it delays optimum treatment of a patient because I am waiting for a letter to come or information to come and I have to bring the patient back. Availability of information at the touch of a button will help improve care for all of those GPs as well as my hospital colleagues, so I find that one difficult.

Q22 Dr Taylor: I suspect he is worried about loss of the paper system which, if you have got time to use it, does give you everything you need.
Dr Braunold: I was talking to what I would call a "Luddite GP" the other day who said he mourns the loss of discharge letters—because they are getting electronic discharge letters, that I would give my eye or teeth for, in his area of Gloucestershire—because he is used to highlighting on it and getting people to code it; and now because he is getting it electronically quicker than waiting three weeks for a letter, he is getting it in two or three minutes, he has actually lost the business process. That is the challenge for us about learning to work differently when we have got better conditions.

Q23 Dr Taylor: Another concern raised to us is from groups who represent patients with long-term complicated conditions, because they are longing for the Detailed Care Record to be out quickly. What can we say to them?
Dr Braunold: That is exactly what we are doing in one of my areas about the Summary Care Records. Because it is going to take a while, one of the real, real benefits that I have not discussed about the Summary Care Record is the patient's record that they see from Heathspace; and that is something that can be put in (all of the information that will help with those pathways) straight away to support those patients and help them wherever they go, because we can put that information in. The patient will have access through the internet, through their own access controls, and they can share it where they wish under their own control.

Q24 Dr Taylor: Why should we not be slowly developing the Summary Care Record to become a Detailed Care Record?
Dr Braunold: Because we need to have quality information that is far more than a general practitioner-originated record. We need to start having coded information from wider places than GPs. GPs only look after patients 36 hours a week. We need to join people up. Frankly, I know the frustration of my colleagues in nursing who cannot access my records.

Q25 Dr Taylor: You are implying there is going to be no hospital information on the Summary Care Record?
Dr Braunold: There will be, but that is joining in 2008 onwards. That will start to be messages around discharge, and messages around the outpatient letters; but it will not be the richness of what you were describing—a conversation with a patient you put in your internal system which you would not necessarily tell me about. I do not want to know every sodium and potassium in the intensive care unit; it is totally inappropriate to be available to me routinely.

Q26 Dr Taylor: It has got to be recorded somewhere?
Dr Braunold: It must be in the hospital system.
Mr Cayton: Richard, you are putting your finger precisely on the point that the Chairman raised earlier, that there are conflicting interests and conflicting views about the best way forward. What we are increasingly trying to create is a system that has some local flexibilities, that has a lot of choices for patients themselves to make about what is shared and what is not shared. As we described earlier, as the Summary Care Record is established, if people want to use it, and if patients agree with their GPs to upload more data to it, then it will become richer and more useful. You are quite right, my experience working with many of the organisations representing people with long-term conditions, they feel very strongly that they want to have a fairly rich shared record and they want it as soon as it can be reasonably provided; but we have many interests to balance in trying to achieve this.

Q27 Dr Taylor: Are the psychiatrists on board?
Mr Granger: I think with 30 mental health patient administration systems the people who have received those probably are. There are specific issues with particular patient groups around concerns about the propagation of information, sexual health and other groups. Gillian might talk about some consultation work we have done there. I want to reassure you on one thing around Detailed Records. We have delivered 13 community hospital patient administration systems; 171 community care PASs; 30 mental health PASs. These are systems that have introduced IT for the first time to quite a lot of frontline NHS workers that are shared Detailed Care Records working across communities. You can go to large parts of the country now, including in this city, and see people who were previously using paper notes, having to go back to offices and having to send letters to colleagues within multidisciplinary teams. My wife has worked in a community setting in the NHS and 30lbs of paper was a typical load she was carrying around as a speech and language therapist; and the only way she could propagate information across the community was by posting stuff; she did not have any other systems. A lot of people are getting systems now that do support that detailed care; but we come back to the problem of getting the warring software suppliers to get their software to work across multiple settings. We have achieved quite a lot of information flow thus far. We are running about 200 million interactions now across the spine, and I think you are going to hear from Patrick O'Connell of BT later who runs that service and you can talk in more detail about that. This is a difficult nut to crack because some people would like all information to be available everywhere; and then at the other end of the spectrum there are the privacy fascists who would like to dictate that nobody has any information available anywhere. We have been trying to forge a path between those extremities.

Q28 Charlotte Atkins: Why was it considered necessary to move patient data to national and regional databases when developing the new records systems? Won't central databases be more vulnerable to security breaches?
Mr Granger: I think there are different vulnerabilities. All information is vulnerable. We had to deal a couple of weeks ago with an incident of some PCT records, paper records, being left in filing cabinets that were trundled off to a scrap yard—a not uncommon occurrence, sadly, with paper records, that they go astray. Computers with records on them that are accessible get stolen from NHS premises; and people maliciously try to break into large central databases. No computers are totally secure; and paper records are not secure either. Where you have a situation where information is being freely available on paper within a hospital setting, it has the vulnerability of being browsed very easily by the very people living in the community that the patients come from. The same can be true in a GP practice. Where you have a central or regional database, you have the vulnerability of systemic examination of information either by people from within that community or strangers. We are very alive to that. There are significant sociological challenges in the busy world of health care around the balance between the ready accessibility of information to enable people to do a job quickly and adequate security. We decided in 2003 to adopt the gold standard, as it existed at the time, of Cabinet Office information security, a standard called e-GIF (e-Government Interoperability Framework) Level 3, which means we have issued 350,000 smart cards to frontline NHS staff and put them through a screening process which is not dissimilar to that which is necessary to obtain a passport, and they have had to be vouched for by senior colleagues in order to gain access to information. That has been a laborious process that has been effected through 4,000 registration points. We are the only piece of civil infrastructure in this country that has done that. We have had a couple of instances now, and one was through the ignorance of a temporary member of staff whose contract was terminated as a consequence of it, and the other was a deliberate decision in a busy A&E department. We have had a couple of instances of local variation and breach of the standards we have stood up: one smart card per person; that card must only be used by that person and so on. The technologies to enable us to move to something slicker than the use of smart cards are immature. We looked at using facial pattern recognition, retinal recognition and so on. Fingerprinting is not great. Although it exists as a mature technology it is not great in an environment where people wear rubber gloves. There are quite a lot of form factors around assuring rapid access to information and it being secure in a clinical setting. There are risks to central databases; there are risks to local databases; there are risks to paper. One of my great sadnesses about the last four and a half years is that we did not have the opportunity to spend two or three years doing benchmarking and cogitation because the benefits of getting systems in have outweighed that; but if we had we could have

collected vast quantities of information about confidentiality breaches caused by paper; because that has been the status quo, and the risks to patients of paper going missing as well. The same is true of other physical media, like X-ray films. Yes, there could be a risk of having a repository with over 200 million X-ray images on it, and other digital images, but there is certainly a risk if you go to the average district hospital and they have to re-shoot 20,000-30,000 studies a year because the X-rays went missing.

Q29 Charlotte Atkins: Given what has just happened with prospective junior doctors, what confidence do you think the public and patients will have in a computer-based system of this nature? Clearly, there were problems with paperwork; I know there were problems with smart cards left lying about and this sort of thing; but, given that very personal, confidential details of prospective junior doctors have gone public, how do you feel that this is gong to affect the public's confidence in being able to develop a system which is secure?
Mr Granger: With regard to today's news, I am both pleased and sorry that I do not run that system. I am pleased I do not run it right now because it has gone wrong; and I am sorry I did not run it because it may not have gone wrong if I had. The only responsibility I will take in that space is that I unfortunately put the network connections in on time. Of course had I failed to do that nobody would have been able to access it, and it would have been my fault. We have had a great deal of assurance and scrutiny about what we are doing in terms of systems security. No system is ever going to be totally secure, but a remarkable number of the general public do entrust information through electronic channels with far lower levels of security than we offer, whether it is to their bank, when they go shopping, or they accept it as a matter of course if they travel by airplane, for example. I think that what we are talking about is a level of concern which is legitimate, and the balance of the benefits of the new system. I think the benefits far outweigh the disbenefits. We have a number of people whipping up anxiety about the disbenefits. They are rather similar to people who have a fear of flying: are we going to ground all airplanes globally because some people are scared of flying?

Q30 Charlotte Atkins: You have just given assurances to people that because you are personally in control of this nothing is going to go wrong.
Mr Granger: No, I did not say that. I actually said all computer systems are vulnerable, and no computer system can be completely secure.

Q31 Charlotte Atkins: You implied that if you had been running the system that was dealing with prospective junior doctors that there would not be a problem. You have the opportunity now to be able to give assurances that you will put in place systems which make sure that will not happen, except in the most extreme circumstances. What would you say to a nervous patient who is going to give permission for their personal details, very sensitive to themselves, going on this system? Given what was happened with the junior doctors, why should they be confident that the system will work for them?
Mr Granger: I would say three things on that. Firstly, I think we have a high quality team deployed and worried about this issue. It is not something we take casually; it is something we take very seriously. I cannot give you a cast iron guarantee that things will never go wrong because that would be misleading you. We take the matter very seriously. Our suppliers have a track record of working in this space. They all do work for security services, for example; and indeed one of them has a team that largely emanates from a security service running their NHS work now. Secondly, we are introducing this functionality incrementally; so it is not a big bang and we are taking things step-by-step, which is a good way of mitigating risk and examining what is going on before proceeding to the next stage. Thirdly, I would say one of the most worrying aspects of the NHS at, say, 2002, and surveys were done in 2002–2003, is that most people that we serve incorrectly believe that the information from earlier in their care is available at the next stage. We have not until recently started to fulfil that understanding that the public have about how the NHS already operates.
Dr Braunold: Can I come in with a couple of points from my perception? If we were to say, "Okay, let us scrap it. It is too hard, it is too difficult, we should not do this, the risks are too great", my own perception is that the technologies exist for information sharing and what people would do (because I see it already) is start sharing information inappropriately. They would use ordinary email systems, they would send people information that is confidential through insecure ways, and, for me, what the National Programme for IT is really about is spending enormous resources but important resources on getting the information governance right so that we share information appropriately. For me as a clinician, the challenge in the last decade was clinical governance, and when it first came in as a phrase I think many clinicians did not understand what clinical governance was: it was a buzz word; they did not know what it meant. Ten years later, people really understand what clinical governance is, what it means to them as a clinician, and they want to raise the standards of clinical care that they deliver to patients. The challenge for the next decade is information governance. I think if I said that to the average clinician in my PCT, they would not really understand their responsibilities around information governance. That is where we are at now. In ten years' time, I believe that people will really understand what their responsibilities are about protecting patients' data, sharing appropriately information and what their responsibilities are about its accuracy and security. I think that that is why we are doing things very slowly, and incrementally. When we looked at the Summary Care Record we could have said to all 152 PCTs, "Just do it", but from where I am sitting we have to do things very slowly and incrementally and evaluate what we are doing. We have got an

independent evaluation that is being commissioned (it was announced yesterday) with the University College of London that will be evaluating all of these access controls that we are describing that are not present in what happened with the junior doctors thing that was declared this morning. These access controls have to be tested to make sure they work as they have been commissioned and tested on a small group of patients before it is rolled out wider. I hope that gives some reassurance.

Q32 Charlotte Atkins: The British Computer Society suggested that you should have a distributed database with information stored locally but accessible in a secure way to clinicians through a web-based search engine. Would that not be a more secure way of doing it and eliminate some of the concerns which patients might have?

Mr Granger: Perhaps we could let you have a note on the number of computers that have been stolen from within the NHS, as best we can calculate it. It is interesting. I do not know whether there are hardware manufactures advising them as well. The costs of doing that are quite significant. You have a complex technical solution. I find it perplexing when we have had 20 years of systems that have been essentially based around a central mainframe or, now, a set of boxes concatenated together with relatively little information getting stored in the end-user domain and it passing securely over networks. We did not want to, frankly, experiment with the very, very large distributed network. None of the leading suppliers of solutions in this space who are willing to bid take financial and completion risk around the delivery came up with that architecture, but they are in the business of actually delivering things, making it work and then getting paid; they are not in the business of producing reports.

Mr Cayton: Could I add, again, perhaps from the perspective of the Care Record Development Board, because the point that you raise, of course, is exactly right. There is nothing more designed to raise people's anxiety than the kind of story that I, like everybody else, heard on the *Today* programme or read in the newspapers this morning. As I was coming here it was a pretty heart-sink kind of moment to hear exactly that story coming out. What we have certainly always argued is that public trust in this system is fundamental to its success, as, indeed, is clinical trust, and I do not think any of us would be, as Richard has already said, remotely sanguine about the fact that we have cracked this, although I have to say that we have continued to deliver and to solve quite difficult debates and problems against a pretty relentless barrage from those who do not think this is the right way to go. What I would want to say about the confidentiality and security issues is, first of all, that we are continuing, as Gillian said, to improve our control and management of those in the NHS through improved support for Caldicott Guardians, the development of information governance rules and structures. The Government has already announced that it is establishing a National Information Governance Board, which is being supported by the BMA and many others, but really the problems about information governance are about sociology and not about technology; they are about human error, as I suspect the issue with the junior doctors database was, and they are about human wickedness and about people actually deliberately doing bad things with data—stealing it, and so on—but there are over 45 laws that apply to data management, confidentiality and security, there are seven codes of conduct, there are 11 sets of standards and guidelines, and those apply now and they will apply in just the same way with an electronic system, and we have been supporting the Information Commissioner in his bid to increase the penalties for people who maliciously steal and misuse data.

Q33 Charlotte Atkins: Have any other countries developed a similar system—either the one that you are suggesting or, in fact, a local distributed database as is suggested by the Computer Society?

Mr Granger: We have the misfortune of being first out of the gate with quite a lot of what we are doing, and different countries have different challenges, but if you look at provision in large providers in the US, for example, Kaiser Permanente or the Veterans Administration, you find large central databases.

Q34 Charlotte Atkins: We are intending to look at those, yes.

Mr Granger: If you look at what has been done in Alberta, you find a large central database but, in fact, set off with a fantasy of consent for the minutiae of information governance at each patient clinician interaction, and they gave up after about six months because, clearly, the doctors had better things to do with their time. If you look at the proposals that are being worked through by regional health information organisations in the US at the moment, they are about delivering HL7 standards based infrastructure to move information between health organisations, which is exactly what the Spine that we now have working in England does. Some of the smaller European countries have spent 15 to 20 years developing county-based distributed systems at very significant cost, and they have had a lot more time. They have different solutions. A number of jurisdictions are currently out to tender to buy something that looks remarkably similar to that which we now have large parts of working in this country. So it is a mixed picture. The structure of the NHS is unusual compared to other jurisdictions. The arrangements we increasingly have with private sector providers of NHS care and the accreditation process we have around them being enabled to display booking information in GP practices, bookings to be made and to interface with our demographic service and security arrangements, and so on, are models about which we have had visitors from Canada and Australia frequently because they see that as a template for their own arrangements.

Dr Braunold: The other area is that I have done a little bit of journeying inside the UK and been to look at where there are some large databases already that are giving benefits. In Scotland, for instance, there are two million patient records of drugs and

allergies that are helping out of hours care in Scotland that are on a single database; in Hampshire and the Isle of Wight there is a repository which holds all of the GP records—the coded section, not the text—and discharge information from the hospitals, and results, and X-rays and letters. There is an enormous amount of information in Hampshire, for instance, on a very large repository. They have all gone for putting information into a big pot, if you like, that various places access rather than distributed choice in those areas.

Mr Cayton: A rather extreme example, but in the Veterans Administration in the States, when they had the terrible floods in New Orleans the Veterans did not lose a single patient record because they were held on a secure database in Texas. Their patients were able to go to veteran hospitals in different parts of America and immediately receive their own patient record, whereas many other hospitals had their entire record systems wiped out. I hope our system will never need to meet that kind of problem.

Mr Granger: I will give you an example of where we have had that kind of problem: the Buncefield oil depot fire wiped out system availability for a number of NHS institutions that had systems run by a company called Northgate for a good couple of weeks, and I understand there may have been data loss as well. We had some difficulties, which I think were growing pains, last year with one of our suppliers who you have appearing as a witness, CSC, where we had some system failures. We did not lose any data and we have, since then, doubled the level of resilience. We do not just have one back-up site and tapes, we have now three back-up sites. There are systemic risks around central systems and there are systemic risks around local systems, and one of things, I think, we need to be mindful of in this country is the mobility of the population. In London one in four patients may change PCT in a year, and having information locked into local systems does not necessarily serve them well. Across the whole country we are looking at increasing mobility of patients as extended choice comes in. We need to be able to move coded information around the country; so I think an architecture that allows an extreme level of heterogeneity of solution and tries to make that standards based. We approached the BCS and asked them if they would like to assist in the accreditation process. It is a question that we continue to work through with them, but there is a balance to strike between having everything that is one (as it has incorrectly been described) monolithic system, having a small number of systems and having massive variability and standards based interaction, because the standards are not sufficiently mature at the moment.

Q35 Charlotte Atkins: You also decided, indeed your evidence says, not to go for any sort of wholesale replacement of existing IT systems. Is not that a change in direction from your original plan?

Mr Granger: There is a mixture. I will be clear with you. We found it very, very difficult to replace existing systems. Brownfield site implementations are incredibly difficult. We did three of them last weekend—Ipswich, Northampton and Surrey and Sussex hospitals. You might have half a million records, 10 to 20% of which are duplicates or corrupted, that have to be cleaned up by staff in the hospital; you might have 30 to 40 feeder systems, some of which require on-line interfaces to the central system; one to 3,000 users operate over one to half a dozen sites in each trust; you have to do the implementation, switch from one system to the other, over a weekend. It is a big heavy-lifting systems engineering job. It is like replacing the core systems in a small government department or small corporation—perhaps a 300 to 500 million pound turnover organisation—in a weekend. They are really difficult to do, which is why we have had significantly more success putting in systems where things did not exist previously or overlaying new functionality. Yes, it is an evolution of what we are doing based on the engineering reality we have encountered. Where we started from in Spring 2002 was a strategy. It was called a strategy and that is what it was. It was not an engineering plan from the ground up. We found data system conversion to be challenging. So we have used a number of existing systems and upgraded them, but that is not the whole story. There are also a significant number of new systems that have been implemented.

Q36 Charlotte Atkins: But you are going to make it more complicated by allowing GPs to choose their own software and, by so doing, are you not then building in issues with it being difficult for those systems to talk to each other and so on? You have gone from one situation to a completely different situation where anything goes.

Mr Granger: From a simplicity perspective for people putting in computer systems that work well across multiple locations, having not too many different types of software is good practice, because when you come to test upgrades you do not have lots of moving parts to enmesh in a complex gearbox. As I said, we have already got 102 different systems that are tested to run over this Spine, so it is already a heterogeneous national IT environment in the NHS in England. We got the message loud and clear from a number of GPs that their affinity for their existing software exceeded what they saw as the value of replacement, and we listened to that. Notwithstanding that, about one in ten GP practices now has a system that had very little penetration five years ago from a company called TPP. There is not enormous liquidity in that market place, there is one dominant player. It is very complex to do the data conversion, but we listened to what GPs wanted.

Dr Braunold: One of the biggest challenges for me when I was brought in as GP Clinical Lead to do some of the engagement work with my colleagues was that clearly we had GPs (and I speak unashamedly as one of them): is how on earth could you engage GPs about something that I think is going to be one of the greatest opportunities for health gain in my generation if we get this right? On the other hand, GPs are at the forefront of computing in the world, frankly, and the risk of losing some of that enormously rich functionality

for the greater good of going to some lowest common denominator was the fear; so we needed to find a solution which would continue to engage my colleagues and make sure that they did not lose the functionality that they were enjoying as we moved forward. We engaged with the programme as Clinical Lead and said: how can we move forward on this issue? It was a really important issue to get right. The GPs System of Choice, which is the OJEC which is going on at the moment, which is an enormously important lever forward for the programme and for GPs and for twenty-first century computing for general practice, enables continued investment in suppliers that are able to meet the standards of the National Programme for IT and show a migration path against the things that the programme is to deliver. Dr Cundy, who you are going to hear from after us in the next session, who is Chair of the Joint GP IT Committee, was one of the GPs that I asked to go to do one of the evaluations of the suppliers who put in to be part of that OJEC. Unlike some of these European OJEC things—those things are usually trying to bring it down to one person to win—this was not an exclusive tendering. It is intended to be open to anybody who wishes to take part who can meet the standards, and as long as they can meet the interoperability standards and the standards that we require for interoperability and a pathway towards integration, then they are welcome to join in, and I am sure you will ask him some more about GPSoC, which has had full, wholehearted support from all parts of the GP economy.

Chairman: We are now going to move on to some questions about timing and timescale. It might be appropriate if I mention at this stage that we are about six minutes away from what we thought would be the end of this session, and in the light of what is in front of me and around the table, that is not the case. I wonder if I could ask for sharper questions. I understand the need for you to have your say, but sharper questions and sharper answers.

Q37 Jim Dowd: You have just stolen my line. I was going to say the whole of the IT project is running behind time and so is this session of the Committee! In part of the evidence it says, "The transformation from paper to digital information will take place gradually up to 2010 and beyond." That sentence is impenetrable. What the hell does it mean and what is the significance of 2010? If it is gradual to 2010, what will it become afterwards?

Mr Granger: If I could just say one thing as a matter of record. It is inaccurate to state that the whole of the programme is late. That is not true. Some of the programme is late, some of it is on time and some of it is early, and that information has been available and certainly the clerk of your committee had some information to that effect into the progress we have actually made.

Q38 Jim Dowd: Can you now answer the question that I asked you?

Mr Granger: Getting hospital doctors' paper-based notes on to computers, for example, or structured communication between hospitals and GPs, requires a level of consensus from the end-user community which cannot be ignored or ridden rough shod over. So, we will not have a paperless NHS for a long time, in fact, we may never have a paperless NHS, because it may not be worth computerising and going to a paperless environment for absolutely everything that we do. Less and less paper is circulating in the NHS. So, if you go to hospitals that have got—

Q39 Jim Dowd: That is what it says. It does not say it might never be completed, it says it will completed but it is vague about when it will be completed. Are you saying this characterisation is just inaccurate?

Mr Granger: No, I am saying it is gradual. Most of what we set out to do in 2002 will be completed by 2010, but during that time a number of other things are now being computerised as well.

Q40 Jim Dowd: Also the Patient Administration Systems have been delayed because they are replacing "legacy" systems. Briefly, can you tell us what defines a "legacy" system and why was it chosen to do that rather than starting from scratch? This must have been understood at the outset, surely?

Mr Granger: There were about 180 major systems installed in hospitals in England in 2002 that ran the core administrative functions, and some of those have already been replaced, some of them have been upgraded.

Q41 Jim Dowd: What is a "legacy" system?

Mr Granger: A system that was already there in 2002.

Q42 Jim Dowd: So where it says "an existing legacy system", the "legacy" word is redundant. You mean existing systems?

Mr Granger: Yes. You have my apologies for the tautology in the drafting.

Q43 Jim Dowd: Why was it not decided to start with these systems from scratch?

Mr Granger: Because there is a vast quantity of data on the existing systems and hundreds of thousands of people trained to use them, and we cannot simply turn them off overnight and wait whilst suppliers develop new ones. The act of replacement, as I described a few minutes ago, is a complex process that, in a hospital setting, you typically have to do over a weekend, and you cannot do the whole of the country in a weekend, or you would be very naive if you tried. It is a gradual process. It is taking us longer than was envisaged in spring 2002, the suppliers have found it more difficult, the data quality is poorer than we thought it would be and it is a difficult job, unlike, for example, putting in picture archiving systems, which was not in the plan in 2002, which we have made excellent progress in and are running to schedule.

Q44 Jim Dowd: That leads me to my concluding question. We have received a number of submissions, one of which says that "for the first three years of the programme, NPfIT was driven in an environment of ignorance of the true NHS environment". Is that why delivery of the new systems has slipped so far behind schedule? Do you respond to that as an accurate assessment of the position before you had any responsibility for it?
Mr Granger: I do not know whether that is evidence you have received from an individual who has been personally disadvantaged by the programme so much or what the perspective is. The fact that we had an awful lot of staff who had 10, 20, in some cases more than 20, years' experience of working in IT in the NHS, working at the core of the programme, using materials that they had developed over that period, I think is a statement which does them a great disservice. I do not recognise that environment at all.

Q45 Jim Dowd: What are the main causes then for the delays, if it was not the fact that the whole thing was far more complicated than was envisaged in 2002 and that the expertise and the assessments of 2002 were fundamentally optimistic and inaccurate?
Mr Granger: Some areas of the programme have got delays, others have not. In terms of the overall 10-year programme that was set out in the contracts we have put in place in 2003–04, we will get most of that work done during that 10-year envelope. I have talked about the fact some aspects are more complicated, others have been quite straightforward. To have gone from an NHS which only had about 10,000 places connected up to the Internet in 2003 to the delivery of a 19,000 end-point network which is backed up everywhere with secondary circuits three months ahead of schedule is not late and is a greater scope than was originally envisaged. To have completed at the end of March the roll-out of picture archiving across the whole of the south of England and London, which was not in the original work programme, is not late; it must, by definition, be early.

Q46 Jim Dowd: One last point, Chairman, and I accept your exhortation about moving on rapidly. When you say it has got more functionality than originally envisaged, is that because the original estimates were just wrong?
Mr Granger: I do not know of a large-scale IT enabled transformation programme in a complex organisation that from its starting point to its mid point has a direct correlation. I think it would be a fantasy to imagine. I know people write fantasies, but in the real world it would be ridiculous to imagine that halfway through a ten-year programme you would only be doing the same things as you set out five years ago. I will give you some examples in addition to the digital imaging. Putting in a new secondary uses service, putting in an email service, putting in the standards for GP to GP record transfer, putting in a new payment system for GPs, taking the atrocious batch legacy number systems that the NHS was reliant on and putting in fresh, modern on-line databases, putting in bowel cancer screening systems, none of those was envisaged in 2002.

Q47 Jim Dowd: The electronic X-ray storage was?
Mr Granger: No, it was not. It was not in the strategy document in 2002.
Jim Dowd: Okay, we will come back to that.

Q48 Sandra Gidley: You have been very bullish about the fact that extra things have been added since the introduction of the system, but you have played down rather what has been delayed. Do you accept that the electronic record system has been delayed?
Mr Granger: Some aspects of it have been delayed by 24 months.

Q49 Sandra Gidley: Is that because of taking on extra tasks or is there another reason?
Mr Granger: The consultation process has been far longer than was originally scheduled, because the work that had been done in 2000 to 2002 by way of preparation required significantly further work. I will not say it was defective, but the work that my colleagues have done around patient consultation and consultation with the professionals who are using the system created an environment in which the specification that was drafted up in 2002 had to evolve, and until the specification was stable it would have been inappropriate to have got on with finalising the software because it would have had to have been reworked at a cost to the taxpayer, to strike a balance between consultation, a ministerial taskforce, professional involvement and rework work that had been undertaken by Anthony Nolan, in particular, through in 2002.
Dr Braunold: I think it may be worth explaining a little bit more that some of the work that Dr Taylor was referring to earlier about how are we going to get to where we are going to in terms of the picture on the lid of the jigsaw puzzle, that consensus building about how it would work—engaging with clinicians and making sure that they, as people who are going to be using the system, has taken time to engage with clinicians and gain consensus about prioritising what will come around the consent model which has taken a very long time—has been very difficult to move forward on content and design in some areas when you are still having discussions about the consent model.

Q50 Sandra Gidley: You have both talked about engaging clinicians. I found it quite interesting to note that the Royal College of GPs, NHS Alliance, the Royal College of Surgeons, the Royal College of Nursing, the British Medical Association, amongst others, all in their submissions to us mentioned that there had not been sufficient engagement with clinicians and with patient groups. A number of patient groups commented in the same way. Is this a bit after the event that we are talking?
Dr Braunold: I am the fourth attempt at clinical engagement. That is the tier that I am: the National Clinical Lead.

Q51 Sandra Gidley: You are "the fourth attempt". What does that mean?
Dr Braunold: I will explain that. There were other clinical engagement efforts that happened before the National Clinical Lead's appointment, three previous ones, and the National Clinical Lead's appointment was praised in the report from the Public Accounts Committee and the National Audit Office in terms of starting to make real efforts and quality improvements in the clinical engagement with the community. We were sponsored by the BMA and the Royal Colleges as jointly owned individuals who were accountable back to those bodies and as named individuals that they would be prepared to work with who were sponsored into the programme.

Q52 Sandra Gidley: How long have you been involved?
Dr Braunold: Two and a half years. I was nominated by the BMA. I was nominated by the General Practitioners Committee. My job-share, Professor Mike Pringle, was nominated by the Royal College of GPs, and we two together work as clinical champions from the general practitioner community with a track record with GPs, who are accountable back to the profession, for making sure that systems are built that are fit for purpose from a GP perspective, and it is our responsibility to do an ambassadorial role for the National Programme from a General Practice perspective. There are equivalent roles. We have hospital doctor colleagues, Dr Simon Eccles and Mr Ian Scott, and we have Jan Laidlow from the Allied Health Professionals and we have our nursing colleagues. We have done quite a lot—I think it is an enormous amount—in terms of setting up advisory groups and interfaces with our colleagues and making sure that they are involved at every stage in every important programme. There is a National Clinical Reference Panel for the Summary Care Record for which every one of those colleges has been asked to nominate people who are able to make sure that the Summary Care Record has the right advice about what should be in it and what should be not in it and that it fulfils the criteria for the Care Record Guarantee, and that has all been slowing things down, frankly, from the original intention because we wanted to make sure that it had proper clinical sign off, and that tension is evident.

Q53 Sandra Gidley: But that is only the last two and a half years. What engagement was there in the first three years?
Mr Cayton: Could I come in here. The Care Record Development Board took over from two committees, one of which was called the National Clinical Advisory Board, on which every single one of those bodies was represented, and that existed well before I became involved in the programme. So, if that group, which consisted of the Royal Colleges and their colleagues, was not delivering four years ago, that is actually the responsibility of the clinicians who lead those colleges. I have had innumerable meetings with Royal Colleges and with the Pharmaceutical Society, and so on, over the last three years. I have had very positive relationships with them. I have actually found them extremely constructive in practice, and I think we are just in one of those situations where what people say in public (because it is a posture to take), "We have not been adequately consulted", is not the same as what is happening in practice. We have had patient organisations involved throughout. Only last week we had an open session in which we had over 30 patient organisations taking part, the Care Record Development Board has an annual conference which is open to the public, and to the press, and to clinicians, and we have had over 100 patient organisations and certainly over 350 people attending those conferences every year. We have actually done a great deal to try and engage with clinicians at all levels, and certainly, since my involvement, I have been personally entirely committed to that process.

Q54 Sandra Gidley: How long have you been involved?
Mr Cayton: The Care Record Development Board was set up three years ago.
Mr Granger: It is undoubtedly the case that we could always do more in this space. It is undoubtedly the case that the concept of professional consensus about some of these issues is challenging. Generally, when you put disparate professionals together on some of these issues, you do not get agreement, you get at least one opinion per person.

Q55 Sandra Gidley: That is within a profession?
Mr Granger: Yes, a medical consensus is undoubtedly oxymoronic, but if you look, for example, at your profession, would you like us to wait until the pharmacists and the GPs agree on how much data would be visible in dispensaries, or would you like us to get on and roll out electronic prescriptions with the benefit that that delivers? We have those challenges across the whole programme because the tribal nature of clinical practice means that these different groups all take different positions and different postures, and we have tried to strike a balance around achieving progress rather than just wait for everybody to agree. I suspect we would be waiting an awful long time.

Q56 Sandra Gidley: I gather the prescriptions are problematic as well, but we are not here to discuss that. We can probe this further with those groups themselves. My final question at the moment: why has so much effort been diverted into Choose and Book rather than into the detailed clinical systems that actually support patient choice?
Mr Granger: I will ask Gillian to come in in a moment on this. If you look at the strategy document from 2002, you will see Choose and Book did not exist. What you will see is electronic booking. One of the many areas where we got additional work was the delivery of choice, and electronic booking was quite a straightforward proposition which had been extensively piloted, which was about packaging up a referral and

sending it electronically. The delivery of an on-line booking system that produces a confirmed appointment connecting up the best part of 10,000 locations with an on-line processing system is something that is far more complicated. So, the task got more complicated with the announcement of choice. It is a government priority and it has been first out of the gate in terms of putting on-line connectivity into GP practices, and it is dependent upon a lot of different moving parts, all working at the same time, only some of which are controlled from the National IT Control Centre in Leeds. I can vouch for the network, I can vouch for the Choose and Book system—I know when that goes down. I run some of the PAS systems already, I only run some of the GP systems. All those bits all have to work in order to complete the transaction. Gillian, you are a user of Choose and Book.

Dr Braunold: I am, and I think that some of the issues are that Choose and Book, being the first out of the stable, have had to take the pain of connecting to the Spine. So, the first thing that people know of is their smartcard. I have heard so many GPs and colleagues around the country call it their Choose and Book card, because they think that this is only to do with Choose and Book and they do not think it has anything to do with the rest of what is being built, and actually it is their key, as guardians of NHS care records, of their patients' data. It is far more important than Choose and Book, but it is just that that is the first out of the stable. It is also, of course, informed around whether there were speed problems, problems with your network or, more likely (which we found to be the case), sometimes it is actually the configuration of the computers at the end-user end, which does not change the experience of the person at the end, although it is taking a long time for it to work, and complaining about Choose and Book when actually you need to do some further diagnosis about what is going on under the bonnet. Choose and Book has had to take a lot of pain, but an enormous amount of the issues for me have been around performance managing the take-up of IT. Speaking as a GP here, and I do not have anything to do with the delivery of Choose and Book from the Department of Health perspective, I personally believe that targets are not the way to get people to use information technology. The NHS is commissioning tools that it expects people to use, and it expects people to use them if they derive a benefit, and I know that clinicians will use tools and use them to greater effect when they see them being beneficial. As you start to find a better use of service delivery because you have got a tool, it spreads like wild fire and people use it more and more, but they need to have time to grow into using those things. I actually believe that the rest of the service which we have protected from having any kind of targets, like the Summary Care Record, and letting PCTs go at their own pace when their GPs and PCTs feel ready to go with the Summary Care Records, is a really important part of how that is going to go forward and grow with confidence, and when people are ready to go they will try it out. I have no doubt that the value of a coded record on the summary, as people see suddenly they have got access to care pathways because they can click on the code, will have GPs and patients crying out for the Summary Care Record faster than we can deliver it.

Q57 Chairman: We did discuss the issue about the content of the Detailed Care Record when we were having the earlier exchanges. What do you say to people who say that the main plank of that—the PAS hospital system being developed by Lorenzo, Millennium—is not going to be providing what they were originally providing. Is that because it is a moving picture? This is an accusation that has been put to us and I put it to you to answer.

Mr Granger: I think the problems are different. The Millennium product from the Cerner Corporation is a very rich system, as I say, in use by a third of hospitals across the US. There are two issues with that. One is the Anglicisation of it so it does things the way we do things here, where we want to, and in some cases we may want to do things differently, so that is a problem with that product. Can we change it as much as we need to and can we take the good things from it, which we currently do not do? That is a kind of process redesign issue. The Lorenzo system is a new build system. What has in fact happened for the first time under the national programme on Saturday morning in Ipswich was that the latest upgraded version of the old product was implemented with quite a lot more clinical functionality, but the core problem we have with Lorenzo is building a new system, a task which is estimated to cost around £250 million and is taking longer than the prime contractors that brought that to us (Accenture and CSC) estimated and has caused the company doing it (iSoft) significant difficulty. In the meantime, we have been getting on putting in systems which deliver immediate benefit and are a transitional step, and with that system we have a problem of getting sufficiently rich functionality developed, but we do not have a problem with Anglicisation because its heritage is in the UK. These were not unforeseen problems, which is why, unlike a lot of other major procurements, and not just in the public sector, we did not just go with one solution. We did not go with a plethora of solutions because of the cost and inefficiency of that, we went with a couple of solutions. It is also why we deliberately did not contract with the suppliers of those systems, because they failed financial viability and scale tests that we set as part of the procurement, and, again, you can see with the passage of four years the accuracy of the procurement approach, which we published in January 2003, and what has actually happened by spring 2007. It will continue to be difficult and, of course, if it was easy from the late eighties when the other major paper factories of civil administration in this country got computerised, it would have already been done. The reason health is being done last is because it is most difficult. Building the software to satisfy a highly educated end-user group who often have quite difficult circumstances around balancing time between accessing data, entering data and dealing with patients creates lots and lots of specific problems.

Chairman: Thank you for that. We are going to move on now to one or two questions about patient consent.

Q58 Mr Jackson: In the pilot of the Summary Care Record, there is an assumption that patients have consented to having their data uploaded into the new system if they do not specifically opt out within a certain period. Is this approach consistent with patients having more control and ownership over their personal data? Can I just say that in evidence we have recently received the point has been made, "We are very concerned that Connecting for Health's insistence that section ten of the Data Protection Act 1998 should remain the exit justification for patients who do not want a Summary Care Record. We believe this is counter to Lord Warner's verbal assurances and also all ethical, professional, moral and legal principles." What is your response to that?
Mr Cayton: It is an awful lot of moral, legal and ethical principles to be against at the same time, and my first statement is I try to be in favour of most legal, ethical and moral principles.

Q59 Jim Dowd: But you are not dogmatic!
Mr Cayton: Let me start off by trying to outline the position that was taken by the ministerial taskforce, because that is the position that we are currently in, and also by clarifying, I hope, what Lord Warner said when he announced that the department was accepting the recommendations of the taskforce. The fundamental debate (and it is an entirely legitimate debate, and I do not think any of us have ever suggested that we take this in a trivial or light way) is a debate between the utility of having a system where informed consent is required explicitly from every person and a system where it is clear that consent is implied and informed consent is a matter of choosing not to take part. We debated that quite robustly in the taskforce, and it is quite clear from experience in other countries and in other systems that if you have an informed consent to be part of the system, then large sections of society, particularly some of the most vulnerable people in society, do not take part. They do not take part because they do not know how to give informed consent, they do not take part because they do not understand what is being asked or offered and they do not take part because of physical immobility—so older people, some of the frail people living at home in the community who might be most likely to benefit. So, there is that issue that arises, an equity issue, and you have to start by believing this is a good thing, which clearly we do. So, there is an equity issue. Are we going to deny the good thing to a large group of patients in the population and, secondly, there is a practical issue for doctors and GPs in particular. We did a sort of back-of-the-envelope calculation, which I am sure we could try to do more accurately if you wanted, and we worked out it would take 100 years of GP time to go through the consent process for every single patient in the country. We were not sure that was ethically a good use of people's time. We came to the agreement (and this was an agreement absolutely with everyone on the taskforce) that the model that we had adopted which said we will inform people very carefully about what is being done, we will give them every opportunity to choose not to take part if they wish to, was the most practical, ethical and appropriate way forward. Clearly there can continue to be a debate about that, but that is the position the taskforce took, including the BMA and the Society for Emergency Medicine and the patient organisations who were there. The recommendation that we should do that and that we should allow people who did not want to have a record to have a number of different positions that they could take: one is to have a shared record but not allow anyone to see it—so to have it uploaded but locked down so that at some stage in the future, should they change their mind, they might be able to unlock it—or not to have any data uploaded to the system at all. The issue that I think your evidence raises around section ten of the Data Protection Act is that we believe that the processing of data in the NHS is actually a requirement for the proper functioning of the NHS. So, for that reason, in order to secure the proper functioning of the NHS under the Data Protection Act, we merely require people to sign a form saying that they understand the consequences and the choices that they are making when they opt out from the system. It is not intended to be in any way a sort of Draconian system, it is not intended to ask anyone to prove anything under section ten, it is merely in order to secure the legality under the Data Protection Act of processing data.

Q60 Mr Jackson: Thank you. That is very comprehensive. Chairman, could I ask two brief supplementaries? Have you estimated the impact of how many patients might opt out and what impact that would have on their application, and, very briefly, with regard to GPs, are you absolutely sure that there are issues about breach of confidentiality for GPs in the system, albeit inadvertent, and their liability for it?
Mr Cayton: Let me take the first one first. Of course, these are only provisional figures, but there are 10.5 million people in Scotland in the Scottish system; there have been 593 opt out requests in Scotland, which is 0.01% of the population. In Hampshire and the Isle of Wight system, 690,000 people, 1,050 opt outs, 0.15%. In the Early Adopter Programme so far in Bolton 0.17%, and in the Wirral 0.01%. So, we are talking about less than 1% of the population when people have the system clearly and properly explained to them and they know what is going to happen in practice.
Mr Granger: Not the big opt out.

Q61 Sandra Gidley: Excuse me, I live in Hampshire. No-one has clearly explained the system to me. I very rarely go to my GP. How am I supposed to know whether I need to opt out or not?
Mr Cayton: I will turn to Gillian because she is working on the Early Adopter Programme.
Dr Braunold: In Hampshire (and it is some time ago) leaflets were sent to the population. I am not responsible for Hampshire, but we have taken some

learning and I can take you through how we are not happy to do it the way Hampshire did it, which is where we have been criticised for not listening. We have been listening very carefully to the ERDIP (Electronic Records Development and Implementation Programme) project, which Hampshire has been, which is one of the NHS IA projects on the electronic healthcare record, and they did a mailshot to every household. We have learnt from what Hampshire did, because we believe that it did not go to every person who needed to learn about it, and I have learnt more about the junk mail rule than I ever want to know, but it exists and you need to send to every addressed adult in order for it not to get thrown away if you have got Safeways or Tescos trying to tell somebody something at the same time. Not only are we sending to every address but we are sending to every adult over the age of 16. Originally the Information Commissioner asked us to write to every adult over the age of 18, but my colleagues in Bolton came back to us and said, "But we have got adults between 16 and 18 who do not live at home", home being with their parents, "they live at another registered address." So, we went back to the Information Commissioner and said, "What do we do about that?" and he said, "Okay, you can send to 16 year olds." So we have now sent to the 50,000 patients who are registered with the first nine practices that we have gone with in Bolton. We have written to everybody, not only those who are 16, but everybody who is going to be 16 over the first three months of the pilot, and they have been sent addressed leaflets. But we do not rely just on that leaflet campaign, we have to then do other methods of communication within the area. There have been lots of newspaper articles and other methods of getting into communities that are going on at the moment in Bolton. We have been stuck a bit by purdah. I am being perfectly honest. From March 15 onwards has not been a brilliant time because we are now in purdah, and until May 4 we cannot do much more in terms of a public information programme in Bolton; but the minute we get past the May elections, we are allowed to do something that is being interpreted as political process because of the political nature of this discussion that we are in now, so we will be able to do a much wider advertorial campaign. We are doing information booths and a public information programme within Bolton where people are coming in, for instance, to Lever Chambers and they asking in depth questions. We have sent out around about—. You have got the figures, Harry, of how many leaflets we have sent out to people in Bolton. There have been requests for something like 900 sets of confidentiality packs from the Bolton population from the 50,000 that we sent out and about 400 of those were altogether from people who had various difficulties, and I think about 60 of those have gone to people with limited eyesight—Braille versions and large print—so we know that we are getting there. One fact that you might find interesting is that I thought maybe people were not reading the leaflet. You know, you send a leaflet to people houses. How do we know they read the leaflet? Unfortunately, we got one letter wrong to one practice. It said that they were registered with a different practice. We had hundreds of phone calls from patients who said, "You say I am registered with practice X instead of practice Y." So they were doing some reading of the material that we were sending them. Nevertheless, the whole project is to be evaluated to check, not only the consent model, but the quality of the information programme that we are doing, because the consent model is predicated on informing the population and, if the population is not informed, the consent model is inappropriate. So, we have an independent evaluation that has been commissioned that is starting on 1 May, and that will look at all the different communication methodology that we are using in Bolton, and it is not just an evaluation for Bolton, it is the whole Early Adopter of the summary record in its first year that is being evaluated, and we are testing different methods of communicating with the patients who are being affected.

Mr Cayton: The Care Record Guarantee is now available in 16 languages, and we are increasing the number of languages as we go. I have brought some examples here if you would like to see them.

Q62 Mr Jackson: I did not get the second part answered about the concerns that GPs have.

Dr Braunold: Very briefly, I did 22 road shows with Professor Pringle across the country and we had concerns from GPs around the time taken to consent, which was, I think, the biggest concern that people had. So, what we are doing with my colleagues is looking through the data quality, which is really important, so that they do not inadvertently send erroneous information. We know that the dataset that is being uploaded in bulk is the drugs and allergies. The reason we have chosen that (and it took some discussion with colleagues across the country about going for that model) is because the drugs and the allergies are likely to be the most accurate subset of information. We are all using datasets, formularies, if you like, so it is not free text, and it is very likely to be accurate, whereas the summary of the significant medical history has the potential to be inaccurate, and that is why it is not going in a bulk, it is going opportunistically one by one so that there is the checking of that by the patient and the doctor before it is submitted. Part of the model is that those are only submitted after a conversation with the patient, and how that is being done is being worked through by our colleagues on the ground who are prepared to put that pain in to testing different models and seeing which works the best.

Q63 Chairman: Thank you for that reassurance, Dr Braunold, that a leaflet delivered through a letterbox is actually read. It is something that some of us have doubted from time to time in this profession. I would like to ask you very quickly what level of consent will be required for the Summary Care Record data for secondary purposes such as clinical research?

Mr Cayton: The law will not change in any way whatsoever, and the law is clear that patient information can only be used for clinical research with consent or entirely anonymised, or, exceptionally, with the permission of the Patient Information Advisory Group which gives section 60 approval as part of the 2002 Health and Social Care Act. The two grounds on which the Patient Information Advisory Group will give consent, which is obviously a parliamentary matter, is if it is clear that getting consent is either impossible or so onerous that it is not appropriate and the public benefit of the research is so great that it justifies doing the research without getting consent. There will not be any difference whatsoever in the legal position of people's data in terms of research with an electronic system than from now. I am just grabbing this back, this particularly useful piece of paper. To put this in context, Biobank, you will be aware of, has recently started to invite members of the public to take part in research. I have to say I was personally quite sceptical and I have been quite interested by the fact that 10% of the people mailed by Biobank in their pilot in Manchester actually responded positively to the invitation to take part in research, and, although a number of those people (and again I am surprised how few but I think it is interesting) wanted to know how their name and address came to be selected and wanted to know who had sent out their name and address, of the very small number—23 who wanted to know how they had been selected, 25 who wanted to know how their name an address was obtained—after they had had a discussion with Biobank 50% of those people continued to go forward to take part. So, I think what this is suggesting, not in any way that we should move away from consent for research, which I think is very, very important, but that the public in this country still have very strong communal interest in clinical research and in a common ownership of the Health Service, which I think is one of the wonderful qualities of our Health Service, that it is a joint enterprise and not a set of private contracts.

Q64 Dr Naysmith: Good morning. Mr Granger, I understand that it is proposed that patients will be able to put some or all of their data into electronic sealed envelopes if they choose to do so, but I also understand that the technology to allow this to happen does not yet exist, is that not rather astonishing?
Mr Granger: Is it astonishing it did not exist by 2002, or is it astonishing that it does not exist yet?

Q65 Dr Naysmith: Is it not astonishing that it does not exist yet? Is it an oversight that we are starting talking about it and yet the technology is not there to do it?
Mr Granger: No, because the consent model which you have heard about around the Summary Care Record has dealt with whether people would like their information withholding or not and the variety of arrangements there, and I think we circulated some information to you around that. It becomes necessary as we move into segmenting a record with the detailed information that will follow as the system evolves. It is difficult to specify, difficult to develop and it reflects the views of certain groups of patients and certain groups of experts, and I think as we go through the evaluation process with the Early Adopters we will get a better understanding of whether we have got .2% of the population potentially driving a very large amount of expenditure on computer software when 99.8% of the population have a very simple requirement that the NHS treats them as safely and as efficiently as possible. So, I think the sequencing is rational based on the way the programme is going.

Q66 Dr Naysmith: When will the sealed envelopes become available? When will that technology be available? Are you saying that it might not if it is such a small proportion that it does not matter?
Mr Granger: The current proposal is that the Spine central infrastructure software release programme in April, May 2008 will deliver the central functionality for sealed envelopes. I do not wish to mislead the Committee. You must recognise that the systems that feed in and out of a central system will also have to be upgraded to comply with that, and one of the challenges we have is that this is not a requirement in other jurisdictions. We have got a plan to deliver it.

Q67 Dr Naysmith: Is it a requirement anywhere else?
Mr Granger: I am not aware of other—
Dr Braunold: I think in France there is a sealed envelope functionality. My French is limited, but what I read of a translated grid showed a sealed envelope functionality with the two levels of sensitivity very similar to the one that we have suggested here, and I think some of the delays that Mr Granger was referring to—. We did a risk assessment of the original sealed envelope proposal through our clinical safety arm of Connecting for Health, and it became very evident that we were at risk of breaching the very confidentiality that the sealed envelopes were there to protect if people did not use them properly. So, you have got this balance of business process and the human beings in the NHS who are not used to this new way of thinking that might well not use the software properly when we design sealed envelopes to protect patients' particularly sensitive items. The other risk was that if we did not have the functionality right, then large swathes of the population would opt out because they would have no confidence in the system. By opting out I mean that they would choose not to share their information. We did some work with the technology office and with clinicians around the sealed envelopes proposal that I have given you as a power point, and I am well aware that the Committee is running late and I am very conscious that you probably do not want me to take you through it, but what I would like to say is that we have proposed two levels of sensitivity there, a normal sensitive barrier that would give an audit trail if somebody opened it who did not have express permission to open it, and a sealed and locked version where it is not even visible outside of the

work group you are in. We took that to the most challenging group of doctors of all that exist—not just doctors, clinicians I should say—the Sexual Health Conference that the CFH ran last month, who are the most sceptical that the confidential data that they deal with in the GUM clinics will not be adequately protected. We took them through the sealed envelope proposals that we have and how we think it will work and we asked them in the evaluation: "On the basis of what you have heard, would you support your local sexual health service using the NHS Care Record Service? Please scale your answer using (1) not at all to (5) very much." I will submit this as a note, but the evaluation showed that 23.8% were on three, 23.8% were on four and 26.2% on five, and the people who were on not at all or the next grade up were 2.4% for each of those categories. So, we were very, very pleased with that outcome for the most challenging group, that when we explained our proposals for simplifying the sealed envelope structure but making it fit for a purpose, we think that we have got the technical specification right for the service.

Q68 Dr Naysmith: You still have not answered my question when you think it will be.
Dr Braunold: Two thousand and eight.
Mr Granger: Software drop, April, May 2008.

Q69 Dr Naysmith: You are confident you will meet that target?
Mr Granger: BT have delivered every one of their central software drops on time for the past 18 months. There was lots of delay before that, but this has become quite a reliable delivery environment now.

Q70 Dr Naysmith: I understand you also commissioned a risk assessment report last year suggesting that it would be best to hold information like this locally rather than on a central database?
Dr Braunold: That was the risk assessment process that I was referring to, which looked at how would we use it and were there risks associated with it; and we redrafted it in line with the recommendations of that risk assessment report.

Q71 Dr Naysmith: So it does follow that?
Dr Braunold: Absolutely.

Q72 Dr Naysmith: You were talking about the presentation you let us have. On the last page it says that information in sealed envelopes can be pulled off for anonymised secondary user purposes, but SUS information data is not always totally anonymous, is it, because it includes postcodes and date of birth?
Dr Braunold: That is what pseudonymised is. Pseudonymised, which is one of my most challenging word to spell, means you could get to some part of the demographics without knowing the full name and address of the patient.

Q73 Dr Naysmith: But someone can find the full name and address of the patient from date of birth and postcode information?
Mr Cayton: I would just repeat the point. There is no difference in the legality or in both professional and legal frameworks. This is a process of clinical research now and there are very, very strict guidelines. My view is that because of the audit trail, for instance, and some of the other securities that lie within the system, the new system should actually allow better use of fully anonymised data. I should say, there is a secondary uses working group of the Care Record Development Board which will report in the next month or so, and that group contains a large range of both patients representing sensitive issues, such as mental health and HIV, and researchers and clinicians. It is chaired by Sir Robert Boyd and I am looking forward to receiving their report which will have a number of suggestions, I think, to even further increase the safety and security of the use of records for clinical research, which I think we all want to achieve because it is in all our interests to continue to do clinical research, including on mental health and HIV.

Q74 Chairman: I think we are down to the last question, and I would like to ask it of you, Mr Granger. We have had a number of submissions that you will be amazed to know about that say there should be an independent technical review of the national programme. How do you respond to this?
Mr Granger: I am interested as to whether the people calling for that are, indeed, themselves independent. We have been as a programme the subject of significant scrutiny, both from the NAO and the Office of Government Commerce and a number of reviews which we have commissioned as a consequence of events or concerns that have occurred over time. Ministers took a decision last year that there was no benefit in a further review of the programme being undertaken, and that was the position that was set out by Lord Norman Warner in the spring of last year.

Q75 Chairman: A technical review is a bit different to reviewing all the issues that are floating around in the media quite a lot of the time. Is that your understanding in terms of overruns? Would it seek to get answers to questions that some people believe remain unanswered.
Mr Granger: We know from 350,000 people using systems that did not exist four years ago with billions of pieces of information flying around the network that did not exist, with hundreds of thousands of people using a security framework that did not exist. At what point do we get to a situation where people's research tool, which is Google, is actually thrown out? They would not go shopping for health advice on Google, but they somehow consider that they can vicariously analyse the performance of a programme using generally inaccurate press coverage. I am not sure. Do we have to get to 500,000 users? This programme was always going to be very challenging; it has been very challenging; it will continue to be very challenging. Where there is specific expertise

that is going to work from an evidence base and improve what we are doing, reduce errors, reduce time overruns, I would say with the time overruns that one of the problems with this programme is there was no financial contingency. So, as a programme director, quality, functionality and time are the three things that we have to deal with and the only expression of dealing with problems on this programme is necessarily time, because we are operating within a financial cap and the functionality demands have tended to increase rather than decrease. If there are people who want to work from an evidence base, the door has always been open for them to come and work with us, but people who just lob cold collations of negative media coverage in so-called dossiers hardly do themselves a service as a serious group of people that are working from a robust evidence base.

Q76 Chairman: They and others around could influence public opinion about this problem.
Mr Granger: Undoubtedly they do.

Q77 Chairman: Would such a review increase, or be likely to increase, public confidence in the programme?
Mr Cayton: Might I just come in there and say that it seems to me that—. I have always said that the Care Records Development Board deals with the issues to which there is no right or wrong answer, only the best answer we can come up with. If there was clearly a right answer to some of these difficult issues, then we would not need committees and we would not need inquiries to look at them. It is only because they are, inevitably, contested issues, both in ethical terms, in terms of good clinical practice and in terms of the functionality of IT systems in the modern world. My feeling is that, through the systems we have got in place, there is a very robust system now of involvement and engagement through the Care Record Development Board and the National Clinical Leads and a large amount of public scrutiny, which I welcome, because I think the kind of scrutiny this Committee gives is part of a proper process of examination of what the programme is doing, we have to move forward on that basis. If we keep going back and saying, "Because I disagree with a decision that has been reached through a public and accountable process, I now want to unpick everything", we will never deliver and the people who will, I think, not forgive us are our children, who live in an IT enabled world now and, I have to say, will be very surprised if in 50 years' time we are saying to them, or perhaps not us, but our children's children are saying to them, "Oh, we gave up because it was too difficult."

Q78 Jim Dowd: Given the scale of the undertaking, as you have described it, given the novelty of a lot of the approaches, how much of your system's software is dot zero releases in the operating systems that are out there?
Mr Granger: None of the operating systems, because they are either industry standard proprietary systems or LINUX. In terms of the application software, almost all of the applications that are being delivered are systems that have been deployed extensively previously or are incremental upgrades of things which were deployed previously. In terms of the core Spine infrastructure, there was some mythology in the Health Informatics Community that the standards existed, HL7 was mature, and so forth. That was completely untrue. We have had to put an awful lot of effort into specifying the standards for messages, around demographics, around booking, around prescriptions, and then the software that BT have built with a number of sub-contractors is brand new software that has been custom-built for the NHS; so that is high-risk, new build software. There was no other way of doing it. I am very pleased a number of other jurisdictions are getting very interested in using that. What I do not want us to end up with in the NHS is a situation we have in a number of other areas of civil administration where we expend a significant amount of money building something which, when it comes up for re-tender, we have a unique supplier and we either have to pay to get other people to come in and bid in order to have a competition for the replacement, or we are held to ransom at the point of replacement. What we need to get to is a sufficiency of open standards, which we are leading a lot of jurisdictions on, so that when we come to re-tender these systems at the end of the contract there is a vibrant market of suppliers in a number of jurisdictions and we do not face that risk on an enduring basis because we are sharing software that is used in other places. I think, in particular, the Welsh Assembly will have some very interesting choices when we turn off the systems on which they are dependent, starting next year, as to whether they use the English solution or they go and build from scratch something that does the same thing.
Chairman: Could I thank the three of you very much indeed for coming along. I am sorry about the overrun in this session. I thought it was likely to happen in view of the inquiry. Thank you very much, again for coming along, and I hopefully it will not be too long before we have our report out in relation to the Electronic Patient Record.

Witnesses: **Dr Martyn Thomas,** visiting Professor of Software Engineering, University of Oxford, **Mr Andrew Hawker,** NHS Patient, and **Dr Paul Cundy,** Chair, General Practitioners' Joint IT Committee, gave evidence.

Q79 Chairman: Could I welcome you very much indeed and, first of all, apologise for the lateness of the hour in terms of this evidence session. I do not have to tell you why, as I understand all three of you have been sat in the room for the last couple of hours. Could I welcome you to our now second evidence session of the Health Committee's inquiry into the Electronic Patient Record and, for the

record, I wonder if I could ask you to introduce yourselves and the positions that you hold. Could I start with you, Andrew Hawker?

Mr Hawker: Certainly. My name is Andrew Hawker. I am now retired. Since Mr Granger seems to take a slightly paranoid edge about some of the things he says, could I stress that for much of my career I worked in selling and installing systems and taking flack in much the same way as he does, although for much smaller types of system, and latterly I worked in a university.

Dr Cundy: I am Paul Cundy. I am a GP. I am the Chairman of the Joint IT Committee for the BMA which represents GPs in the UK and IT issues. In the same paranoid sense, I should also declare that I am the owner and manager of a niche software company that sells to PCTs and other GP system suppliers and practices?

Dr Thomas: I am Martyn Thomas, and I am here on behalf of the UK Computing Research Committee, which is an expert panel of the British Computer Society of the Institution of Engineering and Technology and of the Council of Professors and Heads of Computing in UK Universities.

Q80 Chairman: Once again, welcome. Could I start with a question about the strategic direction of the national programme. You have heard the answer to this question, but I would like to put it to the three of you. The Government is now clearly planning to introduce a central Summary Care Record and a local Detailed Care Record in relation to the programme. Why are two systems necessary? I do not know who would like to start.

Dr Cundy: I am quite happy to have a bash. I recognise your Committee is recognising the volte-face of the programme, because certainly it was true in 2003, when it was first announced as a national programme, it was going to be a single record accessible to anyone anywhere when necessary under the famous three pillars. We now have a very different description, as has been described by Mr Granger, and that is a description which we welcome, but certainly general practice believes that what we should be doing is connecting together the electronic islands that are out there already. So, we believe in a concept of interoperability, and that, therefore, defines each organisation having its own detailed organisational record which has a high degree of relevance to the users in that organisation which exchanges snippets of information (summaries, if you like) through standard-based messaging with other systems where necessary and when necessary. The concept of the Summary Care Record is a concept that some people believe will improve patient safety, and that began as a concept of having a brief extract of terribly important relevant details available wherever you are externally to the local detailed record. The concerns that we have about that is that the Summary Care Record is turning out to be far from a summary care record. We are aware that there are already, even before the evaluation of the pilots is completed, suggestions that the Summary Care Record should also collect data from Choose and Book (i.e. referrals data) and also possibly the electronic prescriptions service. So it is already looking like far more than just a summary record. If that is the case, that raises enormous concerns about consent arrangements, because people are being consented against a summary. It also raises concerns about how you manage a multi-contributor, a multi-organisational record, which is something which has not been tested before. I believe that there should be local detailed records at the level of organisation and whether you want a summary care record or not is possibly a worthwhile experiment.

Dr Thomas: As computing experts, we simply do not want to comment on the clinical need because it is not our expertise. What concerns us is the fact that a very large programme is underway when the specification is not yet clear and keeps changing. At best, that is a grossly inefficient way of developing large IT systems and, indeed, of bringing about large-scale organisational change and, at worst, it is a way that cannot succeed, but time will tell.

Q81 Chairman: On that issue of the specification changing, you suggest Dr Cundy, that you are unhappy with the model of X number of years ago which was going to be a national Spine with 60 million patient records on it accessible from Lands End, not quite to John O'Groats because it stops at the Scottish border, but, anyway, Berwick or beyond. It seems, under those circumstances, that has changed. You are suggesting that the summary situation might be a bit difficult for you as well. I used the expression "political compromise"; maybe I will drop the politics out of this. It was a consensus that had to come about because some parts of the profession did not like the idea of patient records being, presumably, beyond the immediate institution that they live in. Is that a crude and wrong analysis of the situation?

Dr Cundy: It is a perfectly fair observation. Whether it is true, I think I would dispute. I think one of the points to make is that general practitioners have enormous experience of dealing with complex electronic records. Despite the description that Mr Granger gave of general practice systems at the moment, they are world-beating systems. I have a system that I can go from the documents, the letters on my patients, through the pathology results in a couple of mouse clicks to a graph of all their blood pressure observations since inception. We have now recently developed technology, through a project which was begun before the national programme, to exchange GP records wholesale from one practice to another. Six hundred practices in the country have that, and it is almost getting on for 10%, and that exchange can occur in a matter of minutes. If you can exchange information, share information in that fashion, that therefore must question your concept of sharing information under the programme, which is to put it all into one single bucket which may represent mirrors of information held elsewhere and control access to that bucket. We believe that is something which has been untested but we suspect it is something which is probably unmanageable and potentially unsafe because, if we pick up on a point

which was made earlier, different doctors need different information. As Gillian Braunold said, I do not want to know every single potassium result from a patient of mine while they spend ten days in the cardiac dependency unit of the local hospital. What I want to know is that they went in, when they went in, what the diagnosis was, when they came out and what drugs they were on, and that can be sent to me in a completely different way to my having to go into a single large data repository.

Q82 Chairman: It strikes me—this is a general point about the programme—that it is ambitious to say the least, but if you go back hundreds of years in medical history, some of the things that doctors were doing at the time which made major breakthroughs people were sceptical about. People turned round and were questioning what even their peer groups were doing in terms of whether that was the right thing to do, and yet at the beginning of the twenty-first century, certainly in this country, life-expectancy and everything else (until in quite recent years we have children and obesity) has been pretty incredible in terms of the extension of it, and the quality of our life as well has greatly improved because of people doing things for the first time. Quite frankly, if people were questioning it on the basis, "We do not think it will work", or, "It might not be manageable", we may not have made the progress through the centuries that we have done in society in general and throughout the world. Do you not think that this sort of questioning of potentially every little minutiae is something that is non-progressive, for want of a better expression?
Dr Cundy: I am not a Luddite. Most GPs are not Luddites. We are actually pushing for things. Even now that the programme is not delivering the programme we would like to deliver, we have been pushing. That is why our systems are so well developed. I think sometimes the problem is that the agenda we are pushing for is a different one, and that may be because of the position we inhabit in the NHS, which is that we are the guardian of the life-long record. I totally agree that you have to try things, but do you want to conduct your experiment on 56 million patient records or do you want to try some pilots first; and the initial proposal was an experiment on 56 million records, and that was a view that we did not share.

Q83 Chairman: I will move on. I want to ask specifically Andrew Hawker. You argue that all clinical information should be held locally with only a unique patient identifier on the central system. What would be the advantage of this approach?
Mr Hawker: I would echo the earlier comment: you then have absolutely no doubt to whom that information belongs, who is actually managing it, accountable for it, and so on. It seems to me that we are drifting almost into a situation where you have a hybrid system, you have local and national records; it is not clear to me who actually is finally responsible for one or the other. Also, at the same time, and I hope we will come back to this, we are being invited to give, in effect, two kinds of consent. There is one sort of consent if it goes on something called a care record, but there will be some other kind of consent process for the local record—that is as it comes across to me—and both of these do not seem to be a very well thought out philosophy.

Q84 Chairman: Dr Thomas, you wanted to say something?
Dr Thomas: Yes. It seems to me that there are two issues that are being run together here. The overall objectives of the system seem to be trying to tackle two problems in parallel and those two issues are perhaps in conflict. On the one hand, there is the question of putting in good IT to support the clinicians supporting the patients, and I think everybody in the NHS is entirely behind that. Where IT can improve healthcare, it is sensible to deploy it once you are in a position to be able to be able to roll it out without disturbing things too much. There is also the issue of transforming the way that the Health Service operates and the way that the Health Service is managed and the need for information to be available in order to be able to change the management structures. I suspect that there are a lot of stakeholders throughout the Health Service who are resistant to the notion of change of management. That would be absolutely normal in any large organisation. Bringing those two things together and trying to use the IT programme as a facilitator for bringing about managerial and organisational changes that have not already been agreed is, in my experience, never successful.

Q85 Chairman: I am very tempted to refer you back to the report we did on workforce planning, but I do not think we will go there. We are trying to get some sleep without the thought of it at the moment! Is it not really saying the Summary Care Record we are getting is basically because the Government has admitted it can produce what it wanted to do in terms of a national electronic record and, in a sense, they have failed to do that and so this is the compromise that I talked about earlier?
Dr Thomas: I was listening very carefully to the answers you got when you were asking your earlier witnesses about that and it seemed to me that they contained a lot of contradictions and lack of clarity about what they really were trying to do. The notion that you could introduce a Summary Care Record and then use it as the Local Care Record, because it had the flexibility to enable local care groups to upload whatever information they wanted to and could agree to actually share amongst themselves, looks to me like a specification creep that is highly likely to undermine the security policies that are being put in place: because now you are starting to handle data, where at the time you designed the security policies you did not necessarily know that that data was going to be available in that record. So, whilst I sympathise greatly with the motivations of Mr Granger and his team and their enthusiasm for using modern technology (and I sympathise very strongly with the difficulties they have got in actually working out exactly what they can do and on what timescales and what is practical), to do it in the

context of a national programme with declared goals and declared roll-out targets and declared implementations in hospitals across the country and then actually to run a programme which is exploratory in nature is just a backward way of running a very large project, it seems to me. I imagine Mr Granger has got trapped into it by the politics of it. I am not accusing him of incompetence at all, I am saying that, having seen what is happening, we need to back off and say; "let us plan this, so that we can maximise the progress we can make and minimise the financial and timescale risks and contingent damage that we might do to the Health Service in the process".

Q86 Chairman: How do you get large projects if you do not do it like this?
Dr Thomas: Every large successful project is grown out of a successful small project.

Q87 Dr Naysmith: Can I ask Dr Thomas a very quick question. I have seen quite a few computer projects over the last ten, 15 years in local authorities, in universities and in government, and almost every one suffers from this "specification creep" that you are talking about. As people get to know about a project they want to bolt new things in. It happens, in my experience, in every computer project, whether it is large or small, and the clever thing to do is to manage it and stop it at the right point. Is that nonsense or is there some truth in what I have just said?
Dr Thomas: There are two sources of specification change. One is genuine specification change where people discover new requirements or, while a project is actually being developed, the world changes around them and they have to change it; and the other is specification changes that occur simply because you did not investigate the specification well enough at the beginning and, therefore, you discover holes in your own understanding of what the situation always was and always would have been.

Q88 Dr Naysmith: What I am putting to you is that nearly always happens?
Dr Thomas: It nearly always happens because the current style for developing a computing project is simply broken. If you are building a large building, which can very often be an organisational change process as well, what you do is bring in an architect and the architect works with you to really understand your requirements. They formalise those requirements, they come up with high level design and, in the process, they uncover all sorts of conflicts, contradictions, things that you had not heard of. They can bring to bear their own experience in those sorts of buildings, help you to really understand your requirements; then they move round to your side of the table and actually put out a contract to procure the building that has been designed. We do not do that at the moment in IT systems. We put out a contract to procure on the basis of the ill-founded, contradictory specifications with holes in and then, astonishingly, it goes wrong. Of course it goes wrong.

Q89 Dr Naysmith: So your criticism is not just of this project, it is of nearly all?
Dr Thomas: It is of nearly all projects, but this is a project where perhaps we have got a chance of saying: "Hold your horses. We can get to where you want to get to faster, cheaper and at lower risk if we simply reassess what you are doing and can get rid of some of the baggage of having to live up to promises made by people in the past."

Q90 Sandra Gidley: A question for Dr Thomas. Your submission argued that the electronic records system should be introduced as a series of small systems that can be built up into a national system rather than what is happening. The Government seems to be doing the complete opposite of what you are advocating in your submission.
Dr Thomas: Yes. Really what I am saying is what I said earlier: that successful large systems grow out of successful smaller systems. I do not want to really propose technical solutions because I do not believe that the specification, the requirements, are really very well understood yet. So, my instinct would be to do lots of prototyping and work with the clinicians in the frontline to really find out what works for them, what they are happy with, what works with their patients, and then to stand back and decide what you want to do on a national basis, talking to a group of people who now understand the power of the technology better because they have worked with the prototypes, and where you have managed to evolve specifications that have come out of the real experience of the clinicians who will need to use them.

Q91 Sandra Gidley: I may have misunderstood. I got the impression that you were talking about different systems joining together potentially, which would surely have problems if they did not interact with each other?
Dr Thomas: It is generally a better architecture for a large system to have a lot of individual components which can then fail independently, because fail they will, without actually causing widespread disruption. So, if you can build large systems out of small systems which intercommunicate in a standard way, that gives you a much more resilient architecture. One of our concerns is that there does not appear to be an overall dependability case for the national programme.

Q92 Sandra Gidley: A dependability case?
Dr Thomas: There does not appear to be a structured argument that says: here are the quantified goals for the availability of the system, for the reliability of the overall system, for the accuracy of the data, for the number of security breaches that are tolerable—those sorts of issues—and here is a structured argument based on sound evidence that the systems we are building will actually deliver those quantified, dependability objectives. A group of us asked Mr Granger whether such a case was being prepared, and he said he did not have the information to do that because it was actually proprietary to his

suppliers. Therefore his team, by implication, was not in a position to assess the dependability of what they were buying. I was taken aback.

Q93 Sandra Gidley: There are no examples in the past of the sort of approach you are advocating failing?
Dr Thomas: It would be an appalling thing to do, to claim there are no examples of any kind of system architecture failing. I think the computing profession has managed to fail in almost every conceivable way so far, and no doubt will continue to do so, but that is true of all new engineering disciplines. You learn from your failures.

Q94 Chairman: Can I ask you a quick question, Dr Thomas. You wanted everything at the beginning of the journey, as it were, which is the ideal world for anybody who is involved in engineering—and I am a lapsed engineer given that I have been in politics for a long time now—but what was described this morning and what I picked up now and again were issues that are add-ons to this system like electronic imaging transfer. There are some clinicians who feel it is just a wonderful thing to happen. With the model set out and writ down large at the outset, something like that would presumably have been blocked, "Sorry, we cannot do it because it is not what we have set out to do", which is very reassuring from an engineering point of view that this is the project that you are going to deliver over time, *et cetera*. So, from an engineer's point of view, would it limit the ability to be able to do things like add-ons that we have heard about this morning?
Dr Thomas: Clearly you are not a lapsed engineer: once an engineer you are always an engineer; the engineering understanding will never leave you.
Jim Dowd: It is just that he was not a very good one.

Q95 Chairman: Which is how I ended up here, but that is by the by.
Dr Thomas: I am not suggesting for a moment that you should have come up with a specification for all the things that you wanted to do that was completely locked down and that you were not prepared to change.

Q96 Chairman: I just wonder, if it was an add-on in the view that it was not thought about when people sat round in a room and developed this, a system that was rigid would block it off.
Dr Thomas: No, I think the programme could quite reasonably have said: "There are a lot of point solutions in healthcare. We are introducing specific systems to support specific activities that are actually independent and do not need to be highly connected into other parts of the system or the overall architecture. It would be a very powerful thing to do, so let us have a budget for doing that because they will come up." One of my concerns about the way that the programme is going is that it is in danger of locking itself out of the advances that will be made in the availability of healthcare systems around the world. In setting out to be a leader and to develop standards which it hopes will be adopted elsewhere, there is a danger of investing a very large amount in architecture, in software, and so on, which rapidly becomes obsolete in that other people have come up with better solutions and you cannot easily swap them in because you have built something that is too highly integrated.
Dr Cundy: I think that one of the significant failings of the programme was that they did not consult with the user-base whilst they were developing their specification. A good example of that is that, whilst Mr Granger in his first year was dealing with the LSP contracts, we were negotiating our new GP contract, and we signed that off in April 2003. The contracts for the LSPs were signed off in November 2003 and it was not until after that that someone said to him, "Did you not know that there are things in our contract that you have got to deliver", such as the add-ons that he was talking about, QMAS, GP to GP, and he did not know about those; and the LSPs were going round giving presentations to GPs saying, "This is a system we are going to give you, something fantastic. It will give you pathology results", and the GPs were saying, "We have had that for five years." PACS is another good example. Many of the PACS systems being installed now are the PACS systems that were on order books in 2001 to 2004 that were put on hold because a new programme came along. They are essentially the same systems. They will be the eighth version, but they are basically the same product but under a different procurement mechanism. What happened was the programme came along, said, "We are going to do this", and trusts said, "We actually need a PACS system", so that was then brought in. The failure was not adequately understanding the market that Mr Granger was procuring for. He went out and procured, under his experience of procuring, where he has procured before, but he did not put enough time into consulting with the users what it was they needed to deliver the programme. If that had been done, we would have had a much more incremental "building on what we have already got" approach, which I think would have been more successful.

Q97 Mr Amess: Listening to you three gentleman, I think it is a great shame that the three previous witnesses cleared off as soon as you started. I would like to have seen the six of you together, a bit of creative tension, and got the inquiry off to a bit of a bang. All they are going to have to do is read about what you have said, but it cannot be helped. Where is your practice, Dr Cundy?
Dr Cundy: I am in Wimbledon Village, a very informed and affluent population.
Mr Amess: It sure is.

Q98 Jim Dowd: Hardly part of the inner city, is it?
Dr Cundy: No.

Q99 Mr Amess: Dr Cundy, is it a good thing that general practitioners will be offered a choice of suppliers for their electronic record system and does

the decision to offer choice represent a change of direction by Connecting for Health and will it mean a less centralising approach to these issues?
Dr Cundy: It is not a good thing because it is illustrating the precise point I was making earlier. Our new contracts specify that GPs would have a choice of system from a list of accredited systems. That was negotiated between 2002, signed off in 2003. In 2003 Mr Granger signed contracts with the LSPs but did not have GP choice in them. It has taken us three years to get to the stage where we are now, where we are about to let the contracts with the GP suppliers that will give us what should have been delivered in our new contract of 2003. From that point of view it is a very good thing, because it is what the Government is delivering on what it committed to three years ago, but from the point of view is it a good thing as a result of the programme? No, it is not, it has been held back three years by the programme. If they had properly consulted the market place, we would not be three years late with it. Is it a good thing that we have lots of different systems to choose from? Yes, and we have been through this iteration before. I have been in IT now for far too many years, Chairman of the IT Committee for 11 years and I have seen this thing cycled. Prior to the programme we had a thing called RFA (Requirements for Accreditation), which was an attempt to get systems to work together to common standards. That largely failed because the procurement side of it was not aggressive enough, did not have enough teeth. That resulted in a market place where there were about 31 different systems that you could purchase from. Mr Granger's intention was to throw all those away and have, effectively, two or three systems for everyone. That has rolled back and we now have a situation where yesterday we were evaluating applications from nine different systems, which is probably a healthy and vibrant market. It means we will have suppliers who will have to be competing in a properly funded market, on a level playing field, simply on the basis of user functionality, and that is, in my opinion, an ideal position to get to, but it is a position which we negotiated in our new contract, it was not delivered to us by the programme.

Q100 Mr Amess: It does not reflect very well at all on the gentlemen responsible for this and it is a very poor example of joined up government. Is there a financial cost in all this in terms of the delay and the less than satisfactory approach?
Dr Cundy: My only comment is that we offered to meet Mr Granger very early on after he was appointed in early 2003 so that we could explain to him that we had---. This is addressing another point he made earlier. General practice views on what GPs want for IT are actually very clear-cut. There is one committee, it has representatives from the Royal College, GPC, which is effectively the union, and people who use systems. We have a very clear established structure for defining what we want, which is how we were able to very clearly place it in our new contract. If he had come to us and said, "What is it you want?", we would have given him a very clear picture and it may be that the LSP situation would have been different, but it may also be that he was told, under political direction, not to deliver it. I do not know. One can become very paranoid.

Q101 Mr Amess: Very interesting. How I wish he were here now to respond to those points. Finally, Dr Cundy and Dr Thomas, if general practitioners are to have a choice of supplier, should not hospitals and other care providers also have a choice? I am sorry you are being left out of this, Mr Hawker, but you have got more fish to fry later.
Dr Cundy: Yes.
Dr Thomas: Yes, I would think that is almost certainly the best solution.

Q102 Chairman: It leads me into a question in relation to that. I looked at news of IT in my local health economy in the mid nineties. I went to my local hospital, which is now a star via Gerry Robinson on BBC television, Rotherham Hospital, and they have just installed a wonderful PAS system. I actually watched a nurse fill in electronically the discharge, and got the keyboard out, for a patient who was going to be discharged from that ward on that day, and I said, "That is wonderful." I said, "How long will it be before it gets to her GP", and I was told that actually the discharge letters are printed off at night, on the night shift, when the hospital is quiet and hopefully patients are sleeping, and sent out to their general practitioner by mail. I said, "What if someone wanted some immediate help in the community, like a nurse to call round the day they get back at home"? "We phone the local GP up and tell them, or tell the local district nurses that this individual might need that type of help." That was choice inside the National Health Service in the mid 1990s, but my hospital system did not have the ability to talk electronically, to send the discharge papers through to the local GP surgery that was involved in the care of that patient once she had left Rotherham Hospital premises. People have a responsibility and ministers and others have a responsibility both to patients in those circumstances and to taxpayers, but choice is coherent, in as much as we are able to have systems and IT in the National Health Service that does have the ability to do pretty fundamental things like talk to one another and assist patient care. Would you dispute that?
Dr Cundy: No, I would not. I became Chairman of my committee in 1995. In July 1995 I coined the phrase at the British Computing Society Primary Healthcare Group "the electronic islands of the NHS" and the concept of interoperability is precisely what you are talking about. You want the electronic island of hospital to be able to communicate a meaningful message about a patient to the electronic island that is relevant (i.e. the general practice), but it could be the chiropody service or the speech therapist, and that is precisely what interoperability is about and I believe that is precisely what you are seeing the programme now moving towards.

Q103 Chairman: "Moving towards"—after 10 years?
Dr Cundy: That is the message that I heard from Mr Granger's submission, but interoperability is a word that we were bandying around in 1995.

Q104 Chairman: It seemed to me from, both a patient care point of view and a taxpayers point of view, that both of these institutions in terms of the hospital, the acute and the primary sector at local level were funded out of general taxation no matter how it was procured, but there was no link up between procurement and it is complete nonsense, as far as I was concerned, from the use of public money. From the point of view of the GP surgery, I have no doubt that managing patient records electronically, *et cetera*, as opposed to Lloyd George's records, was a lot better—I accept that entirely—but the ability for patient care seemed to be lacking in that respect if we were relying on phone calls and somebody being there to receive the phone call because Mrs B was being discharged that day. I actually thought that that is what the national programme was about, to make sure we did not have that. In a sense it was choice, but it was sensible choice on systems that were compatible, or interoperable, as we now call it?
Dr Cundy: You will be interested to know that in the late 1990s there was a pilot in Kettering where they did precisely do that, they created an electronic discharge for somebody that was communicated electronically within seconds to a local GP surgery.

Q105 Chairman: Why do you think the delivery of the new electronic record system is so far behind schedule?
Mr Hawker: I wish I knew. I was hoping to find out this morning, and I am not really very much clearer, Chairman.
Jim Dowd: We ask the questions. We do not give the answers.

Q106 Chairman: None of us came into politics to answer questions. Dr Thomas.
Dr Thomas: At the time when the schedule was established, they did not know what it was that they were trying to deliver. They had a view as to what it was, but it was not a clear view and it has changed subsequently. It is clear, just from listening this morning, that the specification is still evolving. Under those circumstances, any schedule that you put together, any plan for delivery, is built on sand because you do not know how long it is going to take you to do something if you do not know what it is you are going to do yet.

Q107 Chairman: But it must be the case with a lot of IT programmes, small or large, that things evolve as things go on. Back in the eighties I sat down and talked to software engineers, and I was asking them, "Could you do X and Y?" and we used to add things on on quite a regular basis because it was not set. In actual fact, do you think, as somebody involved in this, that even parameters agreed now, there will not be the same parameters in five years' time, they will have moved on, because it is not a set thing, it is an evolving thing, is it not?
Dr Thomas: Yes, but you need to look at the context. If you are building a single system for a single group of users and it does not need to be highly dependable, then you can use what the industry these days calls 'agile methods'. You can actually work with the users evolving the requirement, building things, delivering functionality, and every week you give them additional functionality. If they do not like it you come in and change it. You can work with people to deliver that, but that would involve having teams of people working with each delivery site developing systems that were unique to them. That is not what the national programme set out to do and, in an organisation the scale of the Health Service, frankly, I do not think it would have been practical to work in that sort of way. Also, you have real problems with the properties of systems that are system level properties. Things like security are only partly dependent on the security of the components, they are really properties that emerge from the integration of components into an overall system, and, therefore, you really do need to plan those carefully from the beginning and to understand what it is you are trying to achieve in those areas from the beginning. The approach that you are describing works wonderfully if you are building an individual website for a commercial customer. It would not have worked in this context.

Q108 Chairman: No, we would not have had the interoperability that we have with this system.
Dr Thomas: No, you do need some central planning for the standards, for interoperability, of course.
Chairman: I think we are going to move on a little now to patient consent and ask Richard to come in.

Q109 Dr Taylor: I hope you will allow me to make two comments before I move on to patient consent. I am echoing David. It is so good to have you three after the bland platitudes we had from the first lot—absolutely refreshing. We were told user involvement was there from the beginning, and you said obviously it was not. Delays have been caused. All the communications were in place in the early 1990s in some hospitals, so it is very refreshing. I wonder if Dr Thomas would agree with one of the experts who has written to us: "To an experienced computer person this system bears all the hallmarks of massive failure. It is simply too big to design, plan, estimate, manage, implement, verify, install and keep alive"?
Dr Thomas: Yes, I would agree with that, the way that it is going. I do not think it is impossible to deliver high quality IT systems to support the Health Service, but I do think it is important to be clear what you are trying to do and, in particular, if part of your objective is to transform the way the clinicians work, then you better design new ways of working and get them agreed before you try to build the systems to support those ways of working.

Q110 Dr Taylor: Thank you very much. I will move on now to consent. Mr Hawker, you have been particularly worried about this. Do you think patients are being given enough information to make sensible decisions about whether their data should be placed on the record or not?
Mr Hawker: If I could move to the Care Record Guarantee, which earlier, I think, we were given to understand is the measure of reassurance that we are meant to have before signing up for the Spine, there seem to me one or two things that I would challenge within the guarantee. My first problem with that is that I do not actually believe some of the things it says. Secondly, a guarantee, so-called, would normally be forever. You do not buy a washing machine with a guarantee and then a year later receive a new version that says, "We have decided after all we do not really feel like doing this particular kind of repair", or whatever, whereas there have been changes over the past five years. In 2003 we were all being told that you have a right to object to information being passed on, even if it is to someone who might provide essential health care—that is 2003—and then the first version of the guarantee said, "You can choose not to have information in your electronic care records shared", but the version we now have has this interesting word, "Usually you can choose to limit how we share the information in your care records." I am sitting at the bottom of the pile reading these things and feeling a little uneasy, because I am being given this document that we are assured everybody reads avidly. I find that very hard to believe, because I have read it many times and it is absolutely covered with question marks and things that I do not quite understand are going on.

Q111 Dr Taylor: Could we know what the document is?
Mr Hawker: Yes, it is the Care Record Guarantee.

Q112 Dr Taylor: Is that sent to everybody?
Mr Hawker: I believe so. I would stress this is called a "guarantee" of how your records will be handled, and it may be premature to raise some of the things, but it does, for example, say that security will be operated in line with internationally approved information security standards. I have various reasons for not believing that, for one thing.
Dr Thomas: It is effectively a meaningless claim. It is not of any technical significance to say that.

Q113 Chairman: No, but you heard the witnesses saying earlier that anything that is done with this patient record will be covered by, if you like, the law and the regulations of this country and international as well. Is that not saying the same thing?
Dr Thomas: Yes, and strongly implying that that meant no change to the position that the patients are in, but once the records are electronically accessible the demand for secondary use goes up and the ease of secondary use goes up, and so a lot of patients whose privacy was never really under threat with paper records, because it would simply have been too hard to go and trawl through large numbers of those records, are now potentially at risk without having changed the legal framework.

Q114 Chairman: That could be said of an electronic doctors practice that has got 10,000 patient records. It would be very difficult for you to go scooping through all of Lloyd George's records to find these individuals but you could go straight into—
Dr Thomas: Absolutely. I do not have the data, but it may be that the police are now routinely asking doctors to give them searches on that data, or it may be that it is legally privileged.
Chairman: I am sorry, Richard. It is not normally something the Chairman does. Please carry on.

Q115 Dr Taylor: Mr Hawker, you mentioned a Department of Health standard letter and the words "concerned" and "distressed". Is there a separate letter, or is that still this blue document?
Mr Hawker: I was sent a document which was headed, rather ominously, "If I do not have a Summary Care Record", in block capitals, and then proceeded to tell me how dangerous that would be for me. I do not want to read the whole thing, but that was the tone of it. It contains a rather interesting sentence which says, "Information in your Summary Care Record could save you and the NHS time, but it could also one day save your life." So this is not just making minor politics, I do not think. It carries on, "The NHS has significant problems with lost records and test results, treatment and prescribing errors and they lead to thousands of preventable deaths and injuries." This is quite ominous stuff, but, frankly, I cannot see the connection. If we create an SCR are we being told that this will eliminate all these lost records and test results? Some of them are the very things that feed into the SCR, i.e. errors in prescribing. Are these all going to be reduced or eliminated simply because we have an SCR. I feel the whole tenor of this is over the top.

Q116 Dr Taylor: You heard the previous witnesses saying 0.001% of people were going to opt out. I forget the figure; it was a not as low as that. Do you think they were accurate with that?
Mr Hawker: I do not know. I can only speak for myself. I am clearly one of the .2%, which on a quick calculation I make to be 100,000 people, which is a whole constituency full, so I do not feel that is a trivial number; but I think here, if you set aside all the political arguments and commercial argument, we have to come back to whether or not an individual patient has the right to say, "I do not want information handled in a particular way", and I was very disturbed to hear the sort of argument that says 98% of people are going to come round, therefore these other troublesome people should be swept aside. That is really taking the IT and making the policy fit round it, and it really ought to be entirely the other way round.

Q117 Dr Taylor: You are absolutely right. Dr Cundy, will GPs agree to upload their systems onto the big system without specific consent from patients?
Dr Cundy: I do not know. The initial indicators from most recent studies are that GPs remain extremely concerned about it. A question was asked, I think by Mr Jackson, about GPs' potential liability if they upload information without knowing whether the patient wants to or not. I believe that contradicts my professional responsibility to protect patients' data. One of the leading medical defence indemnity organisations, the organisations that insure GPs against claims of negligence, has just issued guidance saying that if the GP is not absolutely certain that the patient fully understands and has been fully informed, then he will be liable. I find one of the difficulties about the scope of that, one of the difficulties in this consent debate: it is certainly true that the level of people wanting to opt out of the Summary Care Record, as it is currently described to them, is very, very low. I think that there may be an element of apathy about that, but I certainly know that in my practice patients are more and more wary about what is happening. In fact I actually now have patients who look at the screen, and I say to them, "You are not happy about what we are recording", because they believe that is connected to the Government's computer system. I think that if the Summary Care Record just says you might be allergic to penicillin and you once had a sleeping tablet for a night flight, that maybe is fine, but if it starts becoming a detailed, almost mirror copy of not just a GPs record, because they are proposing to link it to other things (so it has got copies of everything from everywhere), it then becomes a very comprehensive record in relation to which I think patients' view on their consent may change.

Q118 Dr Taylor: Is it realistic to get that degree of consent from patients? Presumably it was the MDU or the MPS that said this?
Dr Cundy: It was the MDU, yes. The debate about whether you should opt in or opt out, ultimately, if you read through everything they have ever produced, comes out to one argument, and that is work-load and rate of uptake. Their own advisory panel said the only argument against it is the rate of uptake. If you have a summary care record, I would like to know in what way is my safety enhanced by your record being there or not being there because I am the patient? So, if I am the only patient on the Summary Care Record and I trip over Mr Granger's carpet in Bradford and my life is saved because I have a Summary Care Record, my life is not threatened by the fact that yours is not there. Therefore, there is no communal safety element; it is simply for the individual to decide. Therefore, why do you have to have an overnight, one-day bulk upload of everything? Most patients will see their GP within three years—statistically 90% of patients will see their GP within three years. Therefore, why cannot you say we will have a slightly slower upload, we will take it on a patient by patient basis? When the patient next comes to see their GP you can discuss whether you want something going on, you can do it slowly over time, and in taking that approach, which is a default opt-in approach, you slowly build the system and that allows time for trust in the system to be developed. One of the problems I have with this system is that it is being imposed on us. In every other element of the NHS we have choice. We can see who we want, when we want, where we want and have what we want done to us except for your record, and that makes me slightly paranoid. Why do they want to do that? So, I would advocate having a default opt-in so everyone is not uploading. As people see their GPs they can then decide to opt in. That spreads out the workload argument as well.
Dr Taylor: The point about choice is a very good one.

Q119 Jim Dowd: Does it exist now with written records?
Dr Cundy: It exists in the sense that—

Q120 Jim Dowd: It is the property of the clinicians and they decide what happens to it. That is what happens now.
Dr Cundy: At the moment with a paper record, you only have one choice of where you put it. In fact my contract says, if I write it, I must write it on a piece of paper sent to me by the Secretary of State, on the MRE, but, yes, you are absolutely right, at the moment if the clinician wants to write a record he can actually write it wherever he likes.

Q121 Jim Dowd: And share it with whoever he chooses?
Dr Cundy: He can, indeed.

Q122 Dr Taylor: But, in theory, the patient has access to all the written notes that are kept now? In theory.
Dr Cundy: No, they have a legal right of access.

Q123 Jim Dowd: So is the fact that it will be so much easier for them if they have got access to their own electronic records going to improve the quality of care, make it more difficult, affect security?
Dr Cundy: I do not know, I have no doubt, I think that is why, to a certain extent, this is an experiment. What I know from my system in my practice is that there are times when I, quite frankly, do not have an immediate clue as to what is going on with a patient, and we have 20 years worth of patient electronic records. Electronic records can be just as confusing as any paper record can be and in my practice I run it very rigidly: my partners are not allowed to do certain things. Despite that, we can still sometimes find it very difficult to not know what we are doing with a particular patient. It can take quite a long time to unravel it. If that is my record on my system that we managed, if I am having to navigate information on a system that is run by someone else, contributed to by lots of different other people, I have no idea whether that will be easy or not. I

suspect it might be potentially difficult, but the answer is I do not know whether it is going to make life better or not.

Q124 Chairman: Can I ask you, Dr Cundy, do you think that summary records have any potential for research or planning in healthcare or do you think they should not have?
Dr Cundy: I think that records should be used as the law currently stands, which means that, if they are anonymised records, then I cannot see any reason why they should not be used for research, but if they are not anonymised, then I do believe that patients should have consensual rights over them.

Q125 Chairman: Have you had that debate within your field, the people that you are working with within this area, about how you could use summary records for research and planning in healthcare?
Dr Cundy: No, I do not think you can use the Summary Care Record because that is clearly identified.

Q126 Chairman: What record would you use then? You have got 20 years of electronic records in your practice. You must have some idea about the well-being or not of a large section of Wimbledon, would you not, and what has happened over decades in terms of healthcare and interaction with drugs in your patients.
Dr Cundy: Yes.

Q127 Chairman: Would it be good to measure that, do you think?
Dr Cundy: Yes, indeed, and we do that on a routine basis on a variety of parameters, but that is a different arrangement. They are patients of my practice, so it is entirely legitimate for me to do that and there is an assumption about consent. I thought what you were asking about was something like SUS, which is a large aggregation of data from different sources, and that being used for research. The circumstances are clearly laid out in law, which is that it should only be used if it is anonymised or with explicit consent.

Q128 Jim Dowd: Could I ask Dr Thomas to start with. I have seen your very distinguished academic record. Have you ever designed and built any systems yourself?
Dr Thomas: Personally designed and built systems, yes.

Q129 Jim Dowd: What sort?
Dr Thomas: Not medical systems.

Q130 Jim Dowd: No technical systems. What were they?
Dr Thomas: The company Praxis that I founded many years ago did do some medical systems development while I was Chairman.

Q131 Jim Dowd: I am sure they did, yes, but what did you do?
Dr Thomas: I have worked on—

Q132 Jim Dowd: Can you give us some idea of the scope and the scale of the systems you have dealt with?
Dr Thomas: I have worked on large-scale operating systems. We have built things for ICL, for example. I actually programmed part of the UNIX implementation that ICL put in as a subsystem of their large operating system. Mostly, in recent years, I have just been managing systems development rather than doing it myself, but, again, some pretty large-scale stuff I have been involved in. I also have audited some large systems. I audited, for example, the new *en route* air traffic control system that was put in down at Swanwick that got into some difficulties. Indeed, it is actually the independent review of the Swanwick system that is my worked example of the way that a select committee can bring about a sensible action by calling for an independent review. Gwyneth Dunwoody's committee instituted that and QinetiQ carried out a thorough review of that system, and it was very helpful.

Q133 Jim Dowd: From what you have said and given the evidence we have received, not just today but beyond, there is no consensus in what this system should do: some people have one view about what it should do and some people have another. Does your prescription of attempting to find that consensus before deciding how to progress really match up to the reality?
Dr Thomas: Yes, I think it does, because I think that there is decades of experience which shows that any other solution has a very high risk of failure.

Q134 Jim Dowd: Most things in life do. Does that surprise you?
Dr Thomas: I think there is plenty of evidence that trying to do organisational change by building computer systems fails and there is plenty of evidence that building large-scale computer systems without getting the specification sorted out at the beginning fails and fails with a much higher probability than if you go about it the other way round.

Q135 Jim Dowd: But if you have a system that meets the maximum requirement expected from the user group as well as the minimum, rather than just the optimal, surely you satisfy everybody?
Dr Thomas: In order to be able to do that you would need to know what the requirements were; so you would still need to engage with the user community to find out the requirements. Whether it is then an appropriate thing to do to try to build the most all-encompassing system you can and give it to everybody, or whether it would be better to have a number of different subset systems that people actually chose between, is a debating point. I would go for the smaller systems, because you do not want—

Q136 Jim Dowd: How do you define "better" and "worse" in your use of language?

Dr Thomas: More dependable, more cost-effective, more likely to achieve the overall objectives within a reasonable cost.

Q137 Jim Dowd: So you are an optimalist rather than a maximalist?
Dr Thomas: Yes, I am an engineer and engineering is a business of making engineering trade-offs. To make sure that you achieve the maximum you can from the minimum expenditure with the highest degree of reliability.

Q138 Jim Dowd: That has clearly changed from when I was involved in it, because our objective there was to give the customers what they wanted and ask them to pay for it.
Dr Thomas: It has moved on from that, because the professional societies now require that engineers take things like safety and general professional behaviour into account rather than just selling people snake oil.

Q139 Jim Dowd: BT say that a Central Record System will be almost impossible to breach. You cast significant doubt on that. What reason do you have for that?
Dr Thomas: It is very difficult to build secure systems and keep them secure. There is a real tension between ease of use and security. The more secure you make a system, the harder it is to use because you have to go through more checks in order to be able to use it. If the intention is to make individuals' records available on the Internet, in order that ordinary members of the public can check their own record, any mechanism that is really robust and that would stop people being able to break through and check somebody else's health record would necessarily have to be quite hard to use and, therefore, finding the appropriate trade-off there is certainly difficult and may even be impossible. It may be that if you had targets for how hard it should be to read somebody else's health record on-line, it would turn out that you could not build a system that was easy enough to use to make it worthwhile having a system at all. One of the things that concerns me about the programme is that there is no definition of what is an acceptable level of security breach. You heard Mr Granger this morning saying clearly that no system would be ultimately secure and, therefore, he accepted that there would be security breaches in his systems. But I have asked him directly whether he has targets for what would be an unacceptable level of security breaches, and he says, "No, I have not." That seems to me to be a mistake, because if you do not know how tolerable it is for a security breach to occur, you do not know how much effort you need to put into building systems that are adequately secure to meet your targets because you do not have the target. So what do you do? Do you go for perfection, which is certainly going to be unachievable but, in any case, is going to lead you down the path of spending vastly more money than you need to have spent, or do you take whatever level of security comes out of the way that you are going to be building the systems within the budget, which may lead to a level of security breaches that turn out to be unacceptable in practice and cause you to have to take the systems off-line?

Q140 Jim Dowd: But your conclusion on the inevitability of a breach is not based on any knowledge of the systems and the architecture that BT have employed but really on a reductive process of experience of previous systems?
Dr Thomas: Absolutely. Nobody outside BT, as far as I am aware, has any insight into the detailed architecture and security policies for the systems they are building. It is confidential.

Q141 Jim Dowd: Nobody outside the BBC thinks they are perfect either, so the idea of getting a solution, I think, will be elusive. Dr Cundy, smartcards and role-based access controls providing effective security in GPs surgeries. Do you agree with that and, if not, what systems do you think should be put in?
Dr Cundy: It has been shown already to be a nonsense. We said that when you issued smartcards, unless they were instantaneous in their ability to access the record you need, they are going to be seen as an imposition, as an obstacle. That is not such a problem in general practice, but in places like A&E departments where patients come in and there is a very rapid turnover and delivery of care, we predicted that what would happen is that someone would come on shift (a hospital doctor, a nurse, a hospital administrator), they would slip their smartcard in, and they would need it, and everyone would just access the records. That is precisely what has happened and, what is more, it has happened with the local agreement of the PCT and I think also, I have to say, the local medical committee.

Q142 Jim Dowd: It is not the smartcards themselves at all, it is the people who use them?
Dr Cundy: It is the people working around something which is seen to be an imposition, and it is part of the trade-off between security and usability. In a general practice it is possible to insist that people log out. We do not actually use the smartcards but you log out when you leave the screen, but in some busy departments it will not be possible. In a theatre, for instance, if a surgeon is operating he might want to know some information about the patient, what does he do: de-glove? So you have immediately got a conflict in what is called role-based access.

Q143 Jim Dowd: What happens presently in a theatre when the surgeon runs into a problem and needs further information?
Dr Cundy: He will probably ask a junior doctor to look through the record; but I think the argument you are heading towards is, because it is not done as well as it could be done now, we should not deal with the systems of the future to be better.

Jim Dowd: That is completely the reverse of my position, but I am only asking questions. What is happening with smartcards is learning to work around them, and so what we need is ever better security technologies.

Q144 Chairman: Can I pursue that a little bit. Is it better technologies? Is not the truth of the case in and around IT that most of the major security issues are human driven?
Dr Cundy: Absolutely.

Q145 Chairman: Is that the case, Dr Thomas? Would you agree with that?
Dr Thomas: There are two main causes of security breaches in socio-technical systems, by which I mean big computer systems embedded in organisations. The human factor is an enormous one. If you want to break a system the thing to do is to corrupt an insider or just to trick an insider, but if you have actually got access to the interfaces to the system and you want to make a technical challenge, then it is usually programming errors, not even design errors but stupid low-level programming mistakes, that give you the ability to break in. That is why systems become vulnerable to viruses and worms, for example.

Q146 Chairman: What happened in banking? My personal bank account records have been electronic for years now, as has presumably the Prime Minister's and everybody who works in this establishment and everybody who works in the UK. There are all these things, not about the human side of it all, about the secure side of it. Why has it not failed? It does not appear to have failed, or has it failed?
Dr Thomas: Yes, it has failed. There is a high level of banking fraud. The banks regard it as confidential information and the policy in the banks is not to have a higher level than the other banks. They do not go for a financial level of fraud reduction. What Barclays care about is whether their record is worse or better than HSBC, but also they care about who is liable for it. It is really a liability issue. One of the main reasons for bringing in chip and pin is that it enabled them to offload liability back on the customer.

Q147 Chairman: That was a fraud about somebody in a restaurant not doing with my card what they should have done. This was not about the system, this was about the input into the system. Is there not a difference when you are talking about security of IT systems?
Dr Cundy: Can I comment on that?

Q148 Chairman: I was asking the engineers to start with, and then I will come on to you two.
Dr Thomas: I do not really understand the question. Banking security gets corrupted in all kinds of ways by phishing attacks on-line.
Jim Dowd: No, that is a software problem. It is a problem with the people who respond to it; it is not a system problem. It is the fact you get an email from somebody who you believe to be your bank wanting all your details and passwords, and some people are gullible and stupid enough—they are probably the people who ring up daytime TV game shows and are wasting their money doing that as well—to turn round and say, "Yes, I will send you my security code", or sending credit card details to unsecured sites!

Q149 Chairman: That is the difference to the security of the system then. You are saying that the security cannot be used as well. My comment is, from a technical point of view, is this going to be as secure as a banking system, not that somebody in a restaurant is going to create fraud by disabusing my credit card when I go to pay my bill? That is a different issue.
Dr Thomas: It is very important to consider that the system is both the technology and the people who interact with it directly. The moment you start focusing just on the technology and on the security of the technology, you miss most of the real problems both in building and making secure.

Q150 Chairman: Should we not go back to live in caves then? Would that be a good idea?
Dr Thomas: No, absolutely not.

Q151 Chairman: Where do we not go back to live in the cave and where do we have an IT system sat in my office over the road there? Where is the judgment on that?
Dr Thomas: I am not arguing that you should not build IT systems and embed them in organisations. What I am saying is that, in deciding what the specification for the technology should be, you actually need to start by looking at the specification for the overall social system and deriving the specification for the technology out of the way that people are genuinely going to behave when faced with the technology. I have been on the steering board for the dependability research project that EPSRC (the research council) has been running, and one of the things that they have done, a big project out of Newcastle, is to send their ethnographers to hospitals to sit and observe for days the way that people do actually work with the systems that they have got in hospitals; and what you see all the time is that people do not use the systems the way that the people who develop them expected them to do. The moment it appears to them that the systems are getting in the way of them doing their job, which they see as treating patients and running the hospital effectively, they start working around the systems. The way in which people work around the systems fall into well-defined patterns, and the psychologists and the social scientists have got a very good handle on the kind of work-arounds that people will use when they start to run into problems, like sharing smartcards, for example. So, you can actually design your technical systems in the knowledge of what will happen under overload situations or crises or where people are just having a bad day and are not working very effectively. You have to do that. The airlines did

not manage to get the accident levels down without taking account of the kinds of errors that pilots made.

Q152 Chairman: Andrew.

Mr Hawker: Comparisons with banks, I think, have come up a few times this morning and there seem to me just one or two dangers. I think Mr Dowd has got his finger on one pulse, and that is that the banks can do a straightforward financial analysis. They can decide: "We will spend this much on security; that will balance against this much we will lose in fraud." You cannot do that with personal records because once my history has escaped it is there, and if it is actually on the Internet it is there for everyone, and that is quite a sobering thought. We are seeing, for example, teachers being the victims of websites organised by their pupils. What happens then if that medical record finds its way onto a site of that kind? I feel at some points we are not looking at the way that technology is happening outside this little world of NHS IT and the way that can have an impact on people, but that is not a problem the banks have. So, if you are trying to make comparisons, I think another useful one might be to look at the kind of internal audit system you will tend to have in a bank and the rather specialised and skilled people that they would employ to do that; and I can find no evidence that within the NHS we have an equivalent kind of privacy skilled auditor internally who can do the sort of investigation and monitoring which forms a part of this social total structure of security which will make me start to believe some of these things in the Care Record Guarantee. What we do have is a steady drizzle of bureaucracy coming out of the Information Governance Toolkit. Chairman, I have read all that. There are 100 different criteria that you meet. You score yourself on those. You go up from one to three on each one and there is a huge problem with that because some of those one, two, three steps are absolutely crucial, like having an information assistance officer or a Caldicott Guardian, others are pure paper work, but you get the same points for each, you add them all up and it goes into a traffic-light rating. Guess which ones people will go for? The other assumption I worry about is that you have all this intense activity but it is all very superficial and it does not add up to a coherent whole. You can score your 70%, or whatever it is, but it does not really mean that you have got the right sort of focused activity within the trust, or the practice, or wherever, and that is where I think you could learn a good deal of lessons from the banks because they have been doing it for longer and there are certain types of people I can identify working in the banking system who are in some ways a worthy adversary for many of the people who attack systems. They are able to think the way they do, they do these kinds of human studies that Dr Thomas has mentioned, so that they are thinking into the mindset. They are not relying on: "We comply with rule 206 in the information toolkit", they are thinking themselves into the problem, and if there is one good thing about the delays, it is that we do have some time to get that right, and I would urge the Committee to try and press that case. Earlier on Dr Gillian Braunold said we have got ten years to go on information governance. That is the problem. We have only recently started going on the information governance programme and, looking at what is happening on the ground, a lot of it is still very embryonic. That is another reason, incidentally, why I have anxieties about trusting this guarantee, because the plans may be there but it is not really happening.

Q153 Chairman: Dr Cundy, did you want to say something?

Dr Cundy: The issue is that what we are talking about is a widely accessible distributed record, the Summary Care Record being available from these 15,000 outlets—I am using the word outlets for them—and security mechanisms, which may or may not exist, which will be overridden by humans. We know that 90% of security breaches are from people employed within the organisation; so we must assume that there will be people who, either by error or with malign intent, will access records that should not be accessed. How do you limit that risk which you cannot limit because you cannot identify the crooks before? You can do one thing: you can alert the person, you can alert after the event, which is a bit of help, but actually the plans for access alerting the audit trails have been massively watered down. My understanding is that the most recent plans are that there will be no alerts from local accessing. For instance, in general practice, if one of my receptionists looked at one of these summary care records, under previous iterations I would have been sent a message saying, "Did you know that your receptionist looked at this patient's record?" That will not be happening because it is a local detailed record, because it is too difficult to manage, because, as Mr Granger says, there are 500 million transactions a day, and I have difficulty enough dealing with 30 or 40 patients, let alone 100 million transactions. The way you deal with that problem, which you cannot stop, is you limit the exposure of the information that you are putting on the system, and that is the trade-off. The trade-off is how accessible is it from how many places against the risk of making that accessible? It would seem innately sensible to me that in a widely accessible system that you cannot really control you should have as little information as possible, that we have a programme which is rolling out something which we know what is going to be in it. We are actually hearing messages that what is going to be in it is much more than we ever conceived. It might actually mirror local detailed records. I think that is an issue that needs to be opened and aired, because patients should have the right to say, "Yes, I am prepared to put my records at risk, I am prepared to put my records on, in effect, what is a sort of plug and play technology." Anyone can come in, plug in, have a look at a record and off they go. If that is a risk that people want, that is fine, but they can only make that assessment if they have informed consent. I think there are many trade-offs, there are many balances here.

Q154 Chairman: You will be pleased to know my final question is directed to Andrew and Martyn. Both of you have suggested that the new system should be independently reviewed and tested before further implementation. What do you think this would achieve? Do you not think that this would really delay the project even further from the alleged delays that we read about now?
Dr Thomas: No, I really do not think it would delay. There is a common myth that planning slows things down. Richard Granger this morning said it would be really nice to have found out what it was we were supposed to have been doing and plan it properly before we started, but it was too urgent to get the systems in and to get the benefits from that and so we just got on with it. I paraphrase him. Yet the consequence of that is that you have two years slippage, and more to come, no doubt, on the care record. I genuinely believe that they are hampered at the moment by the fact that ministers have made promises, that they have published commitments as to the roll out of a particular system, the number of acute trusts that would get particular systems in particular timescales, and that in order to really deliver the sorts of things that the NHS needs and to get the prioritisation right, somehow you have got to shake those things off, and that means getting away from the spin of how successful things are at the moment where typically what you get quoted are input statistics ("We have connected this number of people; there were this number of transactions") rather than output, benefit statistics that actually tell you to what extent healthcare has improved as a consequence of whatever has been done, somehow we have to get away from that and to have a completely independent view as to how well the specification is understood; what can we do rapidly to make the specification of the systems that are going to be built really fit in with the clinical needs? Can we tease apart the issue of providing technical support for technical clinical functions within hospitals from transformation of the Health Service in managerial terms? Is it possible to separate those issues? If it is not, how can we get the appropriate level of organisational buy-in to the specification of the organisational transformations to make it feasible to build the systems that will not be constantly rejected?

Q155 Chairman: That is the suggestion. It is more to do with human resources than the technical issues of the programme, or am I misreading that? I thought you would ask for a technical review, which is something I quoted to Richard Granger earlier as what you had asked for.
Dr Thomas: Yes.

Q156 Chairman: It is a technical review, including human resource aspects in terms of people in the workplace, as opposed to technology in the workplace?
Dr Thomas: It must start with the requirements and how well-founded those requirements are and whether they are complete, whether they are contradictory.

Q157 Chairman: How would a review achieve that, do you think?
Dr Thomas: In the way that reviews always do, by going in and talking to people, by calling for input, by capturing what the programme says the requirements are at the moment, for example, and analysing them.

Q158 Chairman: Going and talking to people up and down the land?
Dr Thomas: If I was, God forbid, asked to carry out such a review, I would start off by looking at all the detailed planning documents and the internal reviews that have been done. We know that consultants have reviewed aspects of the programme, but those reviews are not published. We know that there have been gateway reviews. Those reviews have not been published. The department has refused to release either of those, even under Freedom of Information Act requests. I would start off by trying to find out what actually the current views of the programme are and getting a clear view as to what are the detailed plans, what are the detailed objectives. Let us do a technical review of those plans. How good are they as technical plans? Let us have a look at the risk register. Let us have a look at the project hazard log. Is anybody building a dependability case? Has anybody done a decent safety case for the systems? What plans have been made for the lifetime costs? Is there a proper business justification that shows that the costs actually are less than the benefits that are due to come out? If the answer to any of those questions is, "No", you will have put your finger on something that needs to be fixed urgently.

Q159 Chairman: Do you think that people who are involved in the national IT programme at the moment are aware and conscious of those facts, whether reviews have been published or not in terms of that? Do you think they are not capable of knowing that as something in their daily business, as it were? The programme is not without its problems. Are these people who are developing it not capable of being able to do that?
Dr Thomas: I have reviewed a lot of large technical programmes over the years, and I want to stress, I am not asking to review this one personally, I am not for a second bidding for that job, but my experience of carrying out those reviews is that people get blinded by the fact that they are too close to the project and they get compromised by the fact that they cannot stand back and admit errors. What typically happens is that people start redefining what the milestones meant, in order to claim success for milestones and to put off the day when they have to admit that things have gone wrong, and they start arguing about what it was they really were setting out to do at the beginning, so they start getting a bit weasely about what the specification really was, and the whole business justification is lost because the costs have changed, the specification has changed and the balance between what you are going to get and what it is going to cost you has gone wrong in two directions. The people on the programme are

not motivated to stand back and say that because they have got this vision, "One more heave and we will get there." It takes somebody who does not have a stake in the programme to come in and stand back and say, "The reality is this, and we need to make appropriate changes if we are to achieve sensible things and sensible milestones."

Q160 Chairman: I wonder whether you think it would be an unfair comment, but I think what you have described there in the latter moments is more to do with an inquest than a review. It seems to me that, unless there is anything specific a review would do, most of the issues we have heard about in the last few hours here would be something that would be happening on probably a daily basis, I would have thought. Andrew, you wanted to comment.

Mr Hawker: I did not, in fact, suggest a review, I was trying to be more pragmatic. I did suggest that there should be a test, or some testing that showed that you were actually operating in line with internationally approved information security standards, and, in the end, the simplest way is to have people have a go at getting into it and use other objective measures of whether it is easy or not to get across the security barriers that you have laid down. I think that would be enormously helpful, because you can quote that in your guarantee. You can say, "Look, we have invited these various people to contradict the security and they have failed." If they can do it, then we continue to try to refine it, we learn from that, but simply to draw evermore elaborate models, and so on, I do not think really gets us any further.

Chairman: Could I apologise once again for the lateness of the hour. Could I thank all three of you for coming along. We have had two very interesting, fascinating sessions and I am hopeful than, when our report does come out, it will be a lot more informed because of the two evidence sessions this morning than it has been up to now in terms of what has been floating around in the media. Thank you very much for attending.

Thursday 10 May 2007

Members present:

Rt Hon Kevin Barron, in the Chair

Mr David Amess	Mr Stewart Jackson
Charlotte Atkins	Dr Doug Naysmith
Mr Ronnie Campbell	Mike Penning
Jim Dowd	Dr Howard Stoate
Sandra Gidley	Dr Richard Taylor

Witnesses: **Professor Douwe Korff,** Professor of International Law, London Metropolitan University, **Ms Joyce Robins,** Co-Director, Patient Concern, and **Mr Jonathan Bamford,** Assistant Information Commissioner, Information Commissioner's Office, gave evidence.

Q161 Chairman: I welcome you to the second session of our inquiry into the Electronic Patient Record. For the record, could you introduce yourselves and the positions you hold?

Mr Bamford: I am Jonathan Bamford, Assistant Information Commissioner. Essentially, I am director of data protection development and am responsible for the work of the information commissioner on electronic health records.

Professor Korff: I am Douwe Korff, professor of international law at London Metropolitan University. I am an expert on the European Convention on Human Rights and data protection. I am also on the advisory council of the Foundation for Information Policy Research which made a submission to the Committee.

Ms Robins: I am Joyce Robins, co-director of Patient Concern which is a watchdog group formed seven years ago because it was felt there was a need for a truly independent patient voice.

Q162 Chairman: To start this session I ask a question of all of you. The Government plans to place patients' health data on the new Summary Care Record without their explicit consent provided they do not opt out within a specific period. Is that opt-out approach legal?

Professor Korff: I think that to put data on a particular record depends on a certain legal basis. With free consent almost everything is possible. If data from the Summary Care Record are disclosed to third parties consent will be needed; otherwise, it will be illegal under European law, unless there is very specific statutory regulation.

Ms Robins: I am no lawyer. I am very concerned by the position in which doctors will be put because of this. I sit in the magistrates court. Many people who have been working abroad or visiting families for some months come back to find that court summonses have piled up and they have no knowledge of them. I believe the same will happen here. People will have their data put up in two months' time without their consent. How doctors will defend themselves legally one does not know. It is also the responsibility of the doctor that the patient should be fully informed when data are used. In my view, patients are not being fully informed, as I hope to amplify later.

Mr Bamford: Any personal information on patients must be held in accordance with the Data Protection Act. To do that there must be a proper basis for processing the personal data in the first place, and there is a provision in the Act that allows sensitive data, such as medical matters, to be processed where that is dealt with by a healthcare professional or somebody else who in European terms owes a similar duty of secrecy or, as we say in our law, a duty of confidentiality. On the basis that information is processed by a person who owes that duty it includes people who may be healthcare workers more generally, because the issue of confidentiality pertains to the nature of the information and the circumstances in which it has been provided rather than the nature of the person who processes it. Anybody in the healthcare professions owes a duty of confidentiality. There is a basis for processing it, but that gets one only to the starting line in terms of data protection; as a condition it is a precursor. Therefore, once one has a basis for processing data under the Data Protection Act one needs to make sure that it is done in accordance with the data protection principles. The first principle says that personal data must be processed fairly and lawfully. The issue then arises: is it fair for patient information to be put on a summary care record which will be uploaded on the basis of an opt out or opt in? On the basis that there are some competing interests here, one can argue that some people would want to make the judgment that they do not want their information to go forward. Many others may take the view that healthcare would be improved by a national care system and the ability to facilitate medical treatment in other parts of the country. If like me a person from the North West is on business today in London in relation to those sorts of things fairness can work the other way as well. We take the view that it is entirely consistent with the first data protection principle. If patients are informed that they can exercise a proper choice over what happens to their information on the basis of transparency, and they have the opportunity and time to make that choice, it is consistent with the requirements of the Data Protection Act to provide it on an opt-out basis.

Q163 Chairman: The written submission from the commissioner could be interpreted as saying that the opt out you are talking about would not be

necessary under the Data Protection Act at present. What you are saying quite specifically is that it is. Do you say that effectively if the opt out, which we understand is to be offered—it has been offered in pilot schemes in some parts of the country—was not in place it would be illegal to set up these records?
Mr Bamford: I think it can be argued that it may be unfair in connection with some personal data. Personal data always pertains to individuals and there may be some circumstances in which there is unfairness to individuals if they are not given the chance to exercise their rights in some way. I think we need to be careful about what we are considering here. We recognise that we have a national healthcare system, so the idea that it is not possible to retain any central records of people covered by that system, ie demographic data, is wrong. I think it is acceptable to do that. The issue is to do with the degree to which other information relating to patient care may be available to others beyond the medical practitioner who has the treatment of the individual. Looking at it in the round, with the safeguards in place in terms of summary care records being a subset of the medical records, access to which will be on the basis only of legitimate relationships between those who have some responsibility for care, except in the most exceptional emergencies, which will be audited, the provision of an opt out is a fair and legal way of doing it.

Q164 Dr Stoate: Professor Korff, I have been a GP for a long time. The way it has always worked with the Lloyd George notes is that the physical record belongs to the Secretary of State for Health and the information written in that record is assumed to belong to the GP who writes it. Who owns the information on a computer?
Professor Korff: That is a very old red herring, if I dare say so. The point is not the ownership of the data. In data protection terms you cannot own data as if it is some kind of goods you can sell and do with it as you like as the owner of a car, bicycle or whatever. The whole point about data protection is that it gives individuals rights to control the use of their data. Whether you say that the piece of paper belongs to the NHS or the GP as the guardian of the information on that document is in a way irrelevant to the question of how data protection principles should be applied. Those principles apply if there are data on you or me held somewhere. There are certain strict rules about how they can be used and who can have access to them irrespective of who owns the piece of paper or the computer on which the data are held.

Q165 Dr Stoate: For example, patients cannot go to law and say that they own that data and it cannot be changed and nothing can be done with it because it belongs to them. That is not an avenue they can follow?
Professor Korff: No. Primarily, data protection gives control over it to the subject, in this case the patient.

Q166 Dr Stoate: A recent report from the European Data Protection Working Party stated that "consent in the case of sensitive personal data and therefore in an electronic health record must be 'explicit'. Opt-out solutions will not meet the requirements of being 'explicit'." Does that mean that Connecting for Health's plans go against the law?
Professor Korff: Here you will get an answer different from Mr Bamford's. In a way, you have reached extremely quickly the core of the issue. In my opinion the Data Protection Act is in some respects phrased in too lax a way to meet the European standards. I agree with the European approach which is that there is a need for free and full informed consent for the uploading of data. One major difference between the Act and Directive is that the former gives an exemption for all medical purposes; it is very widely described and includes medical research, whereas the provision about data being treated by people subject to a certain confidentiality requirement referred to by Mr Bamford, which you mentioned earlier, applies effectively only to medical care. I read from the document you just mentioned: "Not covered is further processing which is not required for the direct provision of such services. Not covered is medical research or the subsequent reimbursement of cost by a sickness insurance scheme, or the pursuit of pecuniary claims." That is a massive difference with these kinds of issues. If one uploads the summary care record or the more elaborate care records without making that distinction one is extremely likely to break European law.

Q167 Dr Stoate: This is quite an important issue.
Professor Korff: Very important.

Q168 Dr Stoate: You are quite clear that the current proposals by the Secretary of State for Health would in your view breach European law?
Professor Korff: Absolutely, yes.

Q169 Dr Stoate: Mr Bamford, what do you think about that?
Mr Bamford: I think we need to be careful to read the working party opinion on article 29 in the proper context. It talks through the basis for processing. Once you have established a basis for processing, what safeguards should go with it? When it talks about explicit consent and those sorts of matters it is considering the various conditions that might apply to whether or not there is a basis for processing sensitive data. It is one of those precursor elements to get to the starting line. It talks there about explicit consent as being one basis on which one can process sensitive data. There is another basis on which one can process sensitive data, that is, where it is done by a healthcare professional subject to duties of confidentiality. The UK has not chosen to go down the explicit consent route but to pursue the processing by healthcare professional route with a duty of confidentiality. When it talks about explicit consent we need to be certain whether it is talking about getting to the starting line or about explicit consent in terms of fairness which comes into play

once there is a basis for processing. I know that it is complicated, and that is why the opinion is 22 pages long. Basically, I am saying that in the context of explicit consent in the UK we have gone down a route that does not involve the explicit consent of the patient for the processing of the personal data. We may argue in some other instances to do with a processing activity involving that personal data, such as perhaps a release for medical research, that explicit consent may come back in, but the actual uploading of the Summary Care Record is not based on the explicit consent of the patient.

Q170 Dr Stoate: But the point you have just made is that we have chosen a different route from the rest of the EU.
Mr Bamford: We have not chosen a different route.

Q171 Dr Stoate: We have adopted a different basis.
Mr Bamford: I am just explaining that the article 29 working party paper essentially covers the possibilities in 27 different countries. Some countries, for example France, have gone down the explicit consent route; others like Austria, as I understand it, have said they will pass a law that deals specifically with healthcare records and that is the route they favour. It is possible to have a specific healthcare records law under the EU. In the UK we have just used one of the other facilities that are available. None of these is necessarily right or wrong; they are just different approaches that can be adopted.

Q172 Dr Stoate: It is not a matter of right or wrong, but when somebody decides that he does not like what he has and takes it to European law, as he is quite entitled to do, what happens then? If we have taken a view that is contrary to that of other countries in the EU many people will say that they have a case under European law. What then happens?
Mr Bamford: To clarify the question, are you asking: what rights do people have if they do not like what has happened to their records?

Q173 Dr Stoate: Sooner or later someone will take this to Europe because that is the nature of things. What is likely to happen if that is the case?
Mr Bamford: It would then be a matter for the European Court of Justice to decide whether or not the Data Protection Act provides a proper basis that correctly implements the EU Directive. We would argue that there is a correct basis under the Data Protection Act and that that law correctly implements that EU Directive.

Q174 Dr Stoate: Professor Korff clearly does not agree with you. We have a problem. If we go down a route that affects the records of 50-odd million people and we are getting into problems with European law—we already have two experts who hold contrary views on it—it is not a very good basis to start a process.
Mr Bamford: I do not know whether or not Professor Korff does disagree with me.
Professor Korff: I do disagree.
Mr Bamford: I think that there is a clear basis in UK law for doing what the Department of Health and Connecting for Health have decided to do here. Whether there is some slight differences in the wording between the terms of the European statutes and our domestic statutes is another issue. I sat on the article 29 working party and so I know what went on there. Having sat round that table, I believe everybody recognised that this could be achieved in different ways. What we are talking about are the different ways to achieve it, not that it is necessarily the wrong or unlawful way to do it but whether there is a more favourable or less favourable way to do it. We take the view that this is a lawful way to do it. I do not believe that the article 29 working party is saying anything else.

Q175 Dr Stoate: Professor Korff, how do you view that reply?
Professor Korff: First, I believe that Jonathan is underplaying the status of the working party document. It is a working document, not a final interpretation, but it points out a number of fundamental principles which are quite clear. It is not a matter of saying that this is just an opinion; some of these principles are quite clear. There are two main differences between the Act and the basis upon which the Government seeks to rely in introducing this new healthcare system and the Directive. The first is the difference that has just been pointed out in article 8.3 of the Directive which says that one can process for healthcare reasons, subject to confidentiality. Mr Bamford is quite right that that is an alternative to consent, but that provision in the Directive is narrower than the corresponding one in the Data Protection Act. Therefore, to the extent it is not covered by the Directive it is invalid and one would need consent. It looks tiny but it is not; it covers specifically secondary uses for research purposes which are authorised by the UK Act but not by paragraph 8.3 of the Directive. Mr Bamford can say that we have chosen to go that way. One cannot choose to do something that one is not allowed to do in the Directive. That is a straightforward contradiction between the two. Second, paragraph 8 of schedule 3 of the Data Protection Act—as you will have found out by now, it is a ghastly instrument to read—gives a special exemption. The only way that it can be brought within the Directive is to say that it is one of the special exemptions introduced in article 8.4 of the Directive, but it cannot be for various reasons. It is not specific enough; it does not specify the substantial public interest for which it is introduced. To the best of my knowledge, it has not been notified to the European Commission and therefore it is incompatible with the Directive. Again, one of the major planks on which the whole system is being built is incompatible with the underlying European rules. In addition, Mr Bamford mentioned the European Court of Justice. Quite rightly, the first test would be the compatibility of anything introduced here with the Directive. That would be decided in the European Court of Justice in

Luxembourg, which by the way in the *Lindquist* case was very precise and extensive in its application of these principles. I would be happy to take a case to the European Court of Human Rights in Strasbourg which has also become increasingly aware of and strict in the support of data protection principles. Therefore, to try to say that the UK has a different way of doing things is not good enough if that different way is so outside the European framework such as to violate the fundamental instruments of article 8 of the European Convention on Human Rights and the EU Directive. In my opinion, the system as now proposed violates both.

Dr Stoate: Chairman, this is a rather fundamental point. We have two experts who fundamentally disagree before we have even started the process. One can imagine one might happen as things move along. That has certainly answered my questions.

Q176 Chairman: Professor Korff, if as legislators we were to try to second-guess what would end up in the European Court of Human Rights we would pass very little legislation in this Parliament.

Mr Bamford: Perhaps I may make one point of clarification in terms of other people to whom the Committee may wish to speak. If there is any issue to do with whether the UK Data Protection Act correctly implements the EU Data Protection Directive that is a matter for the Ministry of Justice, as it is now, because that is the body which is responsible for ensuring that we implement the Directive in UK law. If there is a concern about a difference it is for the Ministry of Justice to answer that point. The Information Commissioner is charged with implementing the UK Data Protection Act, and I can give you as many helpful answers as I can about the article 29 working party. I would beseech you to read those conditions again and see them listed as possible and not mutually exclusive alternatives, but I leave the point there. If you have a real concern I believe it is important that you speak to the Ministry of Justice as part of this inquiry.

Q177 Mike Penning: Now that two of our experts have managed to reach complete disagreement on matters of law let us turn to ethics which I believe will be much more controversial. From an ethical standpoint, is it right that patients' data can be placed on an IT system without their explicit consent?

Ms Robins: It is completely wrong. When this scheme was launched we were enthusiastic about it because there are obvious benefits for patients. Records would be easily available and maybe we could see them without having to battle or grovel for them, but as it has gone on we have developed severe misgivings. We were active in the Department of Health's consent initiative four years ago. Since then we and many other groups have worked very hard to try to give patients the confidence to play an active part in their own healthcare. The care records scheme with its assumed consent policy drives a tank through the whole thing. We are back to the old paternalistic idea "We'll do what's good for you; don't you bother your confused little heads." It seems to us that so far so much time and money has been spent on the IT problems and getting the clinicians on board that now there is a push to get it launched at all costs to prove that the money is being well spent and at the end of it patients are being short-changed. If the prime aim is to get 99% coverage we are flying in the face of all medical ethics and to do so it seems that we are relying on three things: inertia, lack of knowledge and fear. That is an extremely worrying precedent for all future consent and confidentiality issues. Perhaps I may quickly refer you to the leaflet that is going out to people in Bolton who are involved in the scheme right now. We have five pages of flimflam. The back page gives a helpline that can be phoned for further information. Right at the bottom in tiny print one sees: "If you want to see what's in your Summary Care Record or you don't want a Summary Care Record at all ask someone in your GP surgery to discuss it with you." The message to patients is that they will be leaned on. Last time I was here terms such as "privacy fascists" and "Luddites" were used. I realise that there are careers to be made here and gongs to be won, but it seems to me to indicate the attitude that patients are likely to meet if they go along with any concerns. I know from my work at Patient Concern that any patient who rings us with a problem about his or her GP will say, "I can't complain because I'll be struck off the list." This will be a real patient fear in this case. I know that it does not happen often; it is a bit like being mugged in the street. It does not happen often but it is a fear in everybody's mind.

Q178 Mike Penning: Professor Korff, does this fly in the face of medical ethics?

Professor Korff: If I may, I think the best thing is to quote the Data Protection Authority's interesting study in 2002 into anonymisation in the healthcare system. It looked at the implications of certain massive systems. It says one of the problems is that the individual human being becomes no longer a subject but an object, a carrier of data, a cost factor, a risk potential, a resource or a production factor. That is exactly what has happened. I think it is unethical to do this kind of thing without the consent of the data subject.

Q179 Mike Penning: Mr Bamford, do you agree that it flies in the face of ethical standards?

Mr Bamford: I would not set myself up as an expert on medical ethics.

Q180 Mike Penning: What do you say as a patient?

Mr Bamford: In terms of record-keeping and data protection people in general have no absolute right, except perhaps in the case of direct marketing, to say that they do not want records about them to be held. If there was such an absolute right I suspect that the police national computer would not have very many records on it.

Q181 Mike Penning: There is a difference between a criminal and a patient. I do not see that link at all.

Mr Bamford: I am not making a link but explaining why there is no absolute right for data subjects as individuals to say that information should not be held about them. In the medical context it is not possible generally for individuals to say that information cannot be held about them unless they can prove they will suffer substantial unwarranted damage and distress. That has to be proved. There are good reasons for this. Presumably, a medical practitioner wants to keep records of the treatment that he has given a patient and that is usually in the patient's record. A GP can be subject to action and he will have to defend his action perhaps in terms of the prescriptions he has issued. Therefore, the idea that a patient can say, "Don't keep any records on me", and then come back at a later point and say, "You were negligent in the way you treated me", and the doctor says he has no records and it cannot be proved one way or the other, is unfortunate in the extreme. There are balances of interest.

Q182 Mike Penning: That is a very long answer to a question which, with respect, I have not asked. My question is to do with ethics, not whether or not there is a legal reason to hold records. That is a separate issue which I believe you addressed in previous answers. As a patient, from an ethical point of view—you cannot answer it from a medical point of view—is there a problem with these records being held on a new IT system, yes or no?
Mr Bamford: I thought I was answering the question by saying I do not think there is an ethical problem if it is accepted that it is right for a medical practitioner to be able to keep a record of his patients.

Q183 Mike Penning: The Government has produced an opt-out system. Is there an alternative to that system? Clearly, it is saying that one can opt out, though it is quite complicated. Can you think of a better alternative system?
Mr Bamford: I can certainly think of alternative systems which would be an opt-in system where every patient would be asked what he or she wants to happen to the records before a Summary Care Record is uploaded.

Q184 Mike Penning: Why is that not being used by the Government?
Mr Bamford: I think the practicalities of doing that are huge. At the end of the day we have a national health system in the UK, so some elements of national records may be appropriate. The issue for us is the extent to which individuals know what is happening. We have been insistent with Connecting for Health, which originally was going to send out only a head-of-household mailing, that mailings should go to individual patients to make sure they are given information about the choices available to them and they have adequate opportunity to exercise those choices. I understand the comments of Ms Robins. From my point of view, in the discussions with Connecting for Health we were told it was important that medical practitioners help people make their decisions because they had to understand the consequences of what they were being told. We did not see it as an arm-twisting exercise; it was making sure that people had proper information on which to make choices that might be hard to convey in a leaflet.

Q185 Mike Penning: It is quite difficult to make a choice if you are automatically in. Most people will not know that. Professor Korff, do you see an alternative to the Government's opt out?
Professor Korff: Yes. First, perhaps I may comment on Mr Bamford's remarks about the opt out. Again, there is a discrepancy here between the Directive and UK law.

Q186 Mike Penning: That does not surprise me.
Professor Korff: One can opt out under the Act only if one can show that one will suffer substantial and unwarranted damage and distress. That is a phrase that you will not find in the Directive. The equivalent in the Directive is that if one has a justified objection one's wishes must be accommodated. If people are worried because they are HIV positive—I gave a speech to such a conference the other day—or because as young women they had abortions that is a justified objection to the data being uploaded. As I understand it, that is not being accommodated because the UK Act provides a bigger hurdle than is allowed under European law. It is a really serious problem. Mr Bamford says that the Information Commissioner just talks about the compatibility of this exercise with the Act and does not want to talk about the compatibility of the Act with European law. I find it very short-sighted. If I was the Information Commissioner I would take a broader view of my powers, but it is up to the commissioner to do that. By all means ask the Ministry of Justice or Department for Constitutional Affairs. I believe that if they look carefully at the law they will find incompatibilities that affect the very basis of what we are talking about here.

Q187 Mike Penning: Ms Robins, on Friday I had a constituent in my surgery who for personal reasons did not want her previous medical records to go onto the IT system. Is there a better system than the Government's opt out, because it sounds as though she will not be able to opt out?
Ms Robins: She cannot have a Summary Care Record put on; certainly that has been agreed. I know that the Department of Health and maybe lots of others would like it to be mandatory, but it is not. We can opt out. My problem at the moment is that informed consent cannot be given unless a person knows what it is. One does not know what it is unless one has seen the record that is going up. It is not that difficult to do. I do not suggest that everyone should sit down with their GPs; that would be ridiculous, but there are other ways. As I said in my submission, the first thing we suggest is that when this bit of rubbish goes out to patients with it should go a copy of the record that is going to go in. Connecting for Health very quickly jumped on me and said that the postal system was not nearly secure enough for that. It is interesting that that is the system on which it is

relying to make sure everyone is informed about it, but never mind. If that is not secure enough why not send a form to people and clearly set out the options? You can see your record and be asked, "If you wish to see your record before it is uploaded tick here"; or, "I have been offered an opportunity to see my record and I do not wish to see it", and you tick there; or, "I do not wish my record uploaded", and you tick here. That does not seem to me to be too difficult or time-consuming, but we do not have that; we have something that deliberately discourages people from doing this. For instance, we are told that part of the record can be invisible. The patient in your surgery can have the sensitive bit of her record not showing when it comes up on the screen and it will be flagged up that she has not given consent to it being seen. When I went to the presentation by Connecting for Health the other week I was amazed to find that that can be overridden with the click of a mouse. A doctor can do it as you sit there with a click of a mouse and without any consent form being signed. Most doctors will act ethically and do it the right way. The patient is there and the GP says that it will be helpful to see it and the patient will say, "All right. I trust you to see it." I have come across plenty of doctors who will not act ethically; they will say they have a difficult patient out in the waiting room who will not tell them everything they want to know and with a click of a mouse consent status is altered. I was appalled to see that that was the case. That is how it is being rolled out at the moment. Patients have no idea that this is going on.

Q188 Mr Amess: I should like to congratulate our clerk for gathering together our witnesses. This is what an evidence session should be about. There is real tension here. I shall do my best to see if we can make it rowdier. This is much more interesting than the rubbish going on at College Green at the moment. Ms Robins, you argued that patients should be able to see what information will be put on the SRC system before it is uploaded. How would this help? Why do you think the Government is not adopting your proposal?
Ms Robins: It is too much trouble. They have said it is not practical. I say that if it is not practical then the scheme is not practical. Under all the informed consent regulations every regulatory body says that there must be informed consent before doctors part with any information about you in any way. If that is how it is that is what we should be doing. Therefore, one has to see it. Another thing patients do not realise, unless they have ever had reason to consult their records, is the number of mistakes in them: 30% of doctors' records contain mistakes. Once that goes up on the computer anybody who has dealt with computers knows what it is like. It is on the computer and that is it; that is fact. As it is it is desperately difficult to alter medical records for very good reasons. The most one can manage to do is have a little note put on the bottom saying that the patient does not agree with it. In the case of summary records it is not too sensitive and the information going up is very limited, but, say, the wrong medication happens to go up. The wrong code can be very easily put up. The patient is treated wrongly. What is then the doctor's legal position? If the patient has seen it and says, "That's not what I am on; I am on something that sounds very much like that", then it can be altered and put right before it is put on. There is a lot of talk about quality control in Connecting for Health. That is where quality control comes in; you see it before it goes on and you make sure it is right.

Q189 Mr Amess: Mr Bamford, what Ms Robins says seems to be commonsense. Why do you disagree with her proposal?
Mr Bamford: I do not want to disappoint you by not arguing with my colleagues, but I agree with a lot of what has been said about the importance of data quality. If you read our evidence you will see that we stress the importance of data quality. One of the features in which we are interested is HealthSpace and the idea that one is able to check the quality of one's own records, the security arrangements around that and we need to understand how those work. But the idea that individuals should be able to see their health records and if they spot a discrepancy or concern voice them is entirely consistent with the requirements of the Data Protection Act. I do not have a problem with that. One of the ideas about going to see the GP to talk about concerns is that that is another opportunity to discuss the information that will be loaded and ensure that it is of the appropriate quality. I agree wholeheartedly that we need to ensure that if information is being put on a system and people believe what computers say it must be of the appropriate quality, but that is not just for the virtuous; it is a requirement of the Data Protection Act. It must be adequate for its purpose and it must be accurate information.

Q190 Mr Amess: Ms Robins, do you really think that Mr Bamford is agreeing with you as he claimed at the start? It does not sound like it to me.
Ms Robins: Not at all. Once it is on HealthSpace it is there; it is uploaded and is a *fait accompli*. We have all seen what happens with websites recently with junior doctors. A lot of patients will wake up to the fact that websites are never secure; whatever you put in place hackers will get in. We had expected some system of smart cards for patients. That was talked about originally. One would go into a secure environment and see it in a secure system, but there is no mention of that any more; it seems to have gone. We now have HealthSpace. The summary records will go on that; there is no plan for the detailed record to go on it. How we get to see that is a question mark for the future.

Q191 Mr Amess: Patients will be able to view their Summary Care Record on the HealthSpace website. Surely, this will allow patients to play a more active role in their own care. When do you expect HealthSpace to be available?

Ms Robins: I do not know when it will be available; it certainly is not available to people in Bolton at the moment. Their records will go up and they have no way of seeing it, unless they go along to their doctors' surgeries. There are a lot of problems about that. People feel that they will be leaned on, and many do not wish to go to their doctors' surgeries. Incidentally, when we rang the helpline to ask whether we could simply write to say we do not want our records to go up we were told that letters were not accepted; we had to make an appointment and go to the surgery. What about people who have great difficulty getting to the surgery? The response was, "Well, we're very sorry; we're not accepting letters. Somehow they have to get there." It is not good enough.

Q192 Mr Amess: Does either of the other two witnesses want to come back on what Ms Robins has just said?

Professor Korff: I make only one point since reference was made to sealed envelopes. It is so important that I do not want to let it pass without a response. In the working party document that the European Data Protection Commissioners have put together there is also reference to sealed envelopes. It has one enormous difference from the sealed envelopes as proposed here. It says: "A sealed envelope should only be openable for each individual instance when a health practitioner wants access to it by the consent of the patient." Therefore, it is not something that can be overridden by anybody except the patient. If a healthcare practitioner wants access to something in the sealed envelope he has to come to me and ask me. Unless I am in a coma or in an accident and emergency ward he will have to ask me and it can be disclosed only if I agree to authorise it, not just generally which is what is proposed for the system, in that specific instance and for that specific treatment. That should be the rule, not that you sign your rights away as soon as the envelope is unsealed.

Q193 Mr Amess: Do you agree with your colleagues?

Mr Bamford: I do not see myself in massive conflict with that. I agree that patient information should be accurate. There is no doubt that the Data Protection Act requires that it be accurate. The next question is: what is the best method of achieving it?

Q194 Mr Amess: What else do you think can be done to give patients more control over their electronic records? Presumably, you do not think they need any more control.

Mr Bamford: I think that as to the mechanisms being set up the proof of the pudding is in the eating, is it not? At the moment we have certain things on pieces of paper which are ideas from the point of view of the Information Commissioner. Some of those are plausible, but it is a matter of how it works in practice. One of the things that we are interested in is how the early adopter sites are working. We have agreements in place with Connecting for Health to be able to go in and inspect one of the early adopter sites to see how certain things have worked in accordance with the Data Protection Act. There are opportunities there for us to look at that, at how the patient leaflet is working and the idea of section 10 notices being a way to opt out. All those sorts of things are open to further deliberation based on the lessons learned from the early adopter sites. I am keen that we use those sorts of opportunities to learn and make sure we go forward with something that is robust and delivers the safeguards that are meant to be in place.

Q195 Mr Amess: Mr Bamford, I think your real forte is to be on the working party on the European Directive. Can either of the other two witnesses shed any light on what further can be done to give more control?

Professor Korff: The most fundamental control is for an individual to be able to say he or she does not want the data to be on the record at all. No real provision is made for that. I think that the people who are putting together the system hope that only 0.01% will opt out and therefore there will not be a real problem. If patients really become aware of what is happening, especially the secondary uses that are regularly allowed, I believe that a much higher proportion will opt out and in that case provision should be made for alternative arrangements. Let me again read the words of the working party: "Any consent given under the threat of non-treatment or lower quality treatment in a medical situation cannot be considered as free consent. Consent given by a data subject who has not had the opportunity to make a genuine choice, or has been presented with a *fait accompli*, cannot be considered valid." Those are not the speculative ramblings of the working party. My colleague sits on it, so I would not say that it ever rambles, but that is a proper statement of European law. Try to bypass that and the alternative is not to rely on consent. In that case you either rely on these two flimsy provisions in the Act, which are contrary to the Directive, or you adopt a specific measure as they do in Austria. I can guarantee that that measure in Austria, or the similar one in Germany, is much more specific and detailed and has much fuller safeguards than are envisaged here: for instance, provisions about sealed envelopes that cannot be opened without the consent of the data subject; and the right of every patient regularly to receive a log of every person in the NHS who has had access to his data, including, I daresay, any researcher who has access to his data and who can be identified. Those are safeguards that can be built in; they are not envisaged here now. If you want to adopt a new statute on this system by all means do so, but go and study the countries that have a longer history of serious data protection like Austria and Germany which have constitutional provisions that make serious attempts at what is called the minimalisation and proper anonymisation of data for longitudinal research studies which are much stricter than are imposed here by the authorities that supervise studies in the UK. There can be much tighter control which I cannot deal with here in five minutes. Many more safeguards can be built in that are not being built in. In addition, the focus should

always be the patient. The first purpose of the system should be the care of the patient; helping civil servants, managers and researchers are secondary thoughts. They should be allowed to the extent that they do not impinge on patient rights; patient rights should not be pushed aside in order to make things easier for managers and researchers.

Q196 Mr Amess: I do not give him an opportunity but I sense that Mr Bamford will agree with everything you have just said.
Ms Robins: I expect the result of the adopter sites will be that 0.01% of people are concerned. I know that because that is the way it has stacked up. It is being done basically as a marketing exercise. People are not being properly informed and therefore that is what I expect to happen. People are not being told any of the detail and so they will not be hammering for information. The whole problem with patients is that they do not know what they do not know. If they are not told they may well never know. I recall that at the previous session Sandra Gidley said that in that part of Hampshire where she lived the scheme had been rolled out and she had not been fully informed. The answer that came back, which was a load of rubbish, was that they did not send it to every single person, for example 16 year-olds living away from home. With all respect to Ms Gidley, I doubt that she was a 16 year-old living away from home. Patients do not understand that the bit about the invisible business can be overridden; they do not know who will have access. Nobody knows. There is talk of NHS Direct and local pharmacists having access and being able to change it. In 2003 there was supposed to be consultation on that but it never happened. It should have happened before anything was rolled out so that people know just who will go not just into their records but their ex-directory phone numbers. We may go on to detailed records later, but when and how the historical data are added is absolutely crucial. You can bet that that will not be done by doctors sitting down with patients. If you had an abortion before you were married or made a suicide attempt 10 years ago will all of that be there? Before we know this sort of thing how can we sign up to it? We are jumping into a void.
Mr Amess: Thank you very much indeed. I can tell you that again Mr Bamford has agreed with everything you have just said.

Q197 Dr Taylor: Just before I move to the Detailed Care Record I want to refer to some fairly strong sentences in Professor Korff's written evidence. In Evidence 64 under "The electronic patient record architecture" you say: "Unfortunately, the idea that everyone should have a single EPR, to be opened in the IVF clinic and archived on autopsy, was adopted in the 1990s as the vision for the NHS Information Management and Technology Strategy. NHS computing strategists have clung to this vision even as the rest of the world has moved on. The vision must be abandoned." Can you expand on that?
Professor Korff: I do not have the exact paragraph before me but I remember it. I did not write that paragraph but I still subscribe to it. The problem lies with the centralisation of the records and the fact that we should have one central record controlled by the NHS rather than dispersed records controlled by those people who treat you with the ability of those to interact where necessary. That is the fundamental difference in vision. The view of the Foundation for Information Policy Research is that the vision that should be abandoned is that of a central system rather than a dispersed one where the different parts can talk to one another where necessary.

Q198 Dr Taylor: Let us explore the Detailed Care Record a little. I think that most of us really do not know what it is. I am not sure that the people who are designing it know what it is. At the moment there are separate clinical record systems in most hospitals for different departments. Is their idea just to link them together and open them up to the whole of the NHS, or is the DCR something designed from scratch?
Professor Korff: The centralised system is designed from scratch.

Q199 Dr Taylor: But that will be an amalgamation of all these local systems?
Professor Korff: It is not an amalgamation; it will suck all of it in, if I understand it rightly.

Q200 Dr Taylor: We will all be there. How feasible is that?
Professor Korff: You should really be talking to the computer engineers. There is a good catchphrase here. If you look at the bottom of page 65, it quotes Professor Anderson: "It is a principle of security engineering that we can build systems with functionality, scale or security, or indeed any two of these attributes, but not all three. Secure and highly functional systems have to be local or compartmentalised; they cannot be all in one system or you will lose either functionality or security."[1]

Q201 Dr Taylor: Therefore, security will be particularly at risk with something as large as this?
Professor Korff: Absolutely.

Q202 Dr Taylor: How have existing doctors been brought in to design these records? Again, you say in your evidence that it is only if systems have really been designed by the doctors who will employ them that they will be really dedicated to using them. The impression I get is that there really has not been much consultation on the design of what goes into these. Would you comment on that?
Professor Korff: That is the idea I have, but you would be better off talking to the general practitioners. The whole concept is driven by a centralising idea rather than by how one can best serve first the patient and then the people in the front line, that is, the GPs and specific consultants, all of whom now have their own system and are quite happy with it. Why do we not let those systems interoperate rather than throw them out of the window and come up with a newly-designed system

[1] Ev 65 (HC 422–II, 2006–07)

which has all kinds of negative impacts, including impacts on its usability and control by the people in the front line?

Q203 Dr Taylor: The Summary Care Record seems to be growing by small degrees and makes consent even more difficult. Do you have to consent to every bit that is added to it? I believe it was Ms Robins who said that one could not give informed consent if one did not know what would be there. As nobody seems to know what will be in the Detailed Care Record it is impossible to get consent.

Ms Robins: I went to the CFH presentation the other week. It has no idea how it will do the Detailed Care Records. It does not know what if anything will be added. We know that hospital tests—x-rays, blood tests and so on—will go on automatically. We have no say in that; we cannot opt out of that, but how will it do the detail of what has happened to an individual in the past? I do not know how any record is of any use without detailed knowledge of what happened in the past. It seems to me that every patient will need a printout of what is going on. No doubt at the time we shall be told that that is not practical either and therefore we shall end up with no opt-out system from the Detailed Care Record.

Q204 Dr Taylor: Are the patients with whom you come into contact particularly worried about mental and sexual health issues?

Ms Robins: Mental and sexual health, terminations and anything of that type are usually matters that people do not want spread around by anybody who happens to look at them. There are so many problems. Smart cards have been passed round between people in hospitals recently. People who work in hospitals tell me that computers are routinely left open for anyone to see. For instance, if there is a celebrity in the hospital—it could be an MP—plenty of people can come and have a look at that. There will be far more of this going on because it is so general and it will be spread so far.

Q205 Dr Taylor: If and when the planning is made for the consent systems for the Detailed Care Record will there be a possibility of having a group of items for which you do not need consent and a group of items for which you do? Is there any way forward like that? Can you see how they can plan for consent for a Detailed Care Record?

Professor Korff: I do not see how technically you can do it. In our submission we make reference to trying to make prescription data a lower level category than, say, HIV status, but since prescription for AZT reveals the HIV status one cannot really do that. It is virtually impossible to make those kinds of distinctions in a sensible way.

Q206 Mr Jackson: I should like to talk about children's health. Providers of children's services have argued that there should be no choice about whether children's detailed health records are stored electronically. Do you agree with that?

Professor Korff: I think it is appalling, quite frankly. First, I suppose that children are defined as people under 18. It is now fairly well recognised that people aged 16 should effectively be treated as adults. In a recent study we did for the Information Commissioner on children's databases we addressed the issue of consent by minors in some detail. Within the NHS and beyond that the Civil Service there is a tendency to try to get consent from children as young as 12 without involving their parents. We have pointed out with reference to the *Gillick* decision and others that the proper way to deal with young children over 12, if you like those who are beginning to become adults, is to involve both them and especially their parents in every instance in which there is no conflict between them, which would be 95% of cases. If there is a conflict between what the child wants and what the parents want one has to come up with a kind of *Gillick* resolution. Is the child sufficiently adult and that sort of stuff? But the Civil Service attitude seems to be to override that and basically try to get consent for a 12, 13 or 14 year-old in the light of rather meagre information and then say that they have consent and that is it. Another problem we have identified—I do not know how it will be resolved—is that parents give consent when a child is three, eight or 10 and is a leukaemia patient and that individual lives to be 23 or 25 and does not like it and wants to withdraw the consent given by the parents. Can one have the data extracted? Can one block a certain volume of data? Researchers say that that will ruin their research. That has not been addressed and I would have thought it is a pretty serious issue.

Ms Robins: I do not disagree with that. It is a minefield. I have not put my mind to this before, but certainly all the rules of informed consent say that if a child is old enough to understand what is going on he or she can give consent. How that is applied to data like this goodness only knows.

Mr Bamford: The Data Protection Act makes no distinction between individuals based on age; the rights are there for all of us. Clearly, our ability to exercise the rights when we are children is a matter for our parents on our behalf, which is what we are talking about here. The idea that children's information is just uploaded automatically but adult information is treated differently is wrong. The same data protection rights are vested in individuals, so the parents would have to be consulted before the children had the intellectual capacity to make decisions for themselves. There is no difference between us.

Q207 Mr Jackson: What is your ideological view on compulsion?

Mr Bamford: It should be on the basis that the parent of a child without intellectual capability should make the decision about whether or not the data are uploaded onto a Summary Care Record, just as if it was an adult making that decision. It would just be done on behalf of the child that is not capable of making that decision. It should not be an automatic upload.

Q208 Mr Jackson: Do you agree that a number of vulnerable patients would in general be more likely to opt out of having data on the system? If so, how do we get round that particular issue?
Ms Robins: The recommendation for the opt-out system by the task force was based on that because with an opt-in system all these vulnerable patients would be left out in some way. I think that the system we now have discriminates strongly against such vulnerable people. They will not know what is going on and their information will simply be uploaded willy-nilly. That is not right. If as I suggested there was some sort of form whereby one had to choose which option to take then if somebody was not competent normally the person who would take decisions for that individual will do it. But a lot of elderly people who may not be fit to hoof down to their doctors' surgeries and argue the question will want to know what is going on and what is on their record. Under this system they will not know because they will have one of these pamphlets which says that everything is for the best in the best of all possible worlds. It comes along with a letter from the doctor's surgery saying that the doctor is very keen on this. What will the elderly and vulnerable people do? They will just be swept along, and I believe this is the wrong way to go.
Professor Korff: I really cannot claim much expertise on how to treat data on vulnerable people, apart from basically agreeing with Ms Robins. It would normally be the legal guardian. What I would say is that you need to be particularly careful in dealing with data on people who are not in a position properly and voluntarily to give it themselves. If anything, you should take the most restrictive approach possible rather than say that you can override it because the individual has Alzheimer's disease anyway. I think it should be the opposite: because a person cannot give consent we must be extremely careful not to assume that we can therefore give it on the individual's behalf.
Mr Bamford: If certain vulnerable groups have different needs in terms of information that should be provided in a way that ensures there is equal transparency for them as for anybody else and an equal opportunity to exercise their judgments on whether or not they want their records to be uploaded. I think it would be appropriate to have different mechanisms in place to allow those who may have difficulties to exercise the choices with which they are provided.

Q209 Mr Jackson: Ms Robins seems to be going against the received wisdom that vulnerable people will opt out. You say that vulnerable people will not opt out, if I understand what you say. The articulate middle class will seek to opt out because they can and those who are not in that position and vulnerable will not do so.
Ms Robins: The task force thought that because people were elderly, vulnerable or whatever if there was any sort of opt-in system they would not be opting in because they would not know what was going on. I say that is not so. This is a system that leaves them out. It will be assumed that you will be swept into it after eight weeks if you have not gone along to your doctor to discuss it. That leaves them out completely.

Q210 Sandra Gidley: Perhaps we can rewind slightly and return to the children's aspect. It is not really about *Gillick* competence as such. To be fair to the royal college and others who raised concerns, their point was that if a child was vulnerable or perhaps being abused then parents would find it much easier to hide it if they could opt out on behalf of the child. Looking at it from a wider child protection angle, does that perspective change your view?
Professor Korff: I really do not see why technology comes in here. If there are child protection issues they should be identified by any practitioner.

Q211 Sandra Gidley: One might not be able to identify them quite so easily.
Professor Korff: I think that one of the stories that goes round is that the computer will identify children at risk, and I find that a problem in itself.

Q212 Sandra Gidley: No; it is about information-sharing and is to do with cases such as Climbie.
Professor Korff: Exactly. The point about Climbie was not that the data was not there but that the people misinterpreted it. It was not a matter of the information not being shared. That is how the Civil Service want to portray it because in that case they can make a case for more data-sharing, but that was not the problem in the Climbie case. I hope you have seen the report that we have done on the children's databases which was commissioned and welcomed by the Information Commissioner. We go into that in great detail and explain why the idea that the computer is better at predicting who will be at risk than health and social work professionals is a myth and wrong. These decisions should be taken by people who have direct access and treat the child and know the family. They are the ones to say they think there is a problem with the child and they will consult another specialist. In the field of child protection when that term is properly used, meaning protection from direct harm, there is no problem whatsoever about data-sharing and it has nothing to do with this NHS system. When one talks about predicting whether children will grow up to reach their full potential and eat enough fruit and vegetables that is a totally different thing. If I may say so, I do not believe that your point is directly relevant.

Q213 Sandra Gidley: Therefore, you emphatically disagree with the Royal College of Paediatrics and Child Health and the British Association for Community Child Health?
Professor Korff: If they say that they need this system in order to protect children from harm I think they are wrong.
Mr Bamford: The argument has never been made to the Information Commissioner that there should be an automatic upload because, as I understand it, parents might act in a way which could mask abuse of the children or whatever. If that argument is made

we go back to the point about what is fair in terms of fair processing. Yes, there are the interests of the individual but there can be other interests as well. If a persuasive argument were made that there was some counterbalancing interest which meant an individual should not really exercise a choice that would be something we could take into account, but I do not really know the full weight of the argument. I can see it being a plausible argument and something that can be looked at. There could possibly be a different approach based on what is fair, because clearly the interests of the individual who is likely to be abused are different from allowing the parents to make a decision for that person.

Professor Korff: There is a difference between uploading to the spine and sharing data. The two should really be kept separate. If there is a child protection issue any healthcare or social work professional in touch with the child is entitled to share that data with any other relevant professional. There is no problem about that under either European or UK law or any ethical issue in that regard. Therefore, they can share the data in the individual case. Whether you can upload it and share a multitude of cases in all kinds of circumstances is a totally different question. I believe that two things are being confused perhaps because of an agenda. The two are totally separate.

Q214 Chairman: Are you saying that parents should not have the ability to opt children's records out of a Detailed Care Record?

Professor Korff: Quite the opposite; they should. There might just be a GP who says he finds it odd that they choose to opt out in a particular instance, maybe because they want to hide the bruises suffered by the child. In that case one should immediately contact the relevant child protection agencies and do something about, but the idea that leaving data on children out of the spine means they will be less protected from abuse is not correct.

Q215 Chairman: We are not talking about the spine but the Detailed Care Record. If the Detailed Care Record becomes our current Lloyd George record, as I have in my doctor's surgery, do you say that somebody on behalf of children who are on the at-risk register should be able to opt them out of having their records kept electronically? Do you say that currently they should not be kept in a GP's surgery electronically? Ms Robins, what is your view on these matters? We are not talking about the elderly. You are quite right in what has been said about it. But what do you say to the Royal College of Paediatricians in relation to the question of whether a person can opt out somebody on the at-risk register from the system?

Ms Robins: I do not think that any of us has a promise that we can opt out of the Detailed Care Record, as far as I know. So far we have had a proper look only at the Summary Care Record, but that does not really address the question. Professor Korff's point is that if a parent is trying to opt out a child that may very well be the exact trigger which will tell all the other people who deal with the child that there is something going on here. Maybe that would be useful. Who knows? I am no expert in this field, but from my work in the family court it was never my impression that child abuse went unrecognised because the data was not passed round; it arose because people did not do their jobs. The person who was supposed to arrive on the doorstep to see the child did not do it.

Q216 Sandra Gidley: What about Munchausen by proxy and that sort of situation? Quite often there is a record of people moving round the country.

Ms Robins: That is true.

Professor Korff: I am sure you can comment that there is a special case which does not require a fundamental change of the architecture and a move to a massive system like this. There could be cases in which people who travel round the country and abuse children in different areas would make it difficult for information on their ill-treatment of those children to become known to different people. At some stage however they will become known. By the time a child ends up in a hospital the hospital will ask for the records from the previous GP and at some stage somebody will light it up. I do not agree with the idea that having this electronically on a central system will make it that much better in these extremely rare cases.

Ms Robins: Things like x-rays and blood tests will be automatically uploaded. We do not have any choice to opt out of that. That is often the case with Munchausen by proxy and that information will be there. If you go from hospital to hospital all of that will be on the record.

Q217 Chairman: I am not sure that it is technically feasible to put x-rays as electronic images on the Summary Care Record.

Ms Robins: I thought we were talking about the Detailed Care Record. We are told by the Department of Health in writing that those will be automatically uploaded; we have no choice.

Chairman: I think we shall move on from this, but we shall look in further detail at the issue brought up in the past few minutes in terms of the rights of people to opt out of the system others who may be in a vulnerable position.

Q218 Charlotte Atkins: Professor Korff and Ms Robins, both of you have raised issues about the protection of sensitive information. Connecting for Health proposes to make sealed envelopes available to protect particularly sensitive data. Ms Robins, you have already raised concerns about how that can be overridden. Is this the way forward or is there an alternative way forward to be able to protect sensitive information such as sexual and mental health records? What would you propose?

Professor Korff: Basically, there are two questions here: first, there is the technology of the sealed envelope. As I understand it, the technology has not been properly developed. I would not buy a car if the engineer told me he was still working on the brakes but by the time I was a few miles away he would probably have sorted it out. Second, to the extent

they have thought about it these envelopes are not sealed very well. It is fairly easy for health practitioners to break them open. When the European working group talks about sealed envelopes they mean a properly sealed envelope which means they have to go back to me to ask whether I want it opened for a particular instance by a particular healthcare professional. That is quite different from a sealed envelope. One has to be very careful about terminology and exactly what will be used. As currently envisaged, I really do not believe it is very useful. In particular, all the data in the sealed envelope as I understand it will be available for research with minimal anonymisation and pseudonymisation. We will have to go back to that.

Q219 Charlotte Atkins: By "minimal" you mean things like post codes?
Professor Korff: It is insufficient. I was hoping that a question on anonymisation and pseudonymisation would come up. I can go into it now or wait for the question to arise.

Q220 Charlotte Atkins: That question will come up later. Ms Robins, what do you say?
Ms Robins: I agree that if we have a sealed envelope that is the way it should work. As the proposal is at the moment, you put your sensitive information in a sealed envelope and you may as well put a nice red arrow saying that that is the information that the person wants to see. There is no undertaking that we will be notified if that sealed envelope is opened. I am not however lying awake at night worrying about sealed envelopes because I do not think they will ever happen. At the previous session Richard Granger in his many comments said that come the day they would have to look at whether enough people wanted them to justify the cost. Come the day, they will decide that not enough people want them to justify the cost.

Q221 Charlotte Atkins: Mr Bamford, as I understand it the Information Commissioner supports the concept of sealed envelopes. How do you address the concerns raised by Professor Korff and Ms Robins, namely that the technology does not exist and therefore it may never happen?
Mr Bamford: I think the important point in your question is that we support the concept of it. The real concern for us as well is how it is delivered in practice. The concept that you might be able to lock down some personal information from the view of others is a privacy-friendly approach and clearly is a good thing. It could happen in all different forms of record-keeping, and here it seems entirely appropriate. How that works in practice as graphically described by my colleagues is yet to be determined. We are concerned about how that works in practice, for example how the seals are broken and in what circumstances. Is it just on the basis of consent, or is it done in some overriding clearly defined emergency? If it does happen like that what mechanisms are in place to audit that access to make sure it is done on a legitimate basis where there is a real need? One would probably argue for a 100% audit in those instances. Is there a need for patients to be told that the seal has been broken and that information has been revealed to somebody? Those can be safeguards that underpin the system and we would be interested in ascertaining how those work.

Q222 Charlotte Atkins: In the meantime do we have to have blind faith in the computer nerds coming up with a system which will actually work? Is that a good basis on which to proceed?
Mr Bamford: I certainly do not share that blind faith argument. We should be very careful about the level of information that goes forward. At the moment, with the Summary Care Record there is comparatively limited information available and therefore it tempers a little bit the element about what potentially may appear there and what may go into a sealed envelope because of its limitations. I think it important that the issue of sealed envelopes is addressed and we find out as soon as possible that the safeguards are robust and effective ones.

Q223 Charlotte Atkins: But is it right to build a system which depends on a technology that we do not yet have? Given that we have not yet got the technology and that there is usually a way of cracking into a new technology a few months or years later, is it right to build a system where we cannot be sure that we can keep that sensitive information secure?
Mr Bamford: It would be wrong for a system to go fully live without that functionality being in place.

Q224 Charlotte Atkins: Apart from the technological approach of the sealed envelope—we do not know whether it will ever happen or it will be secure enough—what can be done to ensure that highly sensitive patient information is protected?
Mr Bamford: Data protection law requires that appropriate security precautions are taken and the propriety of those precautions is judged on the harm that an individual can suffer. The sensitivity of the information goes into that sort of equation about harm and the level of security having to go up. We are concerned and have said to Connecting for Health that there needs to be the highest levels of security to make sure there are no abuses of the system. It is not just the issue of the technical controls; it is the human elements of it. I believe there have been some graphic examples where perhaps security precautions have been circumvented by people logging on for a whole shift, using one card rather than their own cards. That must be stamped out; there cannot be any of that. We are also concerned about a practice called information blagging which essentially means that organisations try to find out information about people, often using public sector databases. We have asked for a strengthening of the penalties for the offence of unauthorised access to information under the Data Protection Act. The Ministry of Justice has said that it will attach a criminal penalty to it, which is good, and Connecting for Health supported us on that.

But it is no good just having a hard sanction in the Act; we need to make sure that everybody is well educated in the health area. As we have blocked off areas that are to do with National Insurance records there is a chance that if we have more centralised health records they will become the target for information blaggers, because that is a way of finding out somebody's name and address and not necessarily all the detailed records behind it. We are also working with Connecting for Health to do a research project to try to tease out where the vulnerabilities are in this. There is no doubt that there needs to be a high level of security in place; it is not an option.

Q225 Charlotte Atkins: Clearly, the vulnerabilities have a lot to do with technology. At what point should the plug be pulled on the system if we are not satisfied (a) that the sealed envelope system is up and running and (b), if it is, that it has been up and running long enough for us to get the complex technological glitches out of the system so it will not be easily accessed by someone who wants to hack into the system?
Mr Bamford: But the system cannot be implemented properly unless it is legal in data protection terms, so there must be the appropriate level of security to safeguard against unauthorised access. It cannot be implemented without that protection in place.
Professor Korff: In my opinion you will never reach that level of security. The people I work with in the Foundation for Information Policy Research tell me that technically for a system as large as this you will not get the level of security that you need to protect people's medical data. The only way is to give up on the centralised concept and go back to a dispersed interconnected system. The simple answer is that it is just impossible; you will never be able to get the level of security that I and Jonathan in his heart of hearts also thinks is required to protect medical data in a massive system like this.

Q226 Charlotte Atkins: Your response to that is to pull the plug now?
Professor Korff: Yes; you have to start with a new system. Do not put it all on a centralised system on this scale because you will not be able to implement the appropriate security levels.

Q227 Chairman: I want to move on to the secondary uses service. Our understanding is that this will make electronic data available for such uses as research, audit and commissioning. This seems to be the focal point for patients' concerns about confidentiality. First, why is that? What can be done to improve the privacy arrangements for the secondary uses service?
Ms Robins: I am not sure that it is the main focus of patients' concerns, because most patients have no idea that it goes on. Before I started to research this and read the submissions I had no idea of the extent to which it went on and where my data was sent and how easily I could be identified. I do not think that most patients to this day know that, and they are certainly not being warned at the moment.

Q228 Chairman: If your record, either the detail or a summary, is available, let us say, wider than your current record and by implication somebody else is using it that is a concern to you. I would have thought it was a fundamental in this debate.
Ms Robins: I am saying that most patients have no idea that this is happening. It seems to me that a lot of the time anonymisation means your name is not there but your full postcode and date of birth are there. I live in a street of 12 houses. If you have my postcode and date of birth you know who I am. It seems to me that the only reason for doing it this way is so people can be re-identified. I gather from the submissions that this has happened quite frequently. Again, patients have no idea that that happens. It will be terrifyingly easy to access information when the system goes on. I imagine that requests for access will proliferate and it will be extremely difficult to resist those. It should not happen.

Q229 Chairman: You do not think this should happen at all, or can we protect privacy better than the system that we understand it will be at the moment?
Ms Robins: Obviously, I accept that data must be used for research but it must be properly anonymised. I would have thought that the area and birth year would suffice. That shows clusters in this or that area of the country or things that have happened in a particular age range. That should be sufficient; otherwise, consent should be sought.

Q230 Chairman: We will have a look at the actual keys involved, but presumably in principle you do not disagree with the secondary uses service in terms of audit, planning and whatever comes of it. Is there a risk that the use of data by secondary users will end up in the European courts? From earlier responses perhaps you will say yes in response to that.
Professor Korff: I will say yes, and perhaps Jonathan will be more modest in his answer. The issue hinges on identifiability. When the data used in research or planning management whatever are so flimsily anonymised that it is very easy to re-identify people in my view they remain personal data and therefore cannot be used without the express, valid and free consent of the data subject. Only totally anonymised data or very seriously pseudonymised data can ever be passed on without with the consent of the individual. In many studies the level of security against re-identification is not sufficient. On top of that there will be a demand for the use of this data in identifiable form to get back to the individual. We have mentioned in our submission the suggestion by the Department of Health that children should be identified as at risk of not eating enough vegetables or not passing enough A-levels. There will be pressure. Once the data exist in this kind of accessible form there will be pressure from authorities to say that they want to use it. There will also be pressure from the immigration authorities to identify illegal immigrants in this way; and there will be pressure from the police and certainly the anti-

terrorist authorities. Because this is a massive database and it is not that difficult to get back to the individuals they will say they want to trawl through it; after all, they have an overriding public interest. That is a serious danger that we will creep into. Data protection commissioners in Germany specifically addressed part of this and said that the law ought to be changed because a doctor would have a right to refuse to give evidence about confidential medical data held by him in trials. Once the data slip out they lose that kind of protection. They felt that the law in Germany which was already quite tight ought to be strengthened. Here the trend is likely to be in the opposite direction. More data will be available, first in so-called anonymised and pseudonymised form, which it will not be—pseudonymised data will be easily re-identifiable—and, second, in identifiable form for all kinds of secondary users that the state thinks are worthy for the purposes of breaching the privacy of the system. It is a recipe for disaster.

Q231 Chairman: Do you have any evidence from any countries where the agencies that rolled off your tongue use electronic patient records? You referred to the police, anti-terrorist authorities and others whose names I have forgotten.
Professor Korff: I can give no example.

Q232 Chairman: There is no country where we can see how data is used in this way?
Professor Korff: The United States anti-terrorist operations are basically trawling through any database they can place their hands on because there are no decent data protection laws in that country. I think that in Europe any country with decent data protection would be faced with an outcry from the Data Protection Commissioner and civil liberties groups if this became public. But that is about the identifiable uses.

Q233 Chairman: Do you think this is happening but is not identified?
Professor Korff: I do not know whether it is happening here.

Q234 Chairman: I do not mean here but in any other country.
Professor Korff: To the best of my knowledge it is not happening in any European country.
Ms Robins: No other country has this database. We are supposed to be leading the world.

Q235 Chairman: There are other countries which have substantial electronic patient record databases and the Committee will be visiting one or two of them in the next few weeks. That is the case. I just want to know whether there is any evidence of the multi-use of other organisations of electronic patient records; if so, the Committee would be very tempted to see how that is done as well.
Professor Korff: To the best of my knowledge nowhere in Europe has this been knowingly done.
Mr Bamford: Perhaps I may answer your second question first. If it helps the Committee we can ask our European data protection commissioner colleagues whether they have any knowledge of the use of electronic patient records. There are electronic patient record systems in Denmark and other places which use the same basis as we do. There are similarities. We can ask and find out whether there has been any pressure or whether it has occurred and let you know.

Q236 Chairman: I would appreciate that.
Mr Bamford: To go back to the original point about whether the secondary uses service is open to legal challenge, the Information Commissioner's office has always taken the view that the starting point, and in many instances the finishing point, for using personally identifiable medical information is the consent of the patient. If there is a situation where there is something specifically provided for in law which balances some other competing need in society—I am thinking of the Health and Social Care Act which has a mechanism for dealing with non-consensual uses of personal information—that must be done at the will of Parliament with proper legislation in place. Here we are talking about something that is meant to work on the basis that it is pseudonymised personal data. If it is done on the basis of true pseudonymisation I agree with Professor Korff. If it is truly pseudonymised and it is not that easy to look back at the records or bring them together and say that they are Jonathan Bamford's or Professor Korff's I do not think it would be open to very much challenge. If the pseudonymisation is not effective then that is a much more open question.

Q237 Chairman: That is my next question. Do you think it will be effective from what we know at the moment?
Mr Bamford: I do not know enough about the pseudonymisation techniques that they are using to provide you with an accurate answer.

Q238 Chairman: Has the Commission looked at that?
Mr Bamford: We have not looked in detail at how far they are pseudonymising this, but having heard what has been said today we will be asking a few questions.

Q239 Chairman: That would be an issue for the Commission?
Mr Bamford: To establish the level of pseudonymisation, yes, it would.

Q240 Chairman: I was going to ask—I think it has been answered—about how anonymised something is if it has a postcode or date of birth attached to it. Do you know of any system where if one is uncomfortable with it it could be removed and patient records could still be used in a way that some people regarded as the general good in terms of research, audit or commissioning? If you have no immediate thoughts on it perhaps you would get back to us. My last question is about the Patient Information Advisory Group which considers requests from researchers for access to identifiable

data without patient consent. How effective is the PIAG at balancing the right to privacy with the needs of researchers? Do you have any views on how that is dealt with currently?

Mr Bamford: Clearly, there is a statutory provision which sets up PIAG. From our discussions with them they do seem to take their responsibilities in weighing these competing interests very seriously. The fact that medical researchers in particular appear to want to find other mechanisms other than the PIAG arrangements leads me to believe that they are, therefore, very strict in what they do, and perhaps rather more strict than the medical research community would wish. On an anecdotal basis I have some confidence in the arrangements that are in place. Clearly, the way this was brought about under the Health and Social Care Act essentially has modified the manner in which the Data Protection Act applies to the release of the information, because it is something that is now required by statutory provision with the safeguard of the PIAG in place to make sure it goes forward only where it is a real pressing need and there are real difficulties in getting patient consent. That mechanism seems to be more or less an appropriate one and is working reasonably well.

Professor Korff: My information is anecdotal rather than detailed. The anecdotes that I get are somewhat different from Jonathan's. PIAG is quite easy about giving access. There are hundreds and hundreds of studies on its website. I went to its website to try to have a look at how many of these studies had been authorised. I sent off an email, to which I have not yet had a reply, asking how many studies did it have and how many individuals were included in each, and to what section of the population did it have individualised access. I have not yet had an answer to that, and maybe you can ask it. It looks as though massive amounts of data are available. I would look to Europe to get some guidance. Is it difficult to get consent and how important is the research? I would go quite a lot further. Is it nearly impossible to get consent? What is the substantial public interest that allows us to override the individual's fundamental right to informational autonomy and start digging through highly sensitive personal data? I would put the balance quite differently. Is there any way in which this research can be done in a totally anonymised or pseudonymised fashion? What is the quality of the pseudonymisation? I would like to look at it further. I have not looked at it in sufficient detail to give a full answer.

Q241 Dr Taylor: In its submission the Academy of Medical Sciences points out how difficult it is to obtain consent for records-based research. It speaks out against pseudonymisation because it says that the identifiers contain useful information for some of the sorts of research that it does. This is a tremendous conflict and I do not know the answer to it. Many of the identifiers that might be stripped from data during anonymisation are useful to research. Postcodes, dates of birth, dates of death and occupations are all routinely used as important factors in analysing population data. It is a huge conflict, is it not? I do not think there is an answer.

Professor Korff: The simple comment is that the fact they say it is very difficult to get consent suggests to me there is a concern that if you explain to people what will be done to their data they may not be quite so happy about it as is otherwise maintained. To me, that suggests this should be taken very seriously, and it may lead to an opt out if you explain it to people. You cannot say that if you explain to people what you will do with their data they will opt out and so you should not explain it to them. That is the opposite of proper data protection.

Q242 Dr Taylor: The academy suggests that the way forward is to engage the public with full information, but it depends on how you give the information.

Professor Korff: Not just full information but consent. For secondary uses you need consent. If statutory authority is given to override somebody's personal autonomy any state organisation or delegated body which says that it will use data on that person's suicide attempt, abortion or HIV status in such a way that it can look at the complete medical record should be extremely strict in applying that. I do not get the impression that they are that strict, and the academy's submission suggests that it does not want to be very strict.

Mr Bamford: Obviously, we are very much of the view that we should go for consent and there are strong reasons why consent is not possible in that regard. I was trying to think of examples to help with the point about what other ways there are to deal with this matter. Some of the pseudonymised techniques use algorithms and things like that to put the data in different forms. Rather than just stripping out certain personal elements of the data one converts it into another form which is not readily recognisable to you or me.

Q243 Dr Taylor: So, there would be a code for your date of birth and postcode that nobody else understands?

Mr Bamford: Yes, there are other ways to do it. The Royal Academy of Engineering has recently published a report on the surveillance society. It has talked about using engineering to protect privacy. There are technical solutions and work is being done on it. Other jurisdictions have employed the use of what would be called trusted third parties who bring together data which might be in a more identifiable form and then analyse it in some way and feed it back without the identifiable details going to the researchers. I believe there is an example of that in Australia involving the provision of healthcare to the aboriginal community. A third party was established. Other models can be used.

Q244 Mr Campbell: What you have said has been very interesting. I have listened to it very carefully. What can government do to deal with these ethical and legal questions? Should it be made a priority of

government with all the things going on in the health service and the campaigns that are running? Is it that big of a priority?

Mr Bamford: I have to answer you from a data protection point of view. I do not believe that the halcyon days of record-keeping on Lloyd George envelopes as the best way to look after people's information are acceptable in a modern world. We must be able to hold it in effective ways which allow people to get the treatment they need.

Q245 Mr Campbell: That system has never gone wrong, has it?

Mr Bamford: I am not the best person to answer that question, but people tell me that it has gone wrong before. Patients have been mis-prescribed drugs to which they are allergic because information is not available to medical practitioners who need it. I do not how true that is and there are others better able to answer that question. But if there is a concern that people do not get the healthcare they need my point of view is that if we need wider record-keeping what is the extent of it? I believe that it is a priority to make sure that if we do need wider record-keeping patient information is properly safeguarded. I did not get the opportunity to answer the question about the Detailed Care Record. My understanding is that that will be available only on a local basis and will not be uploaded. Some of the questions asked later on implied that we were talking about all Detailed Care Records being available on a national basis, which is not my understanding of the situation. Safeguards for lock-down record-keeping at a local level where very detailed information is involved are the sorts of things to which we should give priority to make sure records are secure, robust and accurate. I believe that efforts should be put into that, because hopefully that will enhance healthcare.

Professor Korff: The problem is the proposed architecture and the idea that too much goes to a centralised system and at the front line GPs and consultants own the system. I am not a Luddite; I am all in favour of information technology that can help doctors, nurses and everybody. Data should be shared where it is appropriate.

Q246 Mr Campbell: It is really confidentiality about which you are concerned. If we can get to grips with confidentiality which we have been talking about this morning we will conquer it, but listening to your evidence I do not think we have.

Professor Korff: First, you have to focus the system on the patient. The most important person in the NHS is the patient, not the GP and certainly not the manager. Any system that is centrally designed has a tendency to turn that upside down. You need to build as much as possible with consent and think very carefully when you do not need consent, but most importantly you need an architecture for the system that allows you to build in these principles, and my simple response is that the system that has been proposed does not do that.

Ms Robins: We have not solved the problem of confidentiality; we have not solved an awful lot of questions. I think it is quite wrong to push ahead with what are called early adopter sites before many of these questions have been answered. At the moment the grave impression is that they are making it up on the hoof which is not good enough when you expect people to opt in or out. It is often said that once we have electronic records there will be no more mis-prescribing and lost records. Computers are not that good. But they have to get it in proportion. For instance, an NPSA study showed that for the first nine months of 2006 there were 21,000 errors relating to records that were lost, illegible, delayed or whatever. Of those, 18,000 resulted in no harm at all and 12 resulted in death. Obviously, that is 12 too many, but when it is compared with 5,000 deaths a year from MRSA or one million patients who are seen in the NHS daily it is not an enormous push for a move towards electronic records for that reason. There are other reasons; they can be very useful; they can be advantageous to patients, but at the moment we are not implementing it in the right way *if* it is the right thing to implement. I believe that is the way patients look at it.

Q247 Mr Campbell: Should electronic records be a condition for receiving NHS care?

Ms Robins: I think you are talking about Helen Wilkinson who has been denied registration with a doctor. If you do not have any record at all and there is no name, address or NHS number I see a problem with that, because with any system like this you must be able to know whose record you have; you have to be quite sure that you are not dealing with somebody with the same name who lives in the same locality and looking at the wrong records. Therefore, I think that it is unreasonable for patients to object to giving certain demographic details. When it comes to ex-directory phone numbers it is quite a different matter, but I think it is essential to have the name, address and NHS number for any set of records, simply so that Helen Wilkinson here does not get mis-prescribed because you do not know which Helen Wilkinson she is.

Mr Bamford: As I tried to explain to Mr Penning, the individual has no absolute right in data protection terms to say that no records should be kept on him. There is for direct marketing, but we are not talking about that here. There is a recognition of the need for record-keeping for individuals which is also true in the medical area, so I do not understand how somebody can simply object and not give an NHS number.

Q248 Mr Campbell: You say that it should not be a condition for receiving NHS care?

Mr Bamford: You can have the health service and they can keep the records.

Q249 Mr Campbell: The crux of the question is that when somebody goes to a hospital or doctor he is told, "We can't deal with you." That is what is being said here.

Mr Bamford: They can keep records locally and the issue is whether it is uploaded into Summary Care Records which are available nationally. That is a

matter of choice, but simple record-keeping of itself is something over which individuals have a limited choice.

Q250 Mr Campbell: We are talking here only about electronic records.
Mr Bamford: Yes.
Professor Korff: I think you have to look at it at different levels. If you say, "Unless you agree for all your records to be dealt with in the manner we want to make them available you will not get NHS treatment", that is coercive. If one says that the patient must agree at least to his or her name, address and NHS number to be kept on record so one knows that the individual is entitled to the service in principle that is quite a different matter. You have to differentiate.
Ms Robins: An awful lot of patients who contact us ask whether there is some way they can see a doctor without their records following them because there are many things in them which will influence that doctor in a way that they do not want to happen.
Mr Campbell: That is a good point.
Chairman: Maybe we should pursue the sealed envelopes in relation to that point in our next session. I thank all three witnesses very much for coming this morning and giving evidence to our inquiry.

Witnesses: **Mr Guy Hains,** President, Europe Group, Computer Sciences Corporation, **Professor Brian Randell,** Professor of Computer Science, University of Newcastle, and **Dr Rob Hale,** Confidentiality Working Group, Royal College of Psychiatrists, gave evidence.

Q251 Chairman: I welcome you to the second session of our inquiry into the Electronic Patient Record. For the record, perhaps you would introduce yourselves and the positions you hold.
Mr Hains: I am chief executive of Computer Sciences Corporation. My responsibilities span Europe. Ours is of the order of £$2\frac{1}{2}$ billion organisation in Europe. We are part of a global organisation. I also have specific executive responsibility for CSC's work in this programme and that is a role I have held since its inception. I personally spend a considerable amount of time on the programme.
Professor Randell: I have been a professor of computer science at Newcastle since 1969 following a career in industry in Britain and America. I have been notionally retired for five years, but professors do not really retire. My particular research interest over many years has been to do with system reliability, security architectures and the like. Only in the past year have I taken an interest as an outsider, not as a medical specialist, in the National Programme for Information Technology.
Dr Hale: I am Dr Rob Hale. I am consultant psychiatrist and psychotherapist working at the Tavistock and Portman Clinics in London. I am also a member of the Royal College of Psychiatrists' working party on confidentiality.

Q252 Chairman: Mr Hains, Computer Sciences Corporation has taken over two of the five local service provider contracts from Accenture after it withdrew from the programme.
Mr Hains: Yes, in January.

Q253 Chairman:. As an opening question, why do you believe that you will succeed where clearly Accenture felt it was failing?
Mr Hains: First, obviously I cannot comment on Accenture's ultimate motives for leaving the programme, but I think I can give some good insights on the basis of comparisons. In our execution in the North West and West Midlands, which was our original contract award, our strategy was very much to address the key secondary care environments that we felt would create the central nucleus for the sharing and interoperability that this programme strives to achieve. In the main GPs have reasonable levels of technology. They have chosen multiple systems. Certainly, some of them need better management and security, but generally it is a pretty well automated environment, whereas in the hospital environment in secondary care it has been a very mixed picture. If one is looking for the essence of Connecting for Health that is a very good place to start. We made very good progress in terms of making more than 70 patient administration system deployments in the North West and West Midlands, including 11 acute settings one or two of which were on a very large scale. The most notable among them was University Hospital Birmingham. If we compare that with Accenture's path and plan in the other two clusters in which we now operate, it addressed and made good progress in the primary care and GP sector. In terms of getting energy behind the programme and starting to deliver on the Connecting for Health aspect of the programme, they were not able to make as much progress. Second, within our own contract and supply chain—I am sure this will be relevant to some of the architectural discussions—we are delivering both the functionality and operations, whereas Accenture were relying on other parties to run the operations in the computer centres that supported that programme. That gave them some issues of latency in their deployment and management. Third, as has been commented upon, we have had a longer change management commitment as we move to a change of a major hospital. We have deployed much more assistance in terms of supporting administrative and clinical staff in making the change. I believe that that approach, whilst it has added time at the front end, has helped to industrialise the deployment and allowed us to make more deployments than anybody else. If we can combine the excellent work that Accenture did in primary care with the progress that we are now making in their clusters in secondary care we will get the best of both worlds. Since our

take-over in January we have made a further 51 GP deployments and have just brought on three of the largest hospitals in Ipswich, Bradford and Northampton. Progress is good and we feel that we can succeed where clearly they drew the conclusion they could not.

Q254 Chairman: Professor Randell, in total CSC now holds three of the five local service provider contracts. Do you think this is a serious problem? If so, how do we get more competition in this field?
Professor Randell: I believe that the whole issue of architecture and the role of local service providers needs to be addressed before that more narrow question is considered. When we talk about a local service provider we mean a provider that is providing a service to a number of patients which is equivalent to the population of a medium-size European country. That is not very local in my terms. In this morning's discussions there was a good deal of debate about locally and nationally held data and at times it appeared that "local" almost meant "GP" or possibly "hospital" and "national" meant the entire English nation.

Q255 Chairman: We will move on to that in this session. I am just thinking in terms of the number of LSPs that CSC is now running. Do you think there is anything difficult or wrong with that, not the state of the architecture adopted by them or anybody else running the LSPs at the moment.
Professor Randell: One can say only that from the point of view of reliability in very general terms one likes diversity and a number of independent things on which one can rely if something goes wrong. One can say that the ability to step in in place of Accenture is an example of that. In that sense the fact there were multiple suppliers had some merits. Clearly, one would lose those merits if and when one got down to one supplier, but that is almost a philosophical answer in the context of reliability.

Q256 Chairman: Mr Hains, you are reliant on iSoft's Lorenzo product as your main hospital administration system. When do you expect Lorenzo to be widely available? The obvious question on the back of that is: why has there been such a delay?
Mr Hains: It is absolutely correct that Lorenzo is our kernel; it is the centrepiece and enterprise part of our solution. We chose it originally because of its wide deployment and acceptability in the North West and West Midlands. We also chose it because its future direction was very much tailored to the operating model and forward vision of the NHS. It is not the sole product. Many of the solutions that we have are more best of breed models. We have products called Map of Medicine, Liquid Logic, TPP (for the GP and Primary Care Market) and Medusa. I believe that to characterise it as a sole dependence or the only component of the solution is incorrect. In terms of its delays, I point to a number of factors. There is no question that the ambition of Connecting for Health, in terms of the care pathways and advance vision that the UK has, is demanding in terms of software building. We will guarantee the highest levels of software quality and this procurement has raised the bar considerably within the healthcare provision software industry. It is frankly a much higher bar to jump over. The rigorous testing that is going into even the early development is very different from the way software providers in this market have rolled out systems in the past. That is proving to be demanding. It is a product that will have more and wider use than purely the UK, and I believe that to be a real plus point. In terms of our international work effectively we do the spine in Holland. iSoft is the predominant software in the Dutch environment in terms of healthcare. We think that to have a product that is built for more than the UK has advantages. That adds some more development work to make sure it can be internationalised. Whilst it would be inappropriate today to comment on its financial position, there is no doubt that the uncertainty regarding iSoft and its future ownership has proved an unwelcome distraction. What I can say is that we are fully supportive of iSoft and since the departure of Accenture, which was another interested party in the development, we are very much more focused on Lorenzo. We have 100 people working in the iSoft organisation co-developing that product, and the NHS has also dedicated 23 clinical and healthcare professionals to work full time to ensure that the requirements are optimum for the early delivery. It is getting an awful lot of support to get the fastest timing and delivery is due in the middle of next year.

Q257 Chairman: You have told us why you believe you do not want to move away from iSoft. As you rightly point out, there are other suppliers, but presumably they have to reach the higher bar as well that has been set for the National Health Service. But you still believe that you took the right decision?
Mr Hains: Yes, we do. There are over 103 product and solution providers accredited and certified by the NHS. In terms of areas of specialism, this is not a one size fits all; it is a best of breed-type solution set. We are making good progress with iSoft and believe that it is a very good solution for the NHS.

Q258 Dr Taylor: Mr Hains, I want to turn to some of the detail of the system design because you should be in a position to tell us. Turning to the Detailed Care Record, what will be in it?
Mr Hains: Building on the discussion that preceded this, I should try to make it clear where some of the records are and what the vision is in terms of how they will be made secure and accessed.

Q259 Dr Taylor: Before you go to security, what are they and where will they be?
Mr Hains: The Detailed Care Record is variously at the GP and a secondary care setting like a hospital where your treatment record will be held.

Q260 Dr Taylor: It could be at either?
Mr Hains: That is correct, as it is today and it operates through referrals, results and letters between the two.

Q261 Dr Taylor: I take the Detailed Care Record to equate much more to the detailed hospital notes rather than the GP. I do not wish to be derogatory, but they can write only a very small amount. Will you take into account the detail in hospital notes?
Mr Hains: The system in terms of being able to log both at free text and code level will reside as it does today in the software in hospital systems. That will reside in the location where that treatment takes place on the resident database. I need to make it clear that in terms of the deployments we have made to date this is not a single database. I shall talk a little later about the instances and systems that support that.

Q262 Dr Taylor: As far as I am aware, hospital-based systems at the moment certainly include radiological and pathological results but not what I regard as the nitty-gritty of patient histories, physical examinations and contacts with relatives and details about the patient. How will you include those?
Mr Hains: As to the full systems resident and available at the hospitals it is correct they are variable in terms of the amount of detail held. Some of it is in code form; some of it is in free text, and it is available for all the healthcare professionals in that hospital, if they have the correct and proper access rights to add to that record.

Q263 Dr Taylor: Do you envisage that your Detailed Care Record will completely abolish the need for paper records?
Mr Hains: As a technologist I think there will always be a need for reference to a file of original documents to be held, but the vast proportion of currently held records in not very secure environments generally in hospitals will be replaced by automation.

Q264 Dr Taylor: I do not argue with that. Hospital notes are so difficult to find they are incredibly secure!
Mr Hains: At the moment the simple answer is that individual hospitals can make their own decisions regarding how much data will be stored. The systems have the ability to capture and record that data electronically.

Q265 Dr Taylor: Will they make their own decision whether or not to keep a paper record as well?
Mr Hains: Yes, as indeed they do today.

Q266 Dr Taylor: Practically speaking, we can see that the detail will remain in the paper file and there will be a certain amount of codified information on the computer system and that is really all there is?
Mr Hains: Individual hospitals are making their own decisions regarding that. If one looks at, say, University Hospital Birmingham it has an advanced view; it wants to move to a very high level of electronically-stored records. Other hospitals may choose also to have a reference to paper-held records. We are not mandating the level of efficiency and automation to which those hospitals take their full records.

Q267 Dr Taylor: Will the Detailed Care Record be held at the GP and hospital level?
Mr Hains: Effectively, today most of the medical history will be at the GP level. When one goes to a hospital there will be rules-based access and controls as to who can add to and see that record, and the notes that go back to the GP are likely to be a summary of those outcomes. There will be a residual record regarding that episode held at the hospital with all the detail that takes place. Effectively, as it is today you will have the GP with his records and a hospital with the records of the details of the consultations and departmental activities that have taken place.

Q268 Dr Taylor: Is it only the Summary Care Record that will be available nationally?
Mr Hains: That is the current view. As has been discussed this morning, there are proposals to build upon aspects of the Summary Care Record in future, but at the moment that summary provides a very effective pointer and common reference to where data is held across what is a very complex environment. The answer is that the benefits of the Summary Care Record are in effect to provide consistency of data, to avoid duplication of records and effective electronic linking and connectivity across the health environment. Those who are using it attest to the value of that.

Q269 Dr Taylor: How do you ensure that clinicians have input to what is in the Detailed Care Record?
Mr Hains: In terms of the distinction between the national programme and its vision of a Detailed Care Record that is more a matter of policy. I am here to build the systems to support that. As to the sophistication of the systems that we are making available to hospitals, before we go anywhere near implementation we would work with clinical leads—administrators—to discuss what components, attributes and aspects of the system they want fully to exploit. The system's architecture and its ability to provide that connectivity is common, but there is a lot of local latitude as to how people want to use the systems, what particular emphasis they want the system to provide and, if you like, the depth of the data that they want to provide.

Q270 Dr Taylor: Therefore, in the hospitals that you work with clinicians have a definite say as to what does and does not go into the Detailed Care Record?
Mr Hains: Yes. Remember that in terms of our deployments to date we have been working on the patient administration system. With the recent implementation of Ipswich and others, we are moving out to support more of the clinical practices, but it is absolutely the clinicians who create the records. We work with expert user groups and reference groups because we want to keep a level of commonality in the deployed systems that we provide, but it is absolutely within their control in terms of the specification.

Q271 Dr Taylor: Have you given specific thought to confidentiality and security?

Mr Hains: Yes.

Q272 Dr Taylor: How are you tackling that?
Mr Hains: It works at a number of levels, but in terms of access security which is key the issuing of smart cards is not our responsibility but is really at the start of the life cycle of the security profile. That involves not just the card but effectively a PIN and how it is then implemented into our systems is very complicated. Therefore, individuals can have multiple roles and they can be multiple organisations. Your card is specific to how you operate in the NHS. Your access to data is limited strictly to the role you are performing at that time and the organisation for which you are doing it.

Q273 Dr Taylor: I think we will come to smart cards in a bit more detail. Dr Hale, referring to the Detailed Care Record, what input into this have psychiatrists had round the country?
Dr Hale: This is one of the problems. Speaking from the point of view of my own trust and the Royal College of Psychiatrists, we have not been able to make a great deal of input. Our experience is of learning about the design of the system as it develops. Obviously, there must be flexibility built into the design of the system that one must learn as one creates it in terms of what is appropriate, but there is a problem about taking into account the views of clinicians in the design.

Q274 Dr Taylor: Would you insist on the psychiatric part of a Detailed Care Record to be entirely separate from the rest of the system as on the paper-based notes at the moment?
Dr Hale: If it reflects current practice in most hospitals it would be separate, but obviously there are situations where the two have to be combined. That is obviously the case in, say, liaison psychiatry where one has a patient on a general medical ward who has a psychosomatic condition. In that case the psychiatric opinion is of direct relevance to the care of that patient. In those circumstances it is envisaged that one wants a system that reflects that sort of flexibility. There would be situations where they would be kept separate and situations where they would be combined.

Q275 Dr Taylor: Is that something that you can take into account?
Mr Hains: Yes. This may well be a matter of timing in terms of rolling it out to the different disciplines. We certainly want the input of expert groups as we effectively set the parameters for the system. In terms of the ability to control the visibility of data, some of it is clearly mandated by the national programme and some are inherent in our system. Inherent in the system that we are deploying—even to the extent of the point made this morning—we can suppress the name or address most relevantly for somebody who says that she is a concerned and battered wife who does not want her address visible as she makes her way round the healthcare system. We can do all of those things within the system. Clearly, we have been working not only with the issue of defined access to the systems. For us, in September there will be the establishment of the full legitimate relationship so that across organisations one will really be controlling who can see data. Most importantly—it is not just a footnote—the advantage of the technology is that one has a full audit trail of who has accessed the data which is not true of paper records. I believe that that is both a huge deterrent and, frankly, control as we go forward.

Q276 Dr Taylor: Do you foresee that you will be combining existing computerised records that already exist? Will you be building on those?
Mr Hains: Absolutely. One of the concerns that has been voiced is about the size and the endeavour of this programme. I would point to University Hospital Birmingham which is perhaps the largest one we have done, although Ipswich is probably close to it. We brought into the new system 10.2 million rows of customer data relating to existing patients. This was data that we had to go back and cleanse. Frankly, we had to take out thousands of duplicate records because of the level of computer sophistication in the prior system.

Q277 Dr Taylor: So, this was on computer already?
Mr Hains: Yes. We brought it across in order to make their system work and be operable. All of these systems require us to look at prior data and also interfaces between our core system and other systems that are operating. The deployments that we have done are voluntary on the part of the trusts that have chosen to take the system, so we have to satisfy them not only that we will not interrupt their day-to-day operations but that we can fully underwrite the implementation when it takes place. Needless to say, to satisfy them that we are carrying across all of their existing patient data is an absolute must.

Q278 Dr Taylor: Was there much free text data on that?
Mr Hains: I do not believe there was, but the fact that we are now interfacing to a lot of resident systems that are still there, which we will replace over time, ensures we have that connectivity to the departmental systems which have within them mainly free text data, so the answer is: yes, we have protected that.

Q279 Dr Taylor: Professor Randell, do you have any comments on the security of patient records?
Professor Randell: That is very much an open-ended question. A comment was made this morning about the inability in practice to have great scale and functionality and high security at the same time. I totally agree with that. Another point I stress is that the systems that we need to talk about are not just IT systems composed of hardware and software. The people involved in those systems are an incredibly important part of that. In saying that, I have in mind that I was involved in initiating a very large research project on the dependability of computer-based systems. When I say "dependability" I include reliability, safety and security. Most of the work on that project which involved five universities over six

years turned out to be concerned with research on people with computers in the health area, although that was not the original plan. The sort of things that that project revealed was that when looking at issues of reliability and security the people were of crucial importance. They are both the source of problems and solutions. Typically, the medics are capable of achieving what they want to do despite if necessary the computer, and there are a number of very careful ethnographic studies within our project and many others which testify to that. I give a simple example of how a person can help. Bed management in a hospital may well be done by lying to the computer which is trying to do it naively. I am sure that we will get to more issues of human beings being the causes of losses of security and privacy. But the combination of scale, high security and complicated functionality and the role that people play means that we should not be talking just about computer systems and looking at how well those apparently work.

Q280 Mr Campbell: Do you think that the greater threat to security of the new electronic record systems will come from insiders or outsiders? If it does, why?

Mr Hains: Perhaps I may comment at the moment on the "outsider" piece. We have had to meet some very exacting standards around pure physical access and the level of encryption of any data that moves up and down a wire between a terminal and at any centrally-based or locally-based computer. I can say that under the supervision of the NHS/Department of Health we regularly undertake ethical hacking. We are trying to break our own systems and use the brightest and best, as we do on a global basis. Effectively, we employ a division of hackers to see if they can break the system. I can say that that has not been achieved to date, but as more functionality is added it will be continued. I also need to dispel the myth that this is a monolithic system. In the North West and West Midlands we have implemented just over 70 patient administration systems which are contained in 31 computer images or sets with physical boundaries around them. This is not all on one monolithic system, which is very important. Effectively, the NHS defines what it wants grouped on the system. For example, a large one would be Morecambe Bay Acute Trust where there are 2,500 users effectively on one system compared with Greater Manchester where today it is getting real benefits across various healthcare settings by sharing. They have a system for Greater Manchester with about 13,500 users on it. But it is not one big system; it is divided up, which means a lot for reliability. I absolutely agree with Professor Randell that there is a relationship between scale and vulnerability and many aspects of being able to operate the systems. The other issue is: what security environment wider than the physical environment does one really operate? Here we have chosen to use ISO 27001 which is an all-embracing security policy. It covers not just the assets of the organisation—HR and physical aspects—but also business continuity and all the things one would expect; it is a whole world of security management. We are not just compliant. We have sought and gained certification for that standard for the North West and West Midlands. We shall also be certifying the two additional clusters that we took in January from both an operational and design point of view. I completely agree with some of the issues of scaling. I believe that we have addressed that in this compartmentalised environment and that to take on board a very wide and internationally accredited standard for security is the right framework within which to work. Things like testing of systems on a very regular basis as the programme goes forward not only for hacking but also to ensure you can move smoothly between main data centres and residual data centres are also matters that we shall do on a regular basis. I believe that those issues provide the safeguards.

Professor Randell: I believe that the direct problem will be to do much more with insiders than outsiders, though it may well be that the insider problem is caused by attempts by outsiders to subvert, distract or confuse insiders. One study I have heard about shows the extent of the problem. I believe it was found that in a single North Yorkshire hospital about 30 telephone calls a week were being made by people trying to obtain information illicitly by purporting to be somebody other than who they were. I am sure that that is by no means likely to be untypical. The more one has a system where there is the potential to get lots of valuable information the more one will have such attackers. I do not suggest that those are attackers who will achieve results by hacking into the Internet. I am prepared to assume that insiders being fooled into doing things that they should not do will be a bigger problem. That is why I believe it is crucial to talk about the system as being not just the computer but the set of people around it. It is one thing to try to deal with that sort of problem if one is, say, a military organisation but another matter if one is talking about a situation where the insiders are much less regimented but, though they probably have a rather stronger ethical background, are very likely to be fooled or possibly bribed into breaking security.

Mr Hains: The issuing of smart cards is a very good example. We have to be very aware and super-sensitive to some of these issues. The sharing of smart cards was really about the fact that the system did not provide a sufficiently immediate log on for people who wanted to use the system quickly. The log on times were quite adequate for somebody who wanted to operate the system for an extended period of time. Somewhere between 30 seconds and a minute is often what it takes to fire up your own PC, which is not onerous, but for somebody who really wants to use the system, open a session, do a transaction and close the session that is far too long. In terms of raising the bar we recognise the need for a smart card log on procedure of 10 seconds; otherwise, the ergonomics of the environment will start to open up people's pragmatic behaviour to try to use the system in different ways. I think that the quality of the system and the controls and policy managed locally are all parts of those issues. One is

all too aware that one must have a performance system to which one can rigorously apply the controls and people disciplines required.

Q281 Mr Campbell: Mr Hains, do you argue that the ethics of the National Health Service staff are as important as the technical security measures in maintaining the privacy of the patient data? Are you not just passing the buck a little? I know that you have hackers but what else?
Mr Hains: To go back to the point that we just do not come and implement a system; we are working with the staff of a local trust to provide a good code of conduct as to how those systems will be used but also good training is part of addressing the issues that you have just mentioned. The code of conduct mirrors the code of conduct that would be expected in the NHS today with a paper-based record which has many more vulnerabilities in terms of where it may be left, how it may be handled and through whose hands it will pass, but I think that the system and workflows that we are putting in mirror as closely as possible the ways of working and conduct that I know the NHS demands of its staff. I believe that it is adding to the controls in terms of what takes place within the boundaries of the departments. The path to more connectivity is the programme that we are pursuing with the NHS and how much of that will be opened up will be decided through policy, the expert groups and colleges of medicine. But I think that in terms of the efficiency we are providing in care settings today it very much mirrors and is helping to support and automate good practice as it exists in the NHS.

Q282 Mr Campbell: Dr Hale, I think that in the previous question you touched on the psychiatric records of patients being passed through the system. I think you said you did not believe in that.
Dr Hale: No. I said that there were circumstances in which it was appropriate that it should be a shared record and circumstances where it should be a separate record. The question that arises is whether that separate record has the same access and what access other professionals have to that psychiatric record, which is the envelope.

Q283 Mr Campbell: Is it a matter of getting the balance right in the case of psychiatric patients?
Dr Hale: Yes.

Q284 Mr Campbell: Will it be difficult?
Dr Hale: I think you must start from the assumption that people who consult psychiatrists do so in a state of mind which is different from that when they are well. The basis of that consultation is the entrusting of personal information to the healthcare professional. In those states of mind which they are experiencing, namely the anxiety and depressive states, perhaps the more serious psychotic states, there are various characteristics which alter their perception of systems, in that when they are depressed they have a diminished capacity to trust impersonal systems. We perceive the world as being less trustworthy; we have a greater need to control what is happening to that information. Therefore, that is a very special situation.

Q285 Mr Campbell: Can you give me an example of a patient who in your opinion should not go on the record? What would be the conditions on which that patient's information should go onto the electronic record?
Dr Hale: For a start, I very much agree with what was proposed by Professor Korff and Ms Robins in the previous session, namely that patient consent is absolutely crucial and it must be informed consent to specific information going on the record which is relevant to that particular episode. The professional in conjunction with the patient should have control over the flow of that information and it should not just be passed through a system and then control is lost. All of these matters are very relevant to people who are in states of psychiatric disturbance.

Q286 Chairman: We have touched a little on smart cards. I just want to develop it a little more. We are told that role-based access controls are the best way adequately to protect the privacy of patient records. Do you think that is the case?
Professor Randell: Yes, if role-based access controls are allied to an appropriate security policy model. It seems to me that the appropriate one is that developed in conjunction with the BMA a few years ago at least in part by Professor Anderson. Those together seem to make sense and work reasonably well, perhaps very well, at least in a modestly sized environment. The question is whether they really work in a very large environment where one has tens of thousand and not hundreds of people. It is amazing how many unlikely things will happen. That is the problem of scale. These are things that you could never have conceived should be designed or catered for. They will become almost the norm. If one has role-based access control with a very large number of complicated roles in a situation where there is a lot of changing roles it will be extremely difficult to deal with all the individual decisions that are being made as to who should have what role and what privileges. To validate in a rigorous way that the system as a whole is obeying whatever policies one has decided it must obey becomes a tremendous problem. I cannot give you a mathematical argument as to whether it will work for 10,000 people but fail for 100,000, but I am deeply suspicious of the practical efficacy of such a system. Again, it is a system of computers and the people who manage it and make all of the decisions on roles. The question is how it will work on that scale.

Q287 Chairman: Do you have any experience of any of these systems working elsewhere in the world on a larger scale than in the UK?
Professor Randell: I do not know of systems of this complicated functionality and scale, or possibly just of this scale.

Q288 Chairman: Is your basic theory that if the system comprises 1,000 records one will go, if it is 5,000 five may go and if it is 500,000 it just grows incrementally?
Professor Randell: That is the sort of thing that I am worried about. If one looks at the word "system", one builds systems out of systems. One can use several systems together and what one has again is a system. Errors can permeate from one system to another if there is any means of communication. One tries to put in firewalls and means of preventing this, but as far as I am concerned the whole NPfIT is a system because things are connected together. One has to look very carefully at those connections to make sure that one is not only connecting things together to do what they are supposed to do but ensure that one is not connecting them together in such a way that damage can flow from one system to another.

Q289 Chairman: I accept that, but firewalls are not new in terms of IT systems.
Mr Hains: To look at the whole regime, I believe that role-based access is one aspect. Legitimate relationships and the disciplines around role-based access where one is in the area of records crossing boundaries should be looked at. As to why an individual through either a referral or other granting of right will in effect have the ability to access a record, the reasons will be very explicit and all of that is subject to an audit trail.

Q290 Chairman: You refer to an audit trail. Will the system be able to pick up a breach of what should have happened; in other words, if somebody did access a record he should not have done?
Mr Hains: On inquiry, clearly in terms of legitimate relationships it will track both those and attempted access for which there is no legitimate relationship.

Q291 Chairman: If it was not a role-based access it would highlight that fact?
Mr Hains: Yes. That boundary is also the opportunity for patient consent consideration, because at that point the patient can effect a statement about what he or she does or does not want provided in sensitive areas of mental health or sexually-transmitted diseases. Those are key factors. There is then the sealed envelope and its outline design.

Q292 Chairman: We will move on to that in a couple of minutes. We had the example of a smart card being used in an A&E department. Some hospitals have allowed staff to share smart cards because, as you pointed out earlier, it takes too long for one clinician to log off and another to log on. Is this a serious privacy or safety problem, or is it something that we should see as inevitable in busy departments like A&E?
Mr Hains: From a design point of view we have to respond to it. That must be deemed to be bad discipline and it is really about us being able to provide very short lead times to log on, which need to be at 10 seconds. Clearly, that was a local accommodation due to a poor time to gain access, and that is where there is a weakness in the system. The weakness is that ergonomically people need to circumvent controls and processes because they do not meet the need. We are super-sensitive to that. In terms of both the input we get to modifications and redesign but also in terms of our individual deployments there are regular checks in talking to the end users to ensure this will be fit for purpose. That is a good case where if it was not addressed you would have a clear security opening. That needs to be closed.
Professor Randell: I think that the seriousness of it is a matter for the medics, medical ethicists and so on. Clearly, that was a violation of what was intended. As to whether the figure of 10 seconds is right I would be interested to know how that has been established on the basis of realistic trials and in what sort of environments. I can imagine a trial in one hospital department would come up with a rather different answer from one in an A&E department. An interesting model is the use of smart cards by barmen in crowded bars to ensure that payment goes into the till and that the responsibility for the particular sale is clearly identified. They are also acting on commission. Those are little systems that can be exceedingly fast, but there they have obviously got the ergonomics right. I am not convinced that an A&E consultant will be so easily convinced to change his habits of a lifetime and start working on a new system, particularly if he and the atmosphere around him believe it to be a system that is imposed upon them rather than one they have chosen, learned to trust and see grow gradually into something bigger with which they are still happy. There are big issues here which are not simple technical ones. Clearly, the issue of speed is vital but I do not believe that is the whole problem.

Q293 Chairman: Dr Hale, if consultants accept overall responsibility for a patient under their care could they not also accept responsibility for all the data entered in the course of providing that care? If so, in a sense the sharing of smart card is not really a problem.
Dr Hale: I am not sure I understand the second part of your statement that sharing smart cards is not a problem. I accept the first part of the proposal.

Q294 Chairman: Basically, as a clinician do you think it is difficult to share smart cards in a situation as I described earlier in an A&E department, though I agree that it is a bit more difficult in terms of patient records? You accept that you are responsible for the data that goes onto the record.
Dr Hale: Yes. Assuming as Professor Randell says that I believe the system is one that I want to make work, a delay of 10 seconds should not stop me making use of it.

Q295 Chairman: I accept that. All things being equal—at the moment we know that it is not—if an A&E department gets as smart as the till in the local bar in those circumstances that is not a problem. But what about the sharing of smart cards? I went along

to one of my GP surgeries a few months ago. They complained about smart cards and access. I found out that they had 11 in that surgery but only five GPs. I asked why they had another six smart cards in the surgery and was told that they were for the people who did all the letters. There will be issues about that. This is about patient management. Is the issue of sharing smart cards as big an issue as some would have us believe?
Dr Hale: I think that the situation you describe is one that is bound to recur, and it goes back to the controls one has over staff who may have access but are not bound by the same rules, for example secretaries. They are bound by the same rules as far as the trusts are concerned in terms of conditions of employment, but they do not have professional bodies to whom they are answerable, so the controls and sanctions will be considerably less.

Q296 Chairman: Let us take a GP surgery and Lloyd George records. Anybody who has access to the room in which they are stored can take hours and hours to look for something and find absolutely nothing. That is not the case with IT, is it?
Dr Hale: No.

Q297 Chairman: If one of those smart card holders can access all the records in a GP surgery within seconds will that be a good or bad thing?
Mr Hains: Therefore, the design content of the access control is that an administrator responsible for follow-up letters or referrals is effectively limited to the part of the system that allows her to conduct that task.

Q298 Chairman: Would access to that particular patient record be traceable or measurable?
Mr Hains: Yes.

Q299 Chairman: What I am trying to get at is that we could not have anybody going in without knowledge that that person is surfing the records of a GP surgery?
Mr Hains: Correct.

Q300 Chairman: It was suggested to me that that was wrong because there were 11 smart card holders in one surgery. I want to establish whether or not it is wrong.
Mr Hains: To go back to your comparison, yes, the person may not find the Lloyd George record or may be able to browse and read the complete record, so there are both sides to it. But the design intent is that we have a pretty sophisticated way to limit access to various parts of the system based on what is a very wide range of roles and authorities within the NHS. I believe that it is fulfilling that purpose.
Professor Randell: There is the auditing of accesses in various roles which in principle is obviously a good idea. If, however, one has a system where it turns out that there are huge numbers of audit records being generated to the point where nobody is looking at them, that is a kind of overall system that is not being properly designed. It is unwise to assume that just because something has been audited and the computer asks whether you really want to do this people will always put in the necessary amount of thought. If a doctor is repeatedly asked "Are you sure you are permitted to do this?" the response will become a reflex action rather than one that is thought out. There are human and computer issues that must be properly sorted out in conjunction.
Chairman: I am not sure how one can design an electronic system that is comparable with the human mind and what we as individuals can and cannot do, but we will leave that for another day.

Q301 Sandra Gidley: I come to the subject of sealed envelopes. Mr Hains, Richard Granger in a previous session assured us that technology would be available by April 2008. Are you equally confident?
Mr Hains: There is the issue of specifications.

Q302 Sandra Gidley: I will come to that.
Mr Hains: I believe that is quite important. In terms of the system capability that we have envisaged and for which we have an outline design, it is to the level of the two-part sealed envelope: one that is opened in an emergency and one that is just locked. From the point of view of technology and building it into the system, we understand how to do it, but what we need however is a clear specification.

Q303 Sandra Gidley: You do not have that yet?
Mr Hains: No. We need a clear specification as to how that will be used, in what environments it will be used, how it will be deployed and an idea of the data sets and information that would go into that sealed envelope. We have a timetable.

Q304 Sandra Gidley: How can you have a timetable without a specification? Surely, in any IT project those two go hand in glove.
Mr Hains: I have to say that on this programme it comes down to complex decision-making within the NHS. We have reviews. We have yet to get a fix on the precise operation of how sealed envelopes from a policy, not IT, point of view will work. Clearly, we can build systems that have flexibility. For example, today our systems can respond very quickly to whatever the policy decision may be around consent that is required for the uploading of a summary record. We have built in the capability but it has to be explicit and not mere passive consent. We also have an outline view of how we would implement sealed envelopes, but we need a firm specification on how it will operate. We can stipulate, but not today, that if we are looking for implementation in 2008 then by such and such a date we need a much finer level of clarification as to the exact requirements. We are timetabling many of the requirements of this programme on a forward basis without yet having the full definition of how it needs to operate.

Q305 Sandra Gidley: I am very much warming to the idea of Mr Granger coming back before us. When were you first asked to develop sealed envelopes?
Mr Hains: Perhaps I may first clarify one matter which will help you with Richard Granger's comment. His comment regarding sealed envelopes

relates to the spine. Our sealed envelope environment must be implemented in the local hospital and other systems that we are implementing. As to the LSPs and our role in creating these environments particularly within the secondary care environment, we will be undertaking that following the spine implementation. I know that there is a specification for the spine with a 2008 planned implementation date. I need a more detailed specification to implement those within our LSP environment.

Q306 Sandra Gidley: Is that a different implementation date? Can you give us some idea when that will be?
Mr Hains: It will follow, so it will be either later in 2008 or 2009.

Q307 Sandra Gidley: Are you confident about that?
Mr Hains: Yes.

Q308 Sandra Gidley: But you have not yet had a specification?
Mr Hains: We do not yet have a detailed specification, and I think that the review and discussions that are taking place with all the professional bodies will ultimately define exactly how the sealed envelope will operate. As you would expect, I need to know the types of data and its amount and the capability required in a documented specification for the sealed envelopes.

Q309 Sandra Gidley: Earlier there was some talk that this should be available only with the knowledge or permission of the patient. To the best of your knowledge is that part of the discussion that is taking place?
Mr Hains: No. In terms of making it available I think that from a systems point of view—I need to separate policy from systems—if we build it in it will be universally available.

Q310 Sandra Gidley: Have you stopped just anybody opening it?
Mr Hains: I misunderstood your question. I thought you asked whether the sealed envelope capability would be universal throughout our systems. It will be. It is for policy to decide under what circumstances sealed envelopes may or may not be opened. We will imbed those rules and controls within the system, but I do need a specification with which to do that.

Q311 Sandra Gidley: Dr Hale, obviously you approach this from the perspective of mental health. Given what you already know and have heard today, do you think that the sealed envelope technology provides suitable protection for the sort of information that might be recorded?
Dr Hale: I do not know about the technology, but the starting point of whether the patient has control over what is in that sealed envelope and the circumstances in which it may be revealed is absolutely crucial, so the answer to the question is different.

Q312 Sandra Gidley: Have you been asked to input into that process so that the people who are designing the process eventually get a spec? Where are we going with this as far as your involvement is concerned?
Dr Hale: It must be said that the college has been involved in reacting to proposals rather than at the fundamental design stage. The proposals for sealed envelopes were put forward and we then reacted to them. Further, we have reacted rather than become centrally involved in the question about opting in and opting out of all the record. It may be there were breakdowns in communication but to my knowledge we have not been involved in that central design.

Q313 Sandra Gidley: What security measures are used elsewhere in the world? Is there any evidence base as to whether it works? How much of the programme for IT is just a huge security experiment?
Professor Randell: First, there is danger in assuming that one gets security just by having a good set of security mechanisms like smart cards, role-based access control, auditing and the like. Security failures are typically nothing to do with that. Professor Anderson's most famous paper is one I know very well because a number of years ago it was part of his PhD of which I was his examiner. That was about how systems actually failed to maintain secrets. It is because those mechanisms though individually may be capable of doing what they are supposed to do are imbedded in an overall system such that there are other faults in it. As an analogy, one can have a wonderful door to a safe but if you build it into a bank that is made of rotten plywood it will not do you much good. Perhaps that is a silly way to describe it, but the case is that virtually all security failures do not arise because of the inadequacy of the little mechanisms but the overall system into which they are built and the mistakes made in it. When one has an overall system which involves a huge amount of software there is a tremendous validation problem to deal with. That was a long preamble to your question. I have not been able to find detailed scholarly studies of the effectiveness of such mechanisms—not even smart cards—particularly in a healthcare environment. One can find quite a lot of documents extolling the merits of smart cards but not evidence on which to base policy. It strikes me that sometimes we have policy-based evidence rather than evidence-based policy.
Mr Hains: I think that the National Programme for IT has described the security as state of the art, not breaking new ground and I attest to that. As one looks across from the healthcare environment to banking and other environments one would describe them as being very fulsome in their use of what is the best available today. That must be capable of upgrade and we have to demonstrate that we can do that. I agree with Professor Randell that the issues are not so much technical as about how the systems will be used and the quality of housekeeping and controls. I hope that one of the important messages I have got across is that it is not one large monolithic

system, which is important for a number of reasons. Clearly, it is important for control of access and breadth of access, but it is absolutely the case that more modular, simpler and smaller systems are more easily protected and upgraded in future. That is exactly the approach we have taken. There is emphasis on keeping tight controls and boundaries and, through policy that is directed to us, firm levels of control over message-passing and encryption, making sure that the connectivity that we create is safe. That is the essence of the design.

Q314 Mr Campbell: Mr Hains, we heard in the previous session that Connecting for Health had not set any targets for an acceptable number of security breaches. Is that true? Is there any in your department?
Mr Hains: I think Professor Randell would say that one needs to look at a broad range of measures around the whole area and it is not just "up" times, security issues or the ability to monitor the system that is important. Around the system controls we have a battery of measures with the NHS. Its robustness and ability to withstand tested breaches is part of both our contracted and managed environment with them.

Q315 Mr Campbell: But if there are no target figures how can patients be reassured?
Mr Hains: We measure that in terms of supervised attempted access. We have regular audits and review of the security policies that we have put in place. There is not a target. If your question is whether it is acceptable to have five breaches of security the contracted environment is a no failure approach to security issues. That is the security regime we have been asked to step up to. Both parties understand that no system is foolproof, but in terms of any weaknesses that we find in our system, or is found through audit, we are contracted to remedy it quickly. Any issue where we do not remedy it will be a failure by us as a contractor. Therefore, there is not a statement which says 10 breaches over a period are acceptable; it is a zero tolerance environment. Should we find any issues the contracted remedy is how fast we respond to it and satisfy the authority that we have plugged any hole.

Q316 Mr Campbell: We will watch that space!
Professor Randell: When I and colleagues met Mr Granger a year ago we were absolutely shocked to find that CFH did not have any documents stating things like the reliability and security guarantees. They said that they did not have them because they were regarded as confidential to the suppliers. I still find that absolutely gob-smacking.

Q317 Mr Campbell: That is a good point which we will take up. Why are you and your academic colleagues so sceptical about the security of the new system? Do you think there should be more or improved security? I think the answer is yes.
Professor Randell: Yes, but I do not think that you simply add in more security mechanisms. There is a question of how well trusted and supported it is by the medical profession. A complex system that works has been derived from a simple system that already works and is already trusted. In a number of ways, as a whole, even if not in terms of individual hospitals, it is a huge imposed system that is being forced into environments some of which see it as making them go backwards and replacing systems which are in some ways better for their particular purposes. That is not the way to get a system where the general atmosphere is conducive to trust and support for policies other than by achieving one's goals despite the system. I repeat my comment that I have great faith in the clinicians to do remarkably well for us despite what is being forced on them, and I am very glad of it because I have a very strong bias in favour of the NHS.
Mr Hains: Perhaps I may make just make a couple of comments without breaching my confidentiality agreement with the NHS. It is true that we do not have any specific statement on security breaches. We have extremely well documented requirements to meet on availability, reliability, performance, fix time and defects. Clearly, a security breach would be a defect. It is also an environment in which there is a 100% no data loss requirement. I am pleased to say that no data has been lost. We have now deployed over 70 systems to trusts all of which have been on a voluntary basis. We have laid out our future plans, including sealed envelopes. The trusts can decide when they jump onto the bus. If a trust has a particular feature of its system that it cherishes and does not want to join the programme at this stage it will not join the programme at this stage. Our deployment plans are geared to trusts that understand the system. We demonstrate the system and help them with the change and they voluntarily choose to join the programme as part of their push for efficiency as well as the connectivity that it offers. There are no strong-arm tactics to have people moved to areas of inferior functionality. It is absolutely true that these systems are in many ways different from the systems that they operate today. Change management is involved. We have to support both administrative and clinical teams through those changes, as in any system change. It involves pain on both sides. The fact is that we have deployed systems faster than they have ever been deployed before and no system has been withdrawn once implemented. I believe that we have genuine volunteers at the other end, not pressed people.

Q318 Mr Campbell: How does the failure of the Medical Training Application Service square with the new system? That was suspended. Is it an entirely different system?
Mr Hains: It is entirely different. I do not believe that an attached spreadsheet to a web-based service can be compared in any way at all with a fully engineered enterprise system.

Q319 Mr Campbell: But all of the data was in one place.
Mr Hains: Yes, and it did not have role-based access or any other controls within it. Clearly, it was a seriously flawed way to implement a system. I can

describe it only as chalk and cheese in terms of a pre-formed database attached to a website compared with a properly engineered enterprise system. They are absolutely different.

Professor Randell: Clearly, that was a blunder. The trouble is that blunders happen and the greater the number of people involved the greater the chances of blunders. One way to summarise it is that if you take a very complex manual system and computerise it the best that you can possibly achieve is fewer but bigger failures; the worst is more failures. No payroll clerk has ever mailed a cheque for £999,999 and so on. In the early days a lot of computers did that. When one puts in a very complicated computer system one has to write a programme that will deal with all the circumstances that one can dream will arise. Because one cannot do that successfully there will always be the possibility of failures which with any luck will not arise too frequently, but they are likely to be big ones.

Q320 Mr Campbell: It is interesting that you say that, because Richard Granger also said that if he had been in charge of the system it would not have happened.

Professor Randell: To use a famous phrase coined by Mandy Rice-Davies, he would say that, wouldn't he?

Q321 Chairman: Professor Randell, do you say that these systems are comparable?

Professor Randell: Yes, in the sense that all systems are liable to have failures because of blunders. That is the only comparison I make.

Q322 Chairman: There is a difference between a record brought in effectively for academic purposes as opposed to an electronic patient record. It was a different system?

Professor Randell: It was a very different system.

Q323 Chairman: One should not confuse the MTAS system with the electronic patient record.

Professor Randell: No, but it does give one reason to think.

Q324 Chairman: I have made the comment that we can all go back to the cave and roll a stone over it if we want to, but I do not think many of us are up for that. Dr Hale, in relation to system dependability we heard earlier from Mr Hains that record systems are not kept in one place but in different locations. Because they are kept in different places and are hosted remotely rather than in the hospital or practice that uses them it means that potentially they will be unavailable if the network goes down or the hosting centre loses power, of which CSC has had some experience. For how long do you believe it is safe for a hospital to lose access to all medical records, images and test results that potentially would be hosted elsewhere and not in the actual building?

Dr Hale: I can envisage that it may be minutes or days. It would depend entirely on the nature of the emergency. That is perhaps not a very helpful answer, but in acute medicine it would be a very short period of time, whereas in psychiatry it would be much longer, perhaps a day or so.

Q325 Chairman: If there was a risk assessment of that it would be different in those two circumstances?

Dr Hale: Absolutely.

Professor Randell: The art of designing an overall system like this is to accept that there will be failures and to put in an awful lot of planning as to how to cope with them, and also to put in an awful lot of planning about how to minimise reliance on the system. One example that is well known to everybody here is the Visa electronic payments system which in one sense is incredibly reliable. From a detailed study of it however I am aware that some very careful thought has gone into minimising reliance on any particular part of it, including any particular bank. It really is an issue of minimising reliance. As to the levels of reliability that can be achieved, one of my colleagues who is very much of a specialist in this area gave me some rather startling statistics, some of which I already knew. The Health and Safety Executive is prepared to accept that the very simple system, part of a nuclear reactor, the shut-down system that is one of the precautions in case the reactor overheats and explodes may well fail one in 1,000 times it is used. The manufacturers try to claim that their method of testing it and so on would make it one in 10,000. The HSE was not prepared to believe that. It is typical for well run systems to be more reliable than they can be guaranteed to be *a priori*. If we take something like Microsoft's Windows operating system it is claimed by the company that such a system on average will manage to keep on working for just 3,000 hours before it fails. That is not a huge amount of time, but it is probably a lot better than anybody believes because there are so many other things that can go wrong. Think how they have managed to achieve that: hundreds of thousands, even millions, of people have willingly or unwillingly helped Microsoft to test it. A one-off system—as far as I am concerned NPfIT is a system luckily with a lot of architecture and structure to it—which undoubtedly is in many ways safety-critical and security-critical, hence this session, is very different. The examples that I can quote are somewhat similar. Take a very modern Ministry of Defence command and control system which is a very large networked system. The statistics that I have been given reveal that on average modern command and control systems suffer one failure every 40 days and a dangerous one every five months. Another sort of system which is reminiscent of NPfIT though not in size is a big process control system. That is the sort of thing which will be employed in a huge oil refinery to collect data from thousands of places. A process control engineer will say that as a rule of thumb one can fear that such a system will fail completely about once every two years. My specialist friend has done a lot of work on estimating failures. As a guesstimate, not estimate, he said that NPfIT would be likely to fail about once every four days. He said

that his method of giving a scientific estimate would involve being privy to trials of NPfIT as a whole over a reasonable period—I believe he was talking of weeks or months—and being given details of how many different faults were found during that trial. He has a well established method to come up with a conservative estimate for reliability. I was shocked by those numbers, but it seems to me that there are all sorts of technologies and expertise that Connecting for Health could well be asked to investigate so we have less in the way of anecdote and more in the way of facts. Apparently, there are facts as to what the rules are with respect to reliability but they are not out in the open. Why should we trust them?

Q326 Chairman: Mr Hains, what lessons did you learn from the Maidstone data centre incident last year, and what was the effect of it in terms of what it was hosting and the establishments involved in it?
Mr Hains: The regime to which we are working with NPfIT is a very rigorous set of severity measures for any problems that we may have. Those are geared to requirements rather than any measure of an outage time or whatever. To give an example, if there is only one printer and it is not available at a critical clinic it can be a very serious matter for the people involved. We have a measurement from severity one through five and those are catalogued. We have a statistical basis on which to assess how well our systems are doing. As to the general point in relation to our obligations, before we leave a site and implement a system with a trust we must develop with them business continuity plans which will involve descriptions and the testing of what in most cases will be manual procedures in the event that the system is unavailable. Our job is not done unless we have worked with a trust to agree how it will cope if systems are wholly or in part not available. Regular routines like the printing off of tomorrow's appointments and matters that could cause congestion in the hospital are things that are absolutely considered in terms of the future reliability of the environments. To go back to Maidstone, I believe that the biggest risk in the computer industry generally at the moment is unreliable power supply. Generally across the world power has become more spiky which is ruinous to any sort of IT system. Last year we experienced a power issue at Maidstone which caused a short in our configuration there. It set up a position within a storage device that required experts to come from Japan effectively to reset that system. We transferred the operation between our Maidstone centre and the reserve centre which was effected without data loss, as was the pass back to the primary data site some weeks later. We learnt several things from that. First, we learnt that as we scale up the system it is better to have four centres than two, which is what we have invested in, so that data is now not only mirrored but effectively held simultaneously in two places. We are holding that across four centres, not just two. Second, out of that experience with the authority we have tightened our targets and expectations of how quickly systems need to be brought up. There was a category of systems which were deemed not to be critical—they were non-acute and departmental-type systems—and there was a fairly leisurely take-up. As Dr Hale said, some systems can come up much later. The view was that 72 hours would have been acceptable for that. We have now set a new timetable which says that in any failure of these systems the expectation is one of 24 hours and, within critical environments, clearly a much shorter time is expected. We have learnt from that. We have increased our investment in multiple centres and have worked with the authority to re-evaluate those levels of acceptability in bringing up systems. Just to confirm it, our job is not done unless we have also defined contingency and manual procedures.

Q327 Chairman: I believe that it affected about 72 Primary Care Trusts and eight hospitals which suffered a loss of data for that period of time.
Mr Hains: There was no loss of data; it was loss of availability.

Q328 Chairman: They were unable to get hold of the data for a time. Were there any clinical implications of which you are aware?
Mr Hains: No. Clearly, there was an administrative implication. With our staff who have security clearance to help with administration we went out and paid for additional administration support. Therefore, the pain was administrative. We have no evidence of clinical risk or data loss, and it was inconvenience for which we are really sorry. Our remedy has been the further investment we have made regarding setting up a much more resilient environment.

Q329 Dr Taylor: Professor Randell, in your written submission in heavy type we see the very definite view that "a detailed constructive review of NPfIT in the light of these insights could, we argue, greatly increase the likelihood of the project's eventual success." Can you justify that to us in the remaining two minutes? Obviously, you want one of our recommendations to be that there must be an independent technical review.
Professor Randell: The quickest answer is that there have been so many cases in the past of other systems that have benefited from such a review. One of my colleagues who testified to you earlier, Professor Martyn Thomas, has himself been involved in quite a number of such reviews. I have not. We are talking about a constructive and detailed technical and socio-technical, if I may use that term, review which would work with Connecting for Health and be imbedded in it. That would be of considerable help.

Q330 Dr Taylor: Would that be feasible at this time in the process?
Professor Randell: I believe so, because I think there is a way effectively of turning the whole programme round based on the number of good things that the programme is already doing and into a programme where there is authority as well as responsibility at the trust level and where the LSPs act as services

rather than as controllers. That could have a big effect on lots of the attitudes and worries that we have found extensively documented. One has here not just a technical problem where one big further heave will convince everybody; one has a big social problem to convince a lot of people that it is worth going on with the programme. I think that it is, but we must first change an important aspect of it.

Mr Hains: We have collaborated with the many reviews, both commercial and technical, that have already been done on the programme. The way that our company operates is that this is reviewed by colleagues from the United States and Australia and by other healthcare experts. That review effectively is at each key design phase and is no longer than every two months. Within our worldwide organisation there is constant quality and fundamental design review, particularly as it relates to performance and scalability. Today I have talked a bit about some of the myths that we come across regarding how this system is configured and the degree to which there is fear that in some way it is monolithic. We can only chip away at those issues. I should like to confirm that we are investigating that. Last week across the way in the QEII Centre we talked openly to several hundred nurses about some of the issues that we have referred to today, for example how the systems are used and how some of the policies relate to them but also making real demonstrations of the systems, frankly to take some of the fear out of what is coming and the level of change. I agree with Professor Randell. In terms of our architecture, we are very confident that those good design principles have been deployed but we then need to invest jointly in externalising that message. That can only speed the take up and smooth implementation. We are making those investments and have had a very good response.

Q331 Dr Taylor: Does that reassure you somewhat?

Professor Randell: The sort of review I was talking about was one that was visibly independent, open and public in order to fulfil its role of helping to gain trust. I absolutely agree with Mr Hains on the importance of internal reviews, but I was talking of something rather different.

Q332 Dr Taylor: Is it possible to have a note on one or two of the technical reviews to which you referred that have taken place and the results of them?[2]

Professor Randell: Yes.

Chairman: I thank all of you very much for coming along. I am sorry for the lateness of the hour. We have finished half an hour earlier than our previous session on this subject. I hope we can improve on that by another half an hour the next time we take evidence.

[2] Ev 124

Thursday 7 June 2007

Members present:

Mr Kevin Barron, in the Chair

Mr David Amess	Mr Stewart Jackson
Charlotte Atkins	Dr Doug Naysmith
Sandra Gidley	Dr Richard Taylor

Witnesses: **Dr Mark Walport,** Director, The Wellcome Trust, **Professor Carol Dezateux,** Head of the MRC Centre for Paediatric Epidemiology and Biostatistics, Institute of Child Health, and **Professor Simon Wessely,** Academy of Medical Sciences, gave evidence.

Q333 Chairman: Good morning and welcome to the third evidence session of our inquiry into electronic patient records. I wonder if I could ask you, for the record, to give us your name and the position you hold.

Professor Dezateux: I am Carol Dezateux. I am paediatrician by training. I am a professor of paediatric epidemiology at the Institute of Child Health and an honorary consultant paediatrician at Great Ormond Street NHS Trust.

Dr Walport: I am Mark Walport. I am the Director of the Wellcome Trust. In a previous life, I was a professor of medicine at Hammersmith Hospital, at Imperial College. I am a member of the board of the UK Clinical Research Collaboration and of the Interim Board of the Office of Strategic Coordination of Health Research (OSCHR).

Professor Wessely: I am Simon Wessely. I am a professor of psychological medicine at the Institute of Psychiatry at King's College London. I am also here for the Academy of Medical Sciences.

Q334 Thank you very much and, again, welcome. In broad terms, what benefits can the Secondary Uses Service bring to research in the United Kingdom and what potential do you see in the electronic patient record once it is more widely used?

Dr Walport: This is all about improving patient care. Good patient care depends on having good medical records. As an example, Choose and Book is something that has been introduced as an early phase of the National Programme for IT but how can you Choose and Book if you do not know what the benefits of seeing different individuals are? That requires good data. Frankly, having good healthcare depends on doing research all the time. It is a question of raising the game. I think research is completely integral to good patient care and electronic patient records are a very powerful way of achieving that.

Professor Wessely: We would agree completely. It is an ability to use the enormous data resource of the NHS for the public good in a way that has not been possible before. It can answer questions swiftly and accurately on patient safety. Issues such as MMR and autism could have been dealt with very swiftly and properly. The whole range of opportunities that it provides, we welcome. We feel it will amazingly improve the effectiveness of the NHS and patient safety.

Professor Dezateux: I would like to add to that. Thank you for this opportunity to raise the profile of research using electronic health records. I was a doctor trained in the NHS. Nye Bevan established a health service free at the point of use but the other very important person from my generation was Archie Cochrane who emphasised the need for effective healthcare free at the point of use. England is renowned for initiating the international Cochrane Collaboration which pulls together evidence in an accessible form to inform effective healthcare. For my generation there is no distinction to be made between health services and research for effective health services. Coming as I do from a public health background it is really important that we understand how to protect the health of the public when we are dealing with a much more complex environment where public health concerns require rapid answers. Without an infrastructure built on electronic health records we cannot discharge that public duty effectively. I think it is very important that we get over, using some detailed examples, the important questions that we will not be able to address if we do not have this kind of opportunity in the UK.

Q335 Chairman: A number of witnesses described access to the national electronic record data as a "unique selling point" for research UK. What is your interpretation of a "unique selling point" and do you agree with that?

Professor Dezateux: There is indeed a unique opportunity in the UK, based on the fact that we have a National Health Service, we have a diverse, large population, and we have the opportunities through our public services and our public infrastructures to understand and identify reliably effective treatments and also reliably to identify causes of disease. While there are other countries that have developed their electronic record linkage, notably the Nordic countries and Western Australia and some parts of Canada, in general we have a very long and distinguished tradition of using electronic records in the UK and we rather take for granted, in fact, the ability to link to vital events, the ability to link to cancer registers, but we have to remember that some of the most important health discoveries—the link between smoking and lung cancer, *et cetera*—were all facilitated by these opportunities.

Dr Walport: The greatest advances in health have come from public health measures, going back to the discovery by John Snow in the 19th century that which water pump you took your water from influenced whether you got cholera or not. The opportunity in England to have potentially 50 million health records with good record linkage offers enormously important opportunities for improving patient health. Let me take another specific example. Drug trials, before a drug is released, offer the opportunities to find out the potential benefits and side effects in populations of a small number of thousands of individuals, but the truth is that drugs that are effective also have side effects and if you want to find the rare side effects then it is important that you can find them when you are looking at large populations. So, again, the opportunity to have good record linkage for a population of 50 million means that you can potentially find rare and uncommon side effects of drugs quickly. For example, the association between some of the new non-steroidal anti-inflammatory drugs such as Vioxx and cardiovascular disease would, I think, have been discovered much more quickly if there had been very good electronic patient records and very good epidemiology surveillance of that. This is all about good health actually.

Professor Wessely: Researchers from my institution routinely go to other nations with systems, namely the Nordic countries, to do research that we cannot do in the UK. They are just in the middle of looking at a study on maternal health and schizophrenia in children that can only be done in Denmark and Finland because that is the only way you can assess related events during pregnancy to the later outcome of schizophrenia in the child. I think most people would agree that is incredibly important. We cannot do that in the UK. We have someone who has had to be taught Finnish to go and do these studies in Helsinki. Obviously the data here would be much better, because it is much bigger and more comprehensive.

Professor Dezateux: There has been a huge investment in the human genome project and this country has terrific resource in terms of some large-scale cohort studies linked to biological data. To exploit that and the knowledge and understanding that will lead from that, we really need to capitalise on these opportunities for record linkage to understand the meaning of the genetic changes for future health and to advise the health services wisely about how to use these tests in the future. I think the UK is very uniquely positioned to do that. Already there have been some very important advances building on that and we would like to see that opportunity developed more because we have the opportunity, both in the pharmaceutical industry and in terms of the discovery of causes of disease, to be a world-class leader in the UK in that way. This is really what this will allow us to do.

Dr Walport: Indeed, it is timely, because the front page of *The Independent* today and the lead story on the *News at Ten* last night was a report of an enormous study of genetics of common disease demonstrating new genes for Crohn's disease and diabetes, and in the last few weeks there have been new common genes associated with obesity. These have all benefited from very good cohort studies carried out in the UK.

Q336 Chairman: The initial aim of setting up the Secondary Uses Services was really a way of performance management and payment by results. Do you think Connecting for Health was very slow to recognise the potential for research?

Dr Walport: I think it is getting there. The very term "Secondary Uses" is unfortunate because it seems to me that one of the primary uses of Connecting for Health should, for example, be providing expert systems to help doctors and other health practitioners in diagnosis and treatment. I think this should be a primary use. It comes back to the point I made earlier. How is it important, as it were, to be able to choose between five different clinics and five different doctors if you do not know anything other than waiting times?

Professor Wessely: I quite agree. In the1948 NHS Act research was defined as a primary function of the NHS and I think it is unfortunate they have chosen the term "Secondary Uses Service". However, we do have some concerns on the technical side. To do these kinds of studies takes an enormous amount of expertise, time, and trouble—to do the validation, to do the linkages, to make sure they are accurate and so on. We have some concerns that the Secondary Uses Service, so called, has that ability or expertise or commitment at the moment. That is something that needs to be looked at carefully.

Professor Dezateux: I think Connecting for Health have been very focused on delivering performance management and business and have been instructed to do so. However, our experience over the simulation exercise that was carried out for the UK Clinical Research Collaboration was a very good co-working in openness with those involved in the Secondary Uses Service, with good receptivity really to the opportunities that this provides, so I hope we can move forward positively, building on this dialogue rather than perhaps perseverate about the past.

Dr Walport: I think that is exactly right. I think the direction of travel is right; there now is a recognition in Connecting for Health that research does matter. It is very instructive to look at other countries and other systems. If one looks north of the border in Scotland they have extremely good electronic patient records, particularly in areas such as diabetes. We recently held a meeting at the Wellcome Trust on behalf of the UK Clinical Research Collaboration and had presentations from two of the big American systems; from the US Veterans Administration, with many millions of patient care records, and from Partners Healthcare System in Boston, where, again, they have more than two million records. It is quite instructive that in all of those environments they are using them very effectively. I think this will get much better acceptance when the medical profession at large can see it is enabling the profession to do its work better,

and that is why, in a sense, I think focusing on the management side meant there was much less ownership of the system by the people who had most to gain from it.

Q337 Chairman: Carol, you recently took part in a study to simulate the impact of electronic record data on different kinds of research. What were the main findings of the study?

Professor Dezateux: There were four groups, of which I led one, each of which looked in different ways at different types of study designs, ranging from clinical trials to issues about patient safety to issues about causes of disease. We led our groups in parallel but with a lot of cross-working. The first thing to say is that we were all convinced that there were fantastic strengths in the UK in record linkage and that the opportunities with a largely electronic general practice now, with increasing use of digital information and electronic information in hospitals, needed to be built on, but we looked internationally at leading examples and we felt that political leadership was critical to this. I think we all signed up to that. We felt there was strong consensus across the four areas. The first is identifying patients reliably across these different data sources. We know from the Nordic countries and from Scotland that having a single patient identifier is the most critical factor and mandating its use in all health service encounters reaps enormous benefits. That is the key to the successes in the other countries and where Scotland is ahead of England in this respect. We need to link in all NHS encounters, so the Secondary Uses Services needs to engage proactively the primary care pathology services and, indeed, the private sector. Some of my own interests in assisted reproduction—which is a topical issue at the moment for Parliament—show that we have had, since 1990, a database of more than 1.5 million cycles of treatment. Currently we can link that to nothing. We have learned very little about the long-term effects for mothers and children of assisted reproduction in this country yet there are major public safety issues related to that. We must have this ability to link. We should not have data sets that are not patient-level and that are not linkable, because we cannot answer the important questions that society wants us to address. Following from that, we were all agreed that we needed person-level data. I can give you many detailed examples that show why that is the case and I think this is probably an important point to get across. We want the legacy data—which means we want the data that goes back many years—because one of the important things is the ability to answer questions rapidly and not have to wait to accrue lots of person-years of observation to answer these questions. We need the full demographic record, particularly if we are interested in, for example, environmental exposures relevant to chronic disease, to asthma, to obesity—these really important public health problems that we are going to address. For some opportunities we need real-time access to the data. Clinical trials are an important way to provide reliable evidence about effective treatments. One of the obstacles to delivering those trials in a timely way is that recruitment is low or there are not eligible populations, so we need to be able to look into these data sets and say: "How many people are there out there with these kinds of problems who would be potentially willing to receive an invitation to take part in research?" At the moment it is very, very difficult even to send that invitation to anyone, so we need a "can do" culture shift that allows us to do that but which does not compromise the governance and confidentiality that we all obviously respect. Those points were very common. For the kind of public protection, health protection issues, we cannot invent these infrastructures as the questions arise. This is why we need leadership. We cannot think that somebody is going to come up with an idea about MMR and autism, or somebody is going to think about fire retardants and cot death, or somebody is going to think about pesticides and mal-development of the eye in children. I can produce endless examples of public health concerns where, in order to answer things rapidly, we need an infrastructure such as there is in the Nordic countries where we can look at reliable data and say, "Is there any evidence to support this concern?" If there is: "What kind of more detailed studies should we commission to drill down into this?" We cannot take that first step very easily in this country. I chaired the MRC group looking at the epidemiology of causes in autism. The fastest study came from Denmark. Using data for some two million person-years, they were able to look at children who did and did not have MMR, link them to autism registers, birth registers, and conduct and report a fantastic study in *The Lancet*. It took us four years to do that in the UK. That is the kind of advantage. Very finally: it is communication, communication, communication. That is the other big conclusion from the simulations. We need to get out there and work with Connecting for Health, to get over these narratives that make it clear to health professionals and the public what the benefits are and what the implications are of opting out or withdrawing from this collective good, if you like, the ability to answer important questions conclusively.

Q338 Chairman: What did your particular study find in terms of the accuracy of data and also the issue of the standardised form?

Professor Dezateux: The first thing to say, as a paediatrician, is that one of the outstanding successes has been the introduction of the NHS numbers for babies in 2002 by Connecting for Health. This has enormous potential for us because we have a unique identifier early on. We would like to be able to link mothers to their babies and we would like to be able to link siblings to their siblings because some of the questions that we have are around families. There is not a mandated system for doing that but it is not a technically challenging or difficult to do, given the right leadership and the right go-ahead. There are many examples where there are certain elements of data that are either not routinely collected or where the quality could be improved. I think we need to understand that this is

a process. By linking research to clinical practice and embedding this in clinical communities, which is what Scotland has done, there is this constant interchange that research looks and helps us to understand the quality of the information and provides solutions about improving that quality. If the quality serves both clinical care and research, it is a win-win situation. There are interoperable standards, there are technical solutions to this coming out. I do not think those are major obstacles; I think it is the leadership and the political will to make these things happen that is the most crucial thing from our perspective.

Dr Walport: Could I pick up five points very briefly from Carol's answer. The first is the unique identifier. It is absolutely critical, but it is absolutely critical for clinical care as well. If your name is, let us say, Dr Richard Taylor, there is probably more than one Richard Taylor in the UK.

Q339 Sandra Gidley: Has there not always been a number? I have had an NHS number for years.

Dr Walport: But it is not regularly used.

Q340 Sandra Gidley: Why do you need a new one? You just need to use the old one.

Dr Walport: One needs a number that is recognised and used, but it is not used. That is a problem that has been cracked in Scotland. It sounds trivial but implementing that is a difficult thing to do. That is the first point. The second point is that Carol has illustrated many examples where it would not be possible to get consent in advance because you do not know what you are always looking for. The third point is you do need patient-level data. The fourth point is that actually the identity of the individual is of no interest to the researcher whatsoever; therefore the solution for this is something which is called pseudonymisation, where basically you strip the links—

Q341 Chairman: We are going to ask you questions about that later.

Dr Walport: I will come back to that then.

Q342 Dr Taylor: You have rather floored me because you have pretty well answered all the things I was sort of scheduled to ask. You have made it quite clear that "Secondary Uses" is the wrong title because research is absolutely integral to the improvement of clinical care, so that is crucial. The thing that bothers me is the widespread nature of the availability of recordkeeping when we do go electronic. Richard Granger takes great pleasure in showing us photographs of medical records departments at the moment, which are huge areas stuffed with notes but where nobody can ever find what they are looking for. There is a huge problem with the tremendously easy availability, when it comes, of a vast horde of information. There are practical points. We are delving into the Summary Care Record and the Detailed Care Record, will those be things to which you expect to have access?

Professor Wessely: First of all, you are quite right, at the moment we have a situation where you cannot get records when you need them but it is dead easy to find piles of records left lying around in surgeries and hospitals. In terms of security, we have to remember that it was not a golden age before, where doctors held notes clutched to their chests 24 hours a day. That is just not true, as I am sure you remember. On the second point, I think it depends on the questions you are asking but, ultimately, if the data, for example, can be anonymised, I do not see there should be any restrictions on what data should be available. It is always a tragedy to lose data. If we look at the issue, for example, of postcode, which is semi-identifiable, if you strip postcodes you cannot answer any questions on social differential or geographical access. Huge things then disappear from the agenda. I think there should be a very careful discussion if any data is not going to be available, subject to all the checks, balances and procedures that we are expecting to be in place.

Dr Walport: I agree with that completely. Again, this is about clinical care: the availability of the same set of records in general practice, in hospital, when someone moves from one clinic to another. Clinical practice at Hammersmith was transformed when in the early 1990s we had a digital system for X-rays. Suddenly an X-ray was available: you could look at it in your clinics at the same time as a radiologist was looking at it in their office. It made patient care better. The corollary of that is of course that you do need good governance. I think we are talking here about good governance but, in a sense, the greatest risk to confidentiality is the closer you get to the patient: it is at the point of primary care, it is in the local hospital. That is where there is the greatest danger of inappropriate availability of information to people in the neighbourhood. In the context of research, as I say, the researcher is not interested in the identify to the individuals *per se* but this does need good governance. Things can go wrong electronically, as indeed they did when records were found on tips at the back of Harley Street many years ago—quite sensitive medical records, I seem to recall.

Professor Wessely: To amplify that, when you look at what has happened with leakage of information—and when we wrote the report for the Academy we took a lot of evidence from various sources, including the Information Commissioner—in the research communities there have not been any cases of which the Information Commissioner was aware. There had been no complaints about the use of leakage of personal data from research. There had been numerous complaints about the leakage of personal data in medical care, that is true, and of course there are gross instances of research misconduct, that is true as well, but in terms of public health and epidemiology and confidential information, for that misuse he said they had had no complaints, and we were not able to find examples of where that had happened. That is not to say it will not happen in the future but it is not a major problem and it has not yet been recorded

Q343 Dr Taylor: Will leakage not be much easier from an electronic system than a paper system?
Professor Wessely: I am not a technology expert but I personally would prefer that. Having seen what happened during my lifetime as a doctor and having seen the way in which records are stored in all sorts of settings, I am more confident about new systems. In the new system there will be an electronic trace and the most serious sanctions for people who violate that. At the moment, often you will not know.
Professor Dezateux: I would endorse all those points. I think we need to put boundaries around these concerns because availability does not mean open access. We need to have visible to the public and health professionals the governance framework that informs the access. When I started out in medical research, I could do exactly what Simon said. I ran a study in general practice and I could go and pull out the Lloyd George envelope and read everything that was in there if I wanted but I was only interested in a small bit of it. The difference now is that there is an electronic record and I can say, "Give me these data items. That is what I need to know, I am not really interested in the rest" and I can have an audit trail which shows what I, as a researcher, have done with that and which holds me accountable. I would lose my job if I did something wrong. I think you have to have those sanctions. I would like to give you one example, if I may, of HIV surveillance. I think these issues address very sensitive data where perhaps you would not want to go back to individuals to ask them questions but you can still answer important questions using records. When HIV first emerged as a disease, the risk of a mother who was infected infecting her baby was one in five. Now that risk is less than one in 50. One of the reasons in the last 15 years that there has been this dramatic improvement has been not just effective treatments but our understanding of the time/person/place distribution of HIV. We do that using the leftover blood spots from newborn screening which reflect the mother's antibody status and those are tested anonymously. Since the late 1990s they have been linked to some information at birth registration using the secure system. We have this information now, over the years, of more than two million babies and their mothers. This helps us because we have no biases: we do not socially exclude the populations that are HIV positive. We understand how the epidemic has changed. It has informed antenatal screening, which is one of the big pillars of effective prevention, and it shows us now in the Health Service how effective that system is. So it moved from being research to public policy to health service and evaluation, and you would be hard pushed to put a line down and to say where research becomes clinical practice. In all the years we have done this, we have an honest third-party broker that does this. The laboratory in my hospital sends information to the Office of National Statistics, they link the data, they remove the identifiers, and only then can the laboratory test the samples, when all this has been removed, so that it is very secure. In all the years that that testing has been carried out for the Health Protection Agency, there has not been a single episode of disclosure or breach of patient confidentiality. That is an outstanding success and we need more systems like that, with clarity for researchers and health professionals and parents alike as to where to go for that information. I am sorry for the detail but I think these examples are very powerful.

Q344 Dr Taylor: Going on a slightly different tack, it has been suggested to us that even the police when they are investigating terrorism have only limited access to medical records. Why should researchers be given easier access than the police under those extreme circumstances?
Professor Wessely: I think you just need to ask the general public which they would prefer. It is fairly clear that these are totally, radically different things. Research is part of the function of the NHS; the prevention of terrorism is not. If you want the NHS to improve and to deliver good care, if you want to find out not who is planting bombs on the subway but if living near a power station causes cancer in your children, you need there to be a powerful epidemiologically based public health framework for research. They are just utterly, radically different.

Q345 Dr Taylor: So we would have the public on our side.
Professor Wessely: I would hope so. In fact the evidence shows very clearly that they are.
Professor Dezateux: It also lies in the issues that the police are interested in individuals and the mistrust is that it is going to be used to nail an individual falsely and that there is an error there. You have to remember that in most of this we are not interested in who those people are; we are interested in groups of people but we need to link their information at an individual level in order not to make terribly misleading conclusions from research. That is why we need the individual linkage. Beyond that, we are not interested in the individual.
Professor Wessely: Around the polonium incident, we did a study with H Payne looking at who did people trust to manage it. Fortunately, doctors and scientists were top of the list and the police were quite low. I think people are able to detect differences.

Q346 Dr Taylor: In your submission, Simon, you were very keen to distinguish between what you called *bona fide* secondary users of the data by researchers and other users who might be insurers or the media.
Professor Wessely: The access is within what is sometimes called the NHS family, which includes medical researchers, people who have similar obligations of confidentiality. For example, we cannot do anything without an ethics committee approving what we do. That certainly does not apply to the police or the insurance industry. The research we do has to have some public interest in doing it. It has to be governed by our own research governance arrangements. It has to be governed by our own

Caldicott Guardians. Within the system, there is this very complicated system of checks and balances by which we have to be governed. If we do not observe that we are in deep, deep trouble and it is the end of a job. I cannot simply say, "Give me the data" on this that or the other, I have to apply to an ethics committee, a Caldicott committee, and R&D committee and so on.

Q347 Dr Taylor: Do you think ethics committees are going to be overwhelmed?
Professor Wessely: I do not think any more than they are now.

Q348 Dr Taylor: You do not think this will lead to an explosion.
Professor Wessely: I would think it will almost do the opposite because you might be able to do bigger and better studies that definitively answer questions instead of lots of small things that are inconclusive.

Q349 Dr Naysmith: All three of you have obviously come along very well prepared because you have already answered many of our questions, as Richard said. Could I pursue a little bit more the patient consent systems and the confidentiality aspects. That is something that may not worry medical researchers too much but I know we take it seriously.
Dr Walport: It does worry me.

Q350 Dr Naysmith: Some witnesses have expressed some very strange fears to us already. What do you think of the current systems for protecting the confidentiality of patient data that is used for research, and you have outlined some of them already?
Dr Walport: Confidentiality is extremely important. I do not think anyone should doubt that. I think that is an issue that ethics committees have always taken extremely seriously. The issue then is about consent and where consent is appropriate, and also what you do to maximise the confidentiality in the sense that, as I said before and as Carol has illustrated, one needs patient-level data but one does not need the name of the individual. Therefore, I think the principle of research should be that one should strip away as much identifying information as you can, recognising that if you want to find an association between something in the environment, for example, an electronic power line or a tip, then you might need to have geographical information which if someone were sufficiently obsessive they could dig out but you would have to do that. I think that is where pseudonymisation comes in. The principle there is that you strip out as much as you possibly can but the whole point about pseudonymisation is that ultimately someone is able to link the record to the identity of the individual. One has to recognise that it is not perfect, in the sense that it is not absolutely impossible to get back to the individual. Under some types of research, it may be, but under others, where it comes down to postcode-level information, someone who is determined could do it but they would be breaking the law, they would be breaking the regulations, the ethics.

Q351 Dr Naysmith: How difficult is it, do you think, to strike the right balance between the needs of researchers and patients' rights to privacy? Remember that some of these patients may have fears that they need to have assuaged by the researchers.
Dr Walport: If you asked the patients—and I think that is an important thing to do—patient response is overwhelmingly favourable for this. Cancer Research UK did a study in patients with cancer about their views on cancer registries and the results were extremely supportive down to identifiable information.

Q352 Dr Naysmith: We have had information that people who have had recent experience of the National Health Service think it is wonderful but those who just read about it in the newspapers think it is on its knees, as the BMA said yesterday. It is the people who are not currently engaged with their data being used for research, such as cancer patients, and who read about it in *The Daily Mail* who need to be reassured that things are all right.
Dr Walport: I agree with that completely. That returns to Carol's point about communication. I think it is extremely important that we do explain how data is used and the systems of protection that are there. It is absolutely critical that this is all underpinned by good governance, that the data is held, that there is, as it were, an electronic trace of when records are accessed, but it is very important to distinguish that from a requirement for consent for things when, in truth, it is not possible to gain consent, nor is it even appropriate in the context of clinical care. I will give you an example. There was a hospital which produced a very detailed consent form for surgery—two pages of pretty small print. On the back of it was a little tick box which said "I understand that my tissue may be used for unspecified essential research in the future." If you are admitted to hospital in the middle of the night and you require emergency surgery, then the issue here is proportionality. You want to know what the operation is, who is going to do it, what the risks are, how long it is going to take to recover. The last thing you want to do or indeed the doctor, who is tired from taking consent potentially, is going to want to do is to then go into a detailed explanation of potential uses for research in the future. I think we really have to strike a balance between issues of consent and confidentiality. What really matters is confidentiality and that has to be maintained by, wherever possible, stripping out identifiers but recognising that it is not always possible to do that, and on the other hand providing best generic information through advertisements in surgeries and hospitals that this type of research happens.
Professor Dezateux: I think it is a question of balance but underlying this is public trust. The balance that we need to strike is between the greater public good that will be served by being able to answer these questions and individual rights. There has been an immediate jumping to the idea that individual consent is the way forward. Many people such as Onora O'Neill in her Reith Lectures have

highlighted these issues. In working with a range of publics, from parent support groups for children with rare disorders, congenital disorders, to the publics that are all offered newborn screening, for example, for their child, our experience is that they want to know that there is a safe and secure and transparent system with sanctions. They do not necessarily, as Mark has said, want to be burdened by specific and general consents that are poorly understood. The implications of that are that you exclude sections of the population if you do that. We have a number of studies now looking at general population consents that show that socially disadvantaged and ethnic minority groups are not consenting to the same degree. You could argue this is lack of trust but we could also argue this is the bigger challenge of communicating effectively what we are trying to get at and we would say: "Where is the evidence about health in these marginalised groups? Where will we be if we have not collected it?" The example that strikes at the heart for every paediatrician is the Bristol inquiry. There is a quote from the mother in the Bristol inquiry which is almost tearful to read, criticising the idea of a 30 day post-operative mortality as the outcome of research. She wants to know: When her child grows up will they be able to go to school normally? Will they be able to have normal relationships, families of their own? We can answer none of those questions. It is extremely difficult to get individual consent and follow up those individuals, but with record linkage we could have some information on the table for families that really matters and informs their decision making. I do think this raises a point: we are talking about the NHS family of data sets but, as a paediatrician in *Every Child Matters,* we know very well that we want to understand about educational data, we want to understand about social service data, we might want to look at future employment for some of these life-course questions. We do have the potential to be able to do that and we need to understand that the Secondary Uses Service is one facet of that opportunity but not the only one. I do want to introduce this point, because we are focusing very much on health services but, from where I stand, I am interested in children in terms of the adults they will become, and therefore we need this wider vision of health.

Q353 Dr Naysmith: I would like to put something to Professor Wessely. Within the evidence that was submitted by the Academy it says, "Research is increasingly inhibited by inappropriate constraints on the use of personal health data". How do you justify that statement and could it not be seen as a little bit cavalier and perhaps a touch arrogant as well.

Professor Wessely: I do not think so. We justified that because that was the evidence that we heard from many, many parties. The biggest single thing, I think, was lack of knowledge of the legal framework that permits research to go ahead. There is already, as I think Harry Cayton explained, a system in this country, a very complicated system, of checks and balances and a legal framework that balances off the invasion of privacy (for example, from releasing a name and address to a researcher to contact them) with the public benefit that may come from that research. But there are certainly some people who hold data who are not aware of these systems, they are not aware of the legal protections and the way in which the system works. In particular, we heard time and time again, often at a local level, of people saying, "No, you can't do this" and quoting the Data Protection Act wrongly. Actually the Data Protection Act is a very sensible, albeit incredibly opaquely written piece of legislation. The principles behind it are admirable and do provide a framework for doing what we are doing here, which is trading off sometimes the invasion of privacy that is releasing any information against the benefits. That is the main point we were making. We had numerous examples of important research that was simply not able to go ahead. We had great problems studying cancer rates in Gulf War veterans, for example, because of that kind of complication, which took us a long, long time to overcome. We are saying that it is a question of checks and proportionality. In order to study the health of Gulf veterans, that most people felt was an important question, we needed to know who had gone to the Gulf. We could not get consent for that because we did not know who they were, so already there was a violation of privacy in giving us, many years later, the names of those who had been in the Gulf. Most had left the service. When we did that research, we only had complaints from the relatives of two people who were dead. Because of the nature of the data, we had been unable to get regular notification of death rates because there was not a linkage with death rates. That was the only time that research caused distress—but there was an invasion of privacy, that is true. Similarly, when we then went on to do cancer linkage for this cohort, there was an invasion of privacy there. We have to know the names of people, to know who they were to look at their cancer rates. We could not do that with consent because three-quarters had left the Armed Forces and there was no visible means of tracing them. We do not know where they are, they have disappeared. The numbers are over 100,000. We did the research and we were able to show there was not an association. Most people were very satisfied with that: I do not think anyone felt their personal space, privacy, *et cetera* had been invaded. Certainly no one said that.

Q354 Dr Naysmith: Would you think there was any case for saying that researchers tend to argue for more access to patient data while patients and some clinicians often call for stronger privacy laws?

Professor Wessely: I do not think so. I think researchers tend to argue for a system of transparency and accountability and that the system is sensible and that where it should be a light touch it should be a light touch. We would argue that, when you are talking about an interventional clinical trial, you are dealing with a completely different beast from when you are talking about wanting to link 100,000 cancer records anonymously. These are not the same. We have a system that can be too

onerous on the things that need light regulatory touch; perhaps not onerous enough on some of the things that need more heavy scrutiny. We took evidence from large numbers of patient groups of disease charities who were often baffled by some of the bureaucratic hurdles that already exist to doing research. As Carol has said, many of the people concerned in the Bristol inquiry were simply unable to comprehend why some of the research they wanted to happen could not go ahead, so I do not think it is quite as simple as all that.

Dr Walport: I think it is important to look at the evidence. The Biobank pilot is quite useful. Biobank is the study of half a million people aged between 40 and 69. That was piloted a few months ago in Manchester: 60,000 letters were sent to people out of the blue aged between 40 and 69. Out of those 60,000, there were only 50 who raised concerns and 30 of those individuals subsequently signed up to the Biobank study. That is data from an enormous number of people, approached out of the blue, a healthy population, where only a tiny, tiny fraction expressed concerns. I think it is really important to look at the evidence. The other side in terms of the public support for medical research is that if you look at donations to charity 19% of all public donations to charity are in support of medical research.

Professor Dezateux: Could I raise a point here about access and checks and balances. One of the issues, I think, is clarity about who is the definitive gatekeeper and what the gates are. We have three people in this bed really: the patients, the health professionals and the researchers. We have to make this *ménage a trois* work. It is fine for the researcher to be accountable and have their job on the line if they breach confidentiality but we have to think about it from the perspective of the health professionals. I think a lot of health professionals feel that they have to make that decision for their individual. You could argue that is like medical paternalism. In studies I have tried to do, why is it the doctor is deciding whether their patient should receive an invitation to research? That is often the position they are put in. Because there is insufficient clarity, leadership and guidance to individual clinicians about, if you like, what their cover is, they are worried that they will be personally accountable for releasing or disclosing some information about a patient even though they might believe it is for a good collective cause or for good of health service development, and I think that could be much clearer and simpler. I think it does need some leadership as well as, as I have said, communication.

Q355 Sandra Gidley: I was starting to feel quite reassured by all this, until I heard the suggestion that perhaps we should link more widely to education and social services. You start to think to yourself: where on earth will this end? I want to put something to you to see if it is a possible scenario. You have agreed that patients can easily be identified. In fact, I think, Dr Walport, you more or less said it was essential that you ought to be able to identify patients.

Dr Walport: It depends entirely on the circumstances of the research. Every piece of research needs to be looked at in its own right and the principles should be that the maximum confidentiality should be maintained. For very large numbers of studies, complete anonymisation is possible or pseudonymisation. There are some studies, however, for example, if you want to understand the link between things in the environment, where you have to know where people live in relation to their health. Under those circumstances, pseudonymisation takes you so far but someone who is determined—essentially a criminal—would be able to find out who that person was. Every piece of research has to be looked at in its own right but the principle always is as near to anonymisation as possible.

Q356 Sandra Gidley: The drug industry, the pharma industry are very keen that this goes ahead. They can put together the health data with the mosaic data that is widely available which gives certain information, increasingly sophisticated, on the nature of people in a household, the income level. Is there a scenario where a company could target people and pay them?

Dr Walport: No, I think that is inconceivable. I think there need to be trusted guardians of the data to prevent that happening but also because the reality is that is not what the pharma industry wants this information for. It is not about marketing; it is about drug efficacy and side effects.

Q357 Sandra Gidley: No, they would target them to take part in trials.

Dr Walport: That is a different question, which is the whole question about participation in clinical trials. Again, there needs to be a very significant gatekeeper there. I think everyone recognises that is a really important role for the general practitioner. I think it is very difficult to envisage that there would be a proper approach where, as it were, a drug company could go directly to a patient and say, "I know you have diabetes, therefore would you consent." The model for that—and it is the model that has been for many years actually in paper systems—is that if a new drug is identified which might have value in high blood pressure or diabetes, that has to be tried in patients and there is a gatekeeper there who is a general practitioner who then acts as the conduit and says, "Are you potentially interested in taking part in a study of a new drug?" If they are, then it becomes possible to approach the patient and find out about the trial. There is always a gatekeeper and that is the only way it has ever been possible to do a clinical trial. All electronic systems can do is facilitate the identification. It can facilitate the communication process but they do not change an iota the way in which patients are approached to take part in clinical trials.

Professor Wessely: You are also bypassing that there is an ethics' approval system as well. You cannot get around that. That is illegal.

Dr Walport: I do not think there are any new principles here.

Q358 Sandra Gidley: You mentioned criminals. We hear stories all the time of a laptop being left in a car.
Dr Walport: And notes left on the desk.

Q359 Sandra Gidley: But the amount of data is potentially rather more than a few notes left on a desk.
Dr Walport: It goes back to governance. I do not think anyone anticipates a situation where Connecting for Health would be available on someone's laptop. It is going to be available through carefully regulated systems. I do not think this data will be left lying around.

Q360 Sandra Gidley: Are you telling me that researchers do not use laptops?
Dr Walport: They do, but they are not going to have the records, as it were, dumped from the health system into their laptop. In a sense, this, again, is the general problem and this applies as much to health as it does to research—more so. There need to be proper mechanisms to make sure the computers on which patient information is available are properly guarded. I would submit to you that the issue is much more likely to cause practical problems in a general practice in a hospital than it is in a laboratory.
Professor Wessely: We are not allowed to have personal data on the computer. All the data is on a standalone system which has no external access.

Q361 Sandra Gidley: Could I get Dr Walport's and Professor Wessely's view on whether they think there are advantages in widening health information to link with education and social services databases in the future. I do have some concerns about something that large.
Dr Walport: Is the answer not that all public policy should be based on good evidence? Asking the question very generically is not terribly helpful. I think you have to look at the research question and say: "When we discover something that will be important." Carol has already talked about disadvantaged groups, so, if you like, knowing that people are socially disadvantaged in the context of health research is extremely important, and therefore that type of social linkage is important. I would emphasise that for every case it needs to be looked at by an ethics committee. It does need good governance but actually there is great opportunity for better public policy by using good evidence. In fact, the Council of Science and Technology, of which I am a member, produced a report on the use of data and emphasised the value that could be obtained by linking databases across different departments. I think this is important. For example, it is important to understand about road traffic accidents. Health is intimately linked to our social environment. Again, no one is asking for *carte blanche* to do this because it is always specific. It is not that there will be some gigantic database which will hold life, the universe and everything; it is more that, if a research question is identified which depends on linking social science data of some kind with medical data, then it is looked at, it is assessed in its own right, and if it will give valuable information that could inform public policy then that research should be allowed to go ahead, again under the conditions, as far as possible, of a maximum move towards confidentiality.
Professor Wessely: In the last year we have looked at whether soldiers coming back from Iraq have more road traffic accidents. A simple outcome like that. We have looked at how quickly people from the Armed Forces get jobs and how successful they are in their subsequent careers. We have looked at the educational achievements of children with depression. We would like to look at the educational achievements of children whose fathers have served in the Armed Forces. It is not a blanket thing: for each one we will need ethical approval, Caldicott approval, PIAG approval. There will be a whole system before someone will finally say that is acceptable. We are not simply given the educational records of every child in the UK. That is not what we are talking about. In the system that we already have—and Connecting for Health does not introduce any new legal challenges, as it were—we already have a framework for this. Is what we are suggesting a proportionate interference in privacy? Is it in the public interest? Is there a duty of confidentiality? Is there likelihood of detriment and distress being caused by the research? They are all the things that we have to go through and if we satisfy all those tests I cannot see why that kind of work should not go ahead. Indeed, it does go ahead already, but it would be so much better with proper, single, appropriate data linkage. It would be so much better.
Dr Walport: The word "arrogance" came up earlier. It seems to me you can look at that in two ways. I think it is also arrogant in a way to introduce public policy without being prepared to look at the evidence that underlies that public policy and be prepared to evaluate whether that public policy is good or not. That requires evidence and research.
Dr Naysmith: We all agree with that.
Chairman: Yes, there is consensus on that.

Q362 Sandra Gidley: As the daughter of a soldier, I am not quite sure what public interest is served in knowing whether my educational achievement was effective because you cannot stop soldiers breeding and you cannot stop the children moving schools.
Professor Wessely: You can look at how long they spend on deployment and you could look at what kind of experiences they have had on deployment and what kind of traumas they have experienced and how that is reflected. You could look at whether or not children may need extra help if their fathers have had psychiatric injury, for example. You can look at whether or not the fact that they are spending more and more months away from home is having educational effects. So there are things you could look at which you might have wanted to know.

Q363 Dr Taylor: You have mentioned the Patient Information Advisory Group (PIAG). You, Simon, have said it is a bit too strong.
Professor Wessely: Sometimes.

Q364 Dr Taylor: We have had people saying exactly the opposite, that it is a soft touch, and we have had the Information Commissioner right in the middle saying it is just right. What should be done?

Professor Wessely: PIAG was a bit of an emergency measure. It was brought in in 2000 when the GMC scored almost an own goal with its advice to doctors and threatened to undermine the structure of public health and cancer registers and things like that. PIAG was a way of getting around that. It is not the only check and balance we have; it is just one part of a complicated framework. We obtained as many legal opinions as there are lawyers really as to exactly where it sits in the legislative framework and I think there is a pressing need as we move to a new era with Connecting for Health and new information governance to go back and see exactly what the legislative basis of it is because it is rather complicated. There was a feeling that sometimes it did not give a light touch to some of the examples I have used. We already knew the names of every Gulf War serviceman, all we wanted were the addresses, and we wanted the addresses to get consent in order to get people for research. We did not feel that was quite the same as some of the other issues with which PIAG deal. There is a view that there should be more systems of class support. By now, after *x* number of years, it should be clearer as to what is acceptable and what is not. You should not need to go in every instance; you should really go there for advice when you have something new, ambiguous, different, whatever. The idea of class support does not seem to have happened. There was a view from the research community that there was not perhaps sufficient representation of the people who do use PIAG, being the research community, but overall I should say there is no doubt at all that the Academy completely agrees that we do not have a right to see data willy-nilly. Of course not. There must be oversight. It is absolutely right that oversight balances these various interests and we are utterly in favour of that. We think it could be improved and made simpler where necessary, so scrutiny is given to the difficult cases. Certainly class approval would be one way around that. We thoroughly support the concept in the future. Whether PIAG continues or not, I am not sure, but that structure is needed, no question. We would be shocked if such a system were not there.

Q365 Dr Taylor: You have listed in your evidence ethics committees, NHS data controllers, the Caldicott Guardians as well as PIAG. Should one of our recommendations be that there should be a review and a coming together of those sorts of mechanisms?

Professor Wessely: They have arisen *ad hoc.* Section 60 was a bit of an emergency measure. The legal framework is impossibly complicated. I spent a year trying to write this thing. If you have to read the Data Protection Act, that way madness lies. It could be clarified so people all know what their duties and obligations are. Many people do not. They either think they are more onerous than they are or less onerous, so there is a lot of work that could be done there that would be very helpful.

Dr Walport: I would certainly agree there is the opportunity for greater coherence. One of the issues when PIAG was set up was the philosophy that somehow PIAG might only be needed for a short time because we were moving to a world where consent would be possible for everything. I think it has been recognised that that really is not the case, that there are always going to be unforeseen questions. I think the idea that somehow it was only a temporary measure has been a problem with PIAG. There is a proposal to have a National Information Governance Board. I think that is a good proposal. In that context, it might make sense if PIAG or a successor body became a sub-committee of that because there does need to be a national committee providing regulatory authority, but then the framework for all this does need to be looked at. I think the philosophy that this is somehow a temporary problem and that consent is the answer to everything is wrong.

Professor Dezateux: I think we need a system and PIAG has worked hard and recently introduced a fast-track system. There is an inkling now that there is a differentiation between the proportionality for consents and checks in different contexts. One of the key issues is to distinguish between research that requires you to go back to an individual, where you are interested in that individual and there will be some data around that individual, versus information where you are not going back and there are checks and constraints that would prevent disclosure and where the risk of disclosure is very low. At the present, if you want to do the latter type of research, unless you have a Section 60 exemption under cancer or under health protection HIV, as a researcher you have to demonstrate that you have made all possible attempts to get individual consent before you will have a section 60 exemption approved. This loses research, it loses time in answering important questions as well, and it does not always hang together and make sense in common-sense terms. We need a system. It will possibly be timely to review PIAG because there is this idea that the paradigm is individual consent and I think we need to have a statement that that is not always the case. There are now thoughts about community assent models for some issues that we know are going to come up again and again, where we do not want to have to revisit the infrastructure on a case-by-case basis but we want to say as a society: "We support this infrastructure approach, in a governanced way, to addressing this class of question. We are not going to oblige individual researchers each time to jump through these hoops."

Q366 Dr Taylor: Community assent could take over from individual assent in some circumstances.

Professor Dezateux: Yes. We need public engagement in these sorts of bodies and decisions. Often, in my experience, the public are more permissive and wanting the answers than some health professionals or gatekeepers. There is a

danger that at a certain level within the Health Service the system is being managed by very risk-averse individuals who are worried about litigation. Their primary duty is to be very risk-averse for their institution rather than thinking about what the value is of answering the question that is being posed by the research.

Q367 Dr Taylor: Public engagement is the next matter I want to turn to. The Academy of Medical Sciences has several sections on this. One of the paragraphs ends: "We also warmly welcome recent studies undertaken by the Wellcome Trust and the MRC to investigate public perspectives in this area" and you say that outcomes of this work will be published in April. Have I missed that?
Dr Walport: We have sent you the Wellcome Trust report in advance. It has not been published yet, but we have sent you a copy of it.
Dr Taylor: Should I have seen that?

Q368 Chairman: I do not think it has been circulated.
Dr Walport: I am told you have it. If not, let me know and I will make sure you do.

Q369 Chairman: The last question is to Carol. When you talked about the issue of this research, of having to get back into the system, as it were, and you said that it stops research in a sense, having to use the current system. Do you have an example of what research it has stopped recently and what was the intent of that research? Just one will do.
Professor Dezateux: I can talk about some research in my own department where, in the mid nineties, a national cohort of children were notified to look at the outcome of congenital heart defects that either resulted in a foetal diagnosis or in an operation before the first year of life, and this was published in *The Lancet*. This was a national cohort. There is no information on how many of those children survived to secondary school age based on direct observation, so we got a study which was peer reviewed by the British Heart Foundation and involved all the 17 cardiac surgery centres in the UK to follow these children up through their records in hospital in order to establish how many of them were living and what perioperative issues might predict their survival to 12. We had ethics approval for this with no local investigator status but we then had to go and register this project with every trust that held the data. It took a further 18 months on top of the study to get these permissions through and in some trusts we were asked to resubmit on different forms to their own ethics committee and they sent it out again for peer review even though I think we would all agree the BHF peer review system is pretty excellent. It involved the local clinicians, who were very supportive of this, in immense amounts of paperwork which they were very challenged to handle and do. We traced 98% of these children and we have shown that 25% of them died by the age of 12 and we are currently analysing the reasons. The other thing we wanted to do was to say what was the quality of life of these children and you cannot get that information from records. There was a lot of misunderstanding, I think, on behalf of the clinicians and the trusts about the permission that they could give to write to them. We had to write through all the clinicians to do that. It did not stop our research but only because I have a very determined and passionate research fellow who stuck with this has it been a success and I think there are other examples where people would say, "You know, this is just too hard. I am not going to try and answer this question", and I think this is a real tragedy because these are important questions, and very simple questions often, that we need to address.
Professor Wessely: We wanted to study the outcomes of people who had been discharged from the military for psychiatric reasons, what had happened to them, and we were unable to do that—straightforward could not do it because of the framework.
Chairman: Could I thank all three of you very much indeed for coming along and helping us with our inquiry this morning.

Witnesses: **Mr Patrick O'Connell,** Managing Director, BT Health, **Mr Alan Shackman,** Independent IT Consultant, and **Professor Naomi Fulop,** Chair of Health and Health Policy, King's College London, gave evidence.

Q370 Chairman: Good morning. Could I welcome you to the Committee and thank you for taking part in the third evidence session in our inquiry into the electronic patient record. I wonder if I could ask you, for the sake of the record, to introduce yourselves and tell us what position you hold.
Mr Shackman: I am Alan Shackman. I have worked as an independent consultant since the early 1990s largely supporting NHS organisations on what I will loosely call electronic patient record projects, so I have spent a lot of time with clinicians and managers at the sharp end and have a pretty good idea of what goes on at the sharp end in hospitals, PCTs and GPs. Through 2004 I was NPfIT programme manager for NHS organisations across East Manchester. In the last couple of years I have largely been working outside the health arena, so I suppose I am now an outsider, nevertheless an interested and I think an expert one. As an expert observer of the present NPfIT scene there seems to me to be a number of very obvious things to say, so I have said them.
Mr O'Connell: My name is Patrick O'Connell. I came to BT two years ago as their Managing Director for BT Health.
Professor Fulop: My name is Naomi Fulop and I am Professor of Health and Health Policy at King's College London. Colleagues and I have recently completed a study looking at the implementation of the National Programme for IT at local level, which was published two weeks ago in the *British*

Medical Journal.

Q371 Chairman: I have one general question to all of you. How would you characterise the progress to date on delivering the new electronic patient record systems?
Professor Fulop: From our study I would say it has been deeply problematic from the perspective of local trusts for a whole number of reasons which I can elucidate. As we know, it is seriously behind schedule and that has caused problems at local level which I am sure we will go into. There has been a lot of enthusiasm in the trusts we looked at. We went into four acute trusts for the programme and, while there is a great deal of support for the vision of the programme, there has been a lot of frustration that it has been delayed and there has been some loss of goodwill. One of the key issues which others have identified is that the national programme did not engage local stakeholders, end users, clinicians, managers, and administrators who were actually going to use the systems in the contracting process and so they felt very isolated from that whole process and felt that systems had been imposed on them.

Q372 Chairman: We may want to go into a bit of detail around that.
Mr Shackman: I should say that all my remarks relate specifically to the Detailed Care Record, not to the Summary Care Record, so I give that clarification. The Detailed Care Record is now coming up for two and a half years late, as stated in your briefing document, and by this time next year it is going to be three and a half years late. That is certainly true for the 60% of the country covered by CSC, the iSoft LSP supplier. I think that is a fact. As I read it, Guy Hains of CSC has told the Committee that the new system Lorenzo will not start to be ready until the middle of 2008. Following on from that, since the roll-out cannot be done immediately it surely means that for many trusts the delay is going to exceed four years just to get the first phase done.
Mr O'Connell: I think the programme is following a profile that is somewhat typical of very large national transformation programmes. I have been managing these things for about 24 years now on both the public and private side and I can find no real surprise at the current progress. Typically, they do have a slow start but with the right spirit and the right expertise on both sides they get around the corner and they start to perform, and I think that we will be able to perform on the programme and I think you will see us picking up speed as we go along.

Q373 Chairman: Can I ask you, Patrick, how many Patient Administration Systems you have provided up to date now in hospitals in London?
Mr O'Connell: Up to date I think we have about 18. I think probably your question is aimed at acute, of which there is one, but in terms of patient administrative systems there are about 18. In terms of the RiO system, which serves the mental health community and also the PCTs, we have about 18 of those deployed to date. I might like to add a comment about that in the sense that to some extent these have moved to the right, as is on the record and obvious to everyone, but it is part of the package of a large programme in the sense that some things have come from the other direction. For example, not everything is delayed in the programme; some things are new. If you take the London programme, for example, their PACS is something that arrived in the programme about a year after it started and it had to be accommodated by all parties and performed well and on time.

Q374 Chairman: I realise that. We may want to ask questions on that, but which hospital is the PAS system in in London?
Mr O'Connell: Queen Mary's, Sidcup.

Q375 Chairman: So that is the only one. What is your current timetable for completing the roll-out of the new PAS systems to all hospitals in London?
Mr O'Connell: In a stand-alone capability we should finish in 2009 and complete and integrated in about 2010.

Q376 Chairman: It is very much behind schedule. What are the reasons from your perspective that it is behind schedule in this way? I find it very difficult. I was looking at patient administrative systems in my local hospital over a decade ago. With the new system that we have in here quite clearly it is not going to be the scene that I was looking at in South Yorkshire that is planned for London, but why is there this long delay in putting in a Patient Administrative System that is common throughout London?
Mr O'Connell: I think there are a lot of factors that put the programme where it is today. I started to touch on that earlier in the sense that I think a lot of large programmes, when they start, have a package about this size that you want to do in a certain amount of time, though typically what happens when it starts is that that gets re-shuffled in a bit in the sense that some things are brought forward in time, like PBR, payment by results, some things are added new into this first part, like PACS, which was new, like QMAS, the Quality Management Analysis System, was new, which was brought in, and some things go out. There are other things that people try to do for synergy, for example, the common solution that occurred between London and the south. It was a well-intentioned idea that should work at the macro level but did not work at the practical level because it turns out that the differences were more than seemed reasonable at the time, so I think a lot of factors contribute to how we got to where we are today. I think maybe a more important factor is the fact that the programme is progressing today and that if you look at the non-acutes they are performing and the acutes are on track to roll out starting this summer.

Q377 Chairman: But why is there delay? Yes, the programme is rolling now but why has it taken so long? I think you mentioned synergy. This awful word we have is interoperability. Has it been developing that so that any new system that goes

into a hospital in London will have the potential to be able to communicate electronically with the rest of the National Health Service family, like the local GP surgeries? Why has it taken this long to update, for want of a better expression, the PAS system? Is there any one thing?
Mr O'Connell: No, I do not think there is just one thing that does it. I was trying to explain that I think it is a multiple set of factors that does it in the sense that there is some re-prioritisation which changes schedules. In our particular case in London there was an attempt for synergy that was well intentioned and which at the macro level was reasonable but did not work at the practical level. These things came together to move the programme to the right.

Q378 Chairman: The other one, of course, was the problems that you had with your company in relation to the fact that you switched your main supplier for PAS from IDX to Cerner. Has that been one of the causes of the delays?
Mr O'Connell: I think it is a contributing factor like the other factors are contributing factors in the sense that from my standpoint I think that the common solution delayed the programme, as I mentioned earlier, for all the right reasons which were well-intentioned, and I think that as General Electric came in and bought IDX they took a look at the package and took a look at their corporate strategy and decided not to go forward in a programme space but to go forward in a product space, and we therefore had to exit them and put Cerner in, and that takes some time to do that.

Q379 Chairman: Are you confident that the system you have now will see the timetable met as far as the PAS systems in London hospitals are concerned?
Mr O'Connell: Yes.

Q380 Dr Naysmith: Can I just ask a question which is almost a philosophical question about computer systems? What you say has been true of almost every big computer system I have been associated with in local government, in universities and now in national government. They start off and say this will be done in two years or three years, and nearly every time through the last 20 years that I have been associated with a big project it has taken about double the time they say at the start, so why do people lay the trap for themselves that says, "We are going to finish this in two or three years", when they know there are going to be developments that will slow it up? Is it because you have to say that to win contracts or what?
Mr O'Connell: No.
Dr Naysmith: I think you need to expand on that.

Q381 Chairman: That was a very thoughtful "no" there, Patrick. If you would expand on it we would appreciate it.
Mr O'Connell: I guess I started with the last question first. No, it is not required. You have just tried to make the point philosophically that suppliers say they can do something to win a contract. I would say no, and I would say more than that. It takes three communities—the user community, the buyer community and the supplier community—to make a programme work on schedule. Everybody proposes on day one something that in theory, philosophically, says all three are bounded together properly so that all three move together uniformly. What I find is that all three groups are not uniformly bound together and that causes delays. It is not like a supplier group trying to finesse their way into a large programme. It is the fact that large programmes are often not completely understood up front. Even if someone said, "I would like to move every single physical structure inside the M25 three feet to the right", that is a well understood task but when you do that you might find that the landfill does not really support that thing at the end of the day when you check that 10% of the population have moved. "Sorry, I made a mistake; move it six feet to the north". By the time you have done that three times even a well known problem—I mean by "well known" something you could physically lay out—would probably not go on schedule, so something that is a transformation programme that improves healthcare or the next generation fighter is a lot harder. I think it is the coming together of the three groups. I think it is the level of understanding on day one versus day two years on which more philosophically answers the question than just one element of it.

Q382 Sandra Gidley: Professor Fulop, you undertook some research into the impact of the National Programme for IT in hospitals. Would you for the record like to tell us what the effect of the delays to the new Patient Administration System is?
Professor Fulop: The delays are of great concern to hospitals because, as I am sure everyone here is aware, PAS systems are fundamental to the running of hospitals and so they are desperate to have their current PAS systems replaced and there are concerns about patient safety, so, for example, it might mean that if the PAS system was not working properly they would not be able to call patients in for their operations in a timely manner. One of the trusts we looked at had a very basic PAS system and had very heavy reliance on paper systems and the medical director gave a number of examples of concerns and real cases of patient safety issues with that reliance on paper systems which would have been helped if they had had more sophisticated electronic systems.

Q383 Sandra Gidley: Presumably they had used these paper systems for some time so why is there a new concern about patient safety?
Professor Fulop: Yes, of course they have used paper systems for a long time but then they can see the possibility of what you can do with electronic systems. The medical director in this trust gave an example of being called to give evidence at a coroner's court on a patient who had died of cancer and a contributory factor was that this patient's X-ray had not been read. The medical director's view was that those instances can be reduced with proper electronic systems, so you can have alerts, reminders and so on and you can improve patient safety, so it

is the frustration of relying on old-fashioned systems when they can see the possibility of new ones, but there is also the issue of actually running these legacy systems, the difficulty of getting parts and so on, and concerns that they might crash.

Q384 Sandra Gidley: So that in effect makes it more unsafe than the paper-based system because they have reduced reliance on them. Is that what you are saying?
Professor Fulop: Yes, and considering going off piste, as it were, and replacing the PAS system because they do not want to carry on waiting would obviously be a ridiculous and inefficient use of resources.

Q385 Sandra Gidley: Because technology rapidly gets to its limits and it has needed replacing for some time and the longer we wait—
Professor Fulop: Some of these systems are ten years old, say, and they are out of date. There was a classic example from our study where in one trust they had to get parts from eBay because it is such an old system you cannot get parts any more.
Mr Shackman: Can I come in here because I agree absolutely with that? However, a great many trusts have perfectly good PAS systems. They may not be 100% up to date but they work perfectly well, and I think with them the frustration has been, stepping back a bit, that replacing their existing PAS with an NPfIT PAS of itself will not do a huge amount for them. It is replacing functionality with not dissimilar functionality. The disappointment and perhaps where patient safety comes in is with the delay in starting to implement the all-important clinical support systems that sit on top of the patient administration systems and you cannot think of a better example than a system that supports electronic prescribing. My understanding is that the vast majority of prescribing in the NHS is done by junior doctors in hospitals, who by and large are the least experienced people, so a system that will help them make that safer is really a big deal and people have known that this functionality is available. It has been available for some years. I did a very quick assessment of a pilot some four or five years back and the delay in getting the ground patient administration systems in, whether it be the Cerner system or the iSoft system, is delaying what is really important, getting the clinical support functionality in and, as I say (as a partial outsider now) and have said all along, that is what is really frustrating many people.
Professor Fulop: If I could add another example to the e-prescribing: e-test ordering and browsing, whereby tests are ordered electronically and can be viewed electronically. In one of the trusts we looked at they had implemented that prior to NPfIT and had this great system which the staff loved and, for example, it had reduced duplication of tests, it meant that patients and staff did not have to wait around for tests, it speeded everything up. When you see that possibility that is why others find it frustrating that they have not yet got access to that.

Q386 Sandra Gidley: Patrick O'Connell, do you agree that patient safety has been compromised?
Mr O'Connell: I am not sure I am qualified to talk about patient safety but I can speak about it from a delivery standpoint, so if you phrase the question from a delivery standpoint I will answer it.

Q387 Sandra Gidley: I was asking you to comment on whether patients have been put at risk by the delays that your company have presided over.
Mr O'Connell: That question presupposes that the systems in place today before I put a system in place—

Q388 Sandra Gidley: Sorry—that question presupposes?
Mr O'Connell: We are replacing what exists and from my standpoint I do not think I am qualified to comment on the safety of patients before or after NPfIT.

Q389 Dr Taylor: I am delighted we have got you here, Mr Shackman, with a long memory because I was involved with the fitting and implementation of a PAS system exactly 15 years ago and we had ordercoms about 13 years ago. I fail to see where all the delays have come from. You have been very critical of Millennium Release 0. Is there any improvement with Millennium Release 0 on what was available ten or 15 years ago on PAS systems?
Mr Shackman: I must tread carefully because I am not an expert on Millennium, but my understanding is that Cerner Millennium is a very well proven system. It is working in many places all over the world providing exactly the sort of support that we are looking for here. My understanding is, and I look to Patrick here who will correct me if I am wrong, that Release 0 of Millennium is basically pre-NPfIT software which has been implemented in the UK down in East London, and I am sorry but the name of the trust escapes me. Release 0, as I understand it, had not properly been anglicised. My understanding is that Release 1, which I understand from stuff in the press this week will be available early next year, will be the proper anglicised NPfIT version of it, so today's problems, one would hope, will disappear, but I bow to Patrick who will know a lot more about it than myself.

Q390 Dr Taylor: So does Release 0 do anything more than the original PAS systems that many hospitals have had for quite a long time?
Mr Shackman: No, and alas it appears to do slightly less if we read the reports of those trusts that have implemented it.

Q391 Dr Taylor: So Millennium Release 1 is now becoming available?
Mr Shackman: I understand from the press that it will become available from next year.

Q392 Dr Taylor: What are we getting in London from BT? Is that Millennium Release 0?
Mr O'Connell: To begin with you are getting three R0 releases, then R1, then R2, then R3.

Mr Shackman: I think Dr Taylor may be referring to RiO here as well for the PCTs and for the mental health trusts.

Q393 Dr Taylor: So we will get the updated ones?
Mr O'Connell: Yes.

Q394 Dr Taylor: So they will be able to do more functionality than the ones we have had for along time?
Mr O'Connell: Yes.

Q395 Dr Taylor: A general question to all of you. Do you think the whole Connecting for Health has paid too little attention to hospital systems and has gone down the primary care route rather than the hospital systems route?
Mr Shackman: No, I do not think that at all. Connecting for Health, it seems to me, has done very little for GP systems. As I see it, GPs are continuing to use the systems that they had used before, a lot of them in quite a sophisticated way. Certainly when I go to my GP my practice very much operates an electronic patient record within the practice, and I think many others do as well. The problem has been, I think, that this sort of day-to-day clinical support functionality that GPs have has not been available for community services, has not been available for mental health services and has not been available, or has certainly not been implemented, for hospital services. The pressing need is to make things happen in hospitals.

Q396 Dr Taylor: And it is right that the majority of GP systems that work at the moment are not being ripped out and started again? They are just being built on?
Mr Shackman: That is my understanding. I seem to have reached an age in life when I can never remember the names by which things are called but there is a programme for replacing GP systems, if they want them to be replaced, with an NPfIT version, but so far as I am aware virtually no GPs have seen any change to their systems since NPfIT came along.

Q397 Dr Taylor: And, Mr O'Connell, you would agree that there has been enough emphasis on hospital systems?
Mr O'Connell: Yes. I think from a Connecting for Health standpoint, viewing it from the outside, they are trying to improve healthcare globally in England. It is a global strategy that is being rolled out in increments that gradually ends up with improved healthcare at the end. There are various strategies in different regions. In our region we are rolling out the healthcare in a strategy that we think puts the most amount of capability on the ground as soon as we possibly can with some attention to the needs of various trusts, for example, the acute PAS that goes to Barnet and Chase Farm this summer. It might not improve the capability in a different trust but it will improve theirs, so it is somewhat targeted in how it is rolled out as well as a general roll-out to get a package effect at the end.

Q398 Dr Taylor: Do you want to add anything, Professor Fulop?
Professor Fulop: I have to agree with Alan that the focus has been much more on hospitals than on primary care, but I think the disappointment from the people that we interviewed has been about the loss of this vision of a single integrated system across acute and primary care.

Q399 Dr Taylor: When you say "loss", has that been lost completely?
Professor Fulop: As I understand it there has been a rolling back of that idea.

Q400 Dr Taylor: Where does that come from?
Mr O'Connell: Can I answer that because I would be the one who was rolling it out or back, either way. From our standpoint, there has been a change in London, for example, in the fact that instead of one-size-fits-all we have moved to a new philosophy called best of breed where we have Cerner for acute, we have the CSC RiO for mental health and community health and we have in-practice at the moment as an alternative for GPs, but even though it is a best of breed approach we have three different vendors, and there are many reasons for that, but it still provides a single view in the sense that a single view can be provided in a couple of ways. It can be provided with the same box or it can be provided with different boxes that integrate into a single view. From my perspective in one way we are providing the original vision of a single view. We are implementing it somewhat differently in a way that we think brings more benefit to the users and more benefit to the community as a whole over a variety of factors from capability to cost.

Q401 Dr Taylor: We went to Homerton Hospital yesterday and we got the distinct impression from them that they were absolutely delighted that they had got in first before NPfIT came so they could design their system and get it exactly as they wanted it. Is the effect of NPfIT that it has really taken away the end user input and just delayed things?
Professor Fulop: I think that is problematic. I have to say that I think there is a trade-off between having a national system and local customisation and that balance has to be thought through very carefully, so the more local customisation you have the more you lose the national vision. Under the previous policy, hospitals went their own way and some had PAS systems that were quite far advanced, as you mentioned, and others did not, so I think there is something to be said for having a national policy and national standards, but it is allowing that degree of local customisation where people feel ownership and can adapt the systems to their local needs. I am sure that is technically challenging, but I think it is important.

Q402 Dr Taylor: That should be one of our recommendations if it is not too late?

Professor Fulop: Yes, definitely.
Mr Shackman: I do not see why it is too late. As we have heard, there is a continuing delay before the systems will be ready to be put in. There is plenty of time for some changes to be made. I am particularly interested by the change of philosophy that Patrick was talking about, a move more to a best-of-breed approach, which I observe is not being followed elsewhere in the country but certainly is in London. One of the questions that I have asked—I put it in my written submission but by no means am I saying that this is the right way to go; it merely seemed to me an obvious question to ask even if the answer was going to be no—is, is it possible to give trusts a choice of core system that they take because, as Naomi says, if they have had a hand in choosing, if there is an element of customisation perhaps, based on choice, there is much more chance that they are going to adopt it, implement it properly and get the benefits.

Q403 Dr Taylor: They have got a decision about choice?
Mr Shackman: That is right, and it seems to me that possibly what is now happening in London, to take it one step more, is that if you can have different suppliers to GP systems for community, PCTs and mental health and a third different supplier for hospital systems and, as Patrick says, you can bring those together to produce a common view, which is what BT most certainly will do, then you can probably accommodate choice as well. Let me rephrase that. I asked the question: if it is possible to do that could you also accommodate choice to allow trusts to say, "Mmm, I think we would rather have X than Y".
Dr Naysmith: If I could break in there, yesterday when we were at Homerton I discussed this particularly with the chap whose name I have forgotten who was a consultant for two days a week at the hospital.
Dr Taylor: Eccles.
Dr Naysmith: He said there was an element of choice that was available for local trusts setting this up but they had to—
Dr Taylor: Is that just in London or—

Q404 Dr Naysmith: Just in London, but they had to ask for it and it was a bit discouraging. I wonder whether that is true or not, Mr O'Connell. You will probably know, but he was giving the impression that people were not anxious to encourage new trusts to explore the options that were open to them. You had to have somebody on site who knew that that was possible and was confident enough to do it. Otherwise you were given the job lot. Is there any truth in that?
Mr O'Connell: I cannot speak for all the places but I can tell you that what we are doing now is that we engage the trust far in advance of delivering the system. The reason we engage them far in advance, and we also engage them with Connecting for Health so it is a kind of tripartite system, is to try to ensure that the principles of standardisation and some of the necessary customisations are understood well in advance so that we can meet the needs of a particular trust. It is hard to have a one-size-fits-all for the various different trusts or hospitals in any country, let alone in the city of London, so we engage with them early. Secondly, we have structured our London programme such that we have the ability to configure the code, which is a kind of base code, and then there is a configuration machine that turns things on and turns them off because it is quite a large product that is used in many countries and we select pieces that we want and we modify some others, but we have the ability to do that in London and so we can and in fact have changed the configuration in London so that it is different from the south to reflect the individual needs of the trust or the community as a whole. We do not really say Release 0 of Cerner in London. We say LC 0 or just London configuration 0 and that reflects the customised needs, so to speak, of the London trust or the London community. It also reflects some of the solutions that we have incorporated, given the experience at Homerton or given the experience at another trust. We have the time to incorporate those and we do, so I think it is actually the opposite. We actively engage the trust to find out what they want. I think that they are part of the solution with Connecting for Health. For example, even though RiO is not the point in question here, it is really acutes, you have not really heard much about the RiOs going in and it is quite a large undertaking to put those in, and they have got on well because we are doing the same thing. We collectively engage with the trust, try to make sure that we can fit their complex environment, their needs, and then we roll it in, and we are doing the same thing for the acutes. We just have a bit more flexibility with the acutes.

Q405 Chairman: If the Homerton system is compatible as far as your system is concerned, presumably if you are doing all the PAS systems in London hospitals you will be looking at Homerton and saying whether it is up to muster, will you?
Mr O'Connell: Actually, the London system in a foundational sense reflects the Homerton base line, so, as it is a system that people are happy with and feel is a very good baseline to start from, because we have the ability to customise in the London community we are using that as our baseline and then improving it or modifying things or adding to it as we go along for the various trusts. What Barnet and Chase Farm needs is a little bit different than Homerton but the foundation is a better foundation to start from and we are doing that.

Q406 Chairman: But the customising in Homerton presumably would not be interfered with when they are rolled out with the rest of London? What they have now in terms of their fields, on their database, the way that they are using their system to run Homerton Hospital and the improvements that it is giving them and giving patients, will that change when your system is rolled out?
Mr O'Connell: No, that will not change.

Q407 Chairman: It will not change at all?
Mr O'Connell: No. It will actually be improved.

Q408 Chairman: When you talk about configuration London you are not saying that every PAS system in every hospital in London has to be the same in every detail, the records on it or anything else?
Mr O'Connell: Correct.

Q409 Chairman: That by and large will be a cohort of things in there that will be common, and obviously that will be the case in a record anywhere in the world, but after that there will be local autonomy into the detail of what is on that record and obviously how it is used within that particular establishment?
Mr O'Connell: Yes.

Q410 Dr Taylor: So this flexible, best-of-breed approach is obviously the right one. I do not know if it is fair to ask, but are you aware if Fujitsu or CSC have got the same flexibility?
Mr O'Connell: It is totally outside my remit to comment on that.
Dr Taylor: Yes, I know it is outside your remit. I am ashamed to say I cannot say immediately whether it is in their evidence but it is something we need to find out.

Q411 Chairman: One of the issues that we have heard, not about the acute sector, was about the choice of a general practice system and that you were potentially offered one or two software packages and you must go along with that. Now we understand it is not double figures but it is more than one or two, so the choice in terms of what that establishment wants to make is being made but within a system that is sensible because it will be able to talk to the wider health community at some stage. Your system is giving a base for that and then London hospitals will add on to that base, or is it offering two or three different suppliers of the software?
Mr O'Connell: Fundamentally what we are trying to do is maintain the original vision of a single view so that a patient's record can be viewed in a variety of care pathways.

Q412 Chairman: Would that be just on one software system or would it be potentially on several?
Mr O'Connell: No, it would be on more. The system is an interoperable system because best of breed does a couple of things in the sense that if you have Cerner for one, you have in-practice with the other and you have CSE for the mental health and community, and an interoperable approach allows you to interface different systems in the sense that if Cerner is the right answer today, like in rental cars if you have Avis and Hertz and Avis says, "We try harder", if a number two "try harder" system comes in place we can fit that in without losing the original vision of a single view. Secondly, if you have an interoperable solution it allows you more easily to interface with legacy systems because you already have an interoperable system. Thirdly, it allows you to make slightly more customised modifications in the domain that you are speaking of, like acute, without having to change anything in the GP domain. Finally, it gives you a little bit more of a cost effective solution going forward because you do not have a sole source lock on a single event. You have pieces that can be removed and so not only does it push capability forward; it keeps the price at a more reasonable package. It is a standardised system but it has some flexibility where it needs to have flexibility to address the various needs because hardly anything is 100% identical.
Mr Shackman: My understanding is that within that flexibility all London acute trusts will have the Cerner system, all London PCTs and mental health trusts will have the RiO system and all GPs will have the in-practice system or the alternate. It is a mixture, is it not? There is an element of customisation. The fundamental system is set. I am not saying that is wrong. I am just saying it for clarification.

Q413 Dr Naysmith: What is the understanding of the panel members of the requirements for the Detailed Care Record? What do you believe it should be doing?
Mr Shackman: I have read some of the other evidence and in so far as I have had time I have read through oral evidence. The key thing is that if I had been a complete layman it would not have come across to me. The Summary Care Record is basically an information repository. It is a database that you can look into and I know there is argy-bargy about what goes into it and what does not but it is a database, but a Detailed Care Record is much more than that. The Detailed Care Record is the electronic patient record system that the LSPs are going to deliver. The key thing is that the Detailed Care Record more than a database allows clinicians and others to do things. It allows them to prescribe drugs, to order tests. It allows care plans to be devolved. It allows quite complicated things to be done, so, if a patient is coming in for a hip operation with the right system, at the press of a button you can schedule all the things that need to be done around that—book the theatre slot, book the physiotherapist, book the occupational therapist, even put an appointment in the district nurse's diary so that when the patient is discharged they can be there on day one to provide support. Without getting into the detail of what data is in the Detailed Care Record, I would concentrate on it being an everyday tool that allows clinicians and managers to do things to speed up and make the health delivery process safer. It is what I have meant by an electronic patient record for the 15 years or so that I have been involved in the field.

Q414 Dr Naysmith: I think you have described that very well and brought out what it means. It means that this system has to be able to cope with all sorts of different specialities because patients do not always see just one kind of doctor; they go off for X-rays and radiology and all sorts of other things which, as you suggested, might have to link up with

what used to be called almoners in social services and all sorts of things could be in the Detailed Care Record. Is the system capable of doing that? Is it versatile enough?
Mr Shackman: My understanding is that the Cerner Millennium system is capable of doing that. I do not know what the Lorenzo system is capable of. It is not available.

Q415 Dr Naysmith: But it does mean that data has to be presented in a uniform way from all these different sources that it comes from. Just as one example, last year Richard was at the same meeting as I was, where in Choose and Book one of the problems that hospitals had was that different GPs described different medical procedures in different terms and different hospitals had different ways of describing the procedures they carried out, and Choose and Book was not the same. We were going to order this from that hospital and then you could find problems with what was being defined, and that is happening now.
Mr Shackman: That is surely so. You do have to have people describe things in the same way. I am getting towards the extreme of my knowledge here, not being a medical person, but my understanding is that that is comparatively straightforward to get sorted out within a single organisation, within a hospital or within a PCT. It is much more difficult, I imagine, to get it sorted between GPs and hospitals but perhaps I can just add a small comment about the famous "walk before we run" comment. It has to be absolutely right that the NPfIT vision is looking at doing things consistently across the whole local health community. We have to bear in mind as well that almost all hospitals do not even have some of their internal clinical support systems compatible, never mind doing things across the local healthcare community, which we must do. Again, as a bit of an outside observer, a little air of unreality sometimes descends on me, not because things I hear are wrong but because it is perhaps trying to do too much too quickly before you have even sorted out some of the fundamentals.

Q416 Dr Naysmith: Professor Fulop looked at four different trusts. Can you give us some indication of what the situation was like there?
Professor Fulop: What I would add about the detailed record is that it has not been communicated to people what it is. In fact, I checked on the Connecting for Health website and what is described there is much more limited than what Alan has just described and is quite vague, and that is what we got from our interviews, that it was not clear to people exactly what it was and I think Connecting for Health missed an opportunity there.

Q417 Dr Naysmith: Do you think in the four trusts you were looking at they were collecting and using different data and different sorts of data or was it all standardised and useful?
Professor Fulop: Yes, I would say at the time that we went in there, because there had been very little NPfIT implementation, they were all at different levels, so one had a PACS system, for example, the other three did not or it was very limited. They were quite a good spread. One that I talked about earlier had a heavy reliance on a paper system and very little electronic functionality, so they were not even standardised in terms of the level that they were at in terms of IT organisation, let alone what they were collecting.

Q418 Dr Naysmith: Mr O'Connell, Mr Shackman has described the very detailed and useful working data set. Professor Fulop says that people do not really know what it is meant to contain, so what do you say?
Mr O'Connell: There are various contexts that we are speaking to. I guess, for context, to make sure we are speaking of the same thing, there is a Detailed Care Record and there is a summary record. The Detailed Care Record is basically your medical life history moved from paper into electronic, so that you can back it up so you do not lose the papers, so that you can take advantage of the benefits of the systems of electronic connectivity in the sense of being able to order electronically radiology, a laboratory test or whatever the case may be. I know this is captured in the RiO system, it is captured in the in-practice system, so from our standpoint it is reasonably well understood. Certainly from a technical standpoint the pathways to integrate this data are going to exist and our end plan will be there.

Q419 Dr Naysmith: But they are not there yet; is that what you are saying?
Mr O'Connell: Correct, they are not there yet. They are more in a stand-alone area right now to get the capability on the ground. Once the capability is on the ground so people have systems in place then we will integrate these systems so that they can take advantage of the electronics so that one could have the power of having the Detailed Care Record electronically captured in a single place, backed up so that you do not lose it and so that you can take advantage of the benefits.

Q420 Dr Naysmith: So what will the Detailed Care Record look like in, say, ten years' time compared with now?
Mr O'Connell: I guess, as I said, it will be an electronic version of what you have today.

Q421 Dr Naysmith: What, a big pile of sheets? Are you talking about the paper record?
Mr O'Connell: No. I think the record is driving towards being electronically captured, stored, manipulated and managed, and all the various papers that you see today in various trusts or various facilities from the time you are young to the time you are older will gradually disappear and move into a kind of paperless system where you look at people's records on a screen and if you want to do something you will be able electronically to request something and receive something.

Q422 Dr Naysmith: Where do you think it will be in ten years' time, Mr Shackman?

Mr Shackman: I would go along with that. As to whether it is ever going to be possible to capture everything electronically, I think people do feel they have some sort of God-given right to record some things with a pen. I think the key thing is, as I said before, that the systems support clinicians in the day-to-day things that they do. It is the ordering, it is getting the test results, it is the prescribing, it is recording that the drugs have been given. It is the Choose and Book, which is just an example of functionality. It is smoothing the process between when a patient is discharged to when they get home. Let me give an example, if I may, from my own local hospital: after an out-patient appointment the doctors dictate into a Dictaphone, that goes to a secretary, that gets typed up, a month or so later the letter gets sent to the GP practice, when it gets to the GP practice the first thing that happens is that it gets scanned electronically onto the system. The systems that we are talking about really ought to make it possible for that whole process to be done there and then without this almost ludicrous manual intervention, but to do that, difficult though it is proving to get the systems in, the real issue, if I may say so, is the change management, changing the process, which goes beyond the remit of Connecting for Health and I understood was going to be covered by the work of a Modernisation Agency which no longer is with us, so I struggle a bit to find any concerted way of helping make the process change happen whereas of course there is a most concerted way of actually getting the technology in.
Professor Fulop: Can I support that point from our research. Patrick mentioned that we had an understanding from a technical point of view and I think that is the root of the problem, is that there has been a focus on technical issues and not enough focus on what we might call the socio-cultural issues and change management issues in implementing these systems from a clinical point of view and from a managerial point of view, and I think that absolutely has to change and we have got 20 or 30 years' evidence from the research literature on other implementation of IT innovations about that need and it is rather surprising that that failure has happened again.

Q423 Dr Naysmith: That was very obvious to us at Homerton yesterday that the clinicians needed to lead the project if it was going to get the hospital staff involved properly. My very final question is to Mr O'Connell really. This standardisation between hospitals and between Primary Care Trusts and between different kinds of settings in the NHS is very important for research purposes and for communication. Was there any involvement of the Royal Colleges in standardising and defining terms and descriptions? Did that happen, do you know?
Mr O'Connell: I am sorry, I do not know that, I do not have the answer to that question.

Q424 Dr Naysmith: I do not know whether you came across that, Professor Fulop? What involvement was there of different disciplines in designing standardisation?
Professor Fulop: What I can say from our research is that at a local level, clinicians and managers did not feel involved in those discussions.

Q425 Chairman: When you talk about a Detailed Care Record and a Summary Care Record, which we will move on to hopefully in a few minutes' time, what is your general understanding, that I as a patient will have two records, one detailed, one summary, in ten years' time? Is that what it will be?
Mr O'Connell: My understanding of the two records is that the Detailed Care Record, as I said earlier, is a complete electronic capture of your basic record. The summary record to me is a bit of a safety net for unplanned events that would occur, so for example—

Q426 Chairman: Right, so there would be the two records. Is that your understanding as well?
Mr Shackman: Yes, very much. The key thing is the detailed record and all the functionality that goes with it.

Q427 Chairman: You think there will be two as well?
Mr Shackman: But you extract what doctors decide is necessary to support emergency care if you are away from home. I was interested reading Dr Braunold's oral evidence, I think I am right in saying that she said that in a few years' time she thinks that the summary record will become much less important because the key information will be in the detailed record or there will be less need for the summary record. It is a sort of stand-in because we do not have the detailed record yet, so to my mind the summary record is very much what falls out of the detailed record rather than being something completely different.

Q428 Chairman: Why I ask the question is that of course Detailed Care Records are held presumably electronically both in my GP's surgery and at my local hospital because I was an in-patient for a while many, many years ago and there are going to be two Detailed Care Records, are there not?
Mr O'Connell: No.

Q429 Chairman: There will only be one, so your understanding is that everything that comes from a past system in London will be passed down to the GP or vice versa?
Mr O'Connell: The intent of the Detailed Care Record is to be a single repository of your medical history or your health care record in a single place in addition to the other benefits that we have talked about.

Q430 Chairman: Is that everybody's understanding? Naomi, is that what you understand also? Hopefully you do not, but if you went into the acute sector all the information that would be held there would be then passed down to your Detailed Care Record presumably?
Professor Fulop: My understanding is that the vision was that it would not be passed down, it would be available so that hospital staff and primary care

staff, wherever they were, would log in and they could look at my detailed record. That is what my understanding of the vision was.

Q431 Chairman: So it could be held on two different databases but just made available?
Professor Fulop: This is going beyond my understanding of the technical issues. My understanding is that there was one database to which a number of different people in different places had access, tell me if I am wrong, that is what I thought the vision was.

Q432 Chairman: We will discuss the summary one later but I want to know about the Detailed Care Record. I think we know potentially what it is but where is it, is it on more than one database; it must be, must it not?
Mr O'Connell: The Detailed Care Record is intended to be a single repository and intended to be typically in a single place. However, in the realm of computer science sometimes it may be convenient to have something in a different location depending on usage of a particular aspect of it. So I think the physical location of a database with the physical location of items in computer science is probably less relevant than the concept of a single Detailed Care Record for a person.

Q433 Chairman: I have spoken to a number of people, not in formal evidence sessions, and they say quite clearly, "I am a GP and there are some things that are on your Detailed Care Record in the local hospital which I do not need to know, probably the discharge is all I need to know electronically," you are discharged from there so my GP would not necessarily want to keep the Detailed Care Record in my local district general hospital, or indeed in a London hospital if I was ever taken into there. Personally speaking—and I am not speaking for the Committee on this—I am confused about what the Detailed Care Record is, is it one or is it more than one? I understand that the detail that may be on it would be far more detailed than on a Summary Care Record—and we will get to Summary Care Records and I think we know what the plan is with the Summary Care Record—but I would like to know what the plan is with the Detailed Care Record. Is acute and primary going to come together on one plan?
Mr Shackman: Can I most unhelpfully say that I think I am about as confused as you are.

Q434 Chairman: Thank you, that is reassuring, Alan!
Mr Shackman: Certainly it seems to me that if the GPs are going to continue with their own GP system, then information that they have put in will be on their system and the information that comes from the hospitals or elsewhere may be on a database elsewhere but, as Naomi said and I think you have as well Mr Barron, not everyone needs to know everything. Your GP is not in the least bit interested in the detailed day-to-day nursing care plan but is very interested in the discharge summary, so this may also be unhelpful, to my mind it is not something that matters terribly, but that is just to my mind.
Chairman: Are we going to have two records, or three records I ought to say in these circumstances, or possibly four or five, if I travel around the country a lot and I have got a complaint that takes me to the acute sector now and again so I am logged into somebody else's computer in a hospital system? How is it going to work?

Q435 Sandra Gidley: If there is a mental health trust that is a separate record yet again or is not?
Mr O'Connell: It is separate data in the sense that data from mental health is different to data from acute health, but the point is to have a single, Detailed Care Record that may be stored on more than one database for computer science reasons, and people who have the proper access and proper authority may be able to download parts that they want, so a GP is likely to keep things in a GP's surgery that he wants to keep right there, so if you want to say that is a separate record you could say that but in an LSP there is a single record that is used by a variety of people in a variety of circumstances but it is the basic record. The GP may download something, mental health may keep a piece of it if they want, but it is the same ultimate record tied to the same parent record.

Q436 Chairman: It is not physically in one place?
Mr O'Connell: Correct.

Q437 Chairman: It is called a record but it is an amalgam of where I have interacted with the health care system in a detailed way?
Mr O'Connell: Correct.

Q438 Chairman: I think I have got that now. Have you got it, Alan?
Mr Shackman: I might have, yes.
Professor Fulop: I think we have to find a way of communicating it in such a way that healthcare professionals and the public understand at a very basic level what it is.

Q439 Charlotte Atkins: I think that discussion has probably demonstrated that the Detailed Care Record however we define it will require a lot of local IT systems being linked together to share information, but how long are we going to have to wait for this given that most hospitals have not yet received even a basic system? We were at Homerton yesterday and although they have their own system they were not able to communicate that electronically to the GP because the GP, as the Chairman was saying, might only be interested in the final discharge summary or notes, and maybe that is not a big issue, but given that they were really moving quite impressively to an electronic almost paperless system within the hospital, if that is going to work effectively for all hospitals there are going to have to be linkages with GPs as well and when do you think that is likely to happen given that we are now proceeding so slowly through this route?

Mr O'Connell: In 2009 we hope to have the stand-alone capabilities integrated so that the sharing of the record in authorised, appropriate ways has occurred, so this year and next year we are rolling out the basic stand-alone capability for the community as a whole to have that established and once it is established that we have the capability then we intend to link it together.

Q440 Charlotte Atkins: So that is the stand-alone but will that then be fully questionable by the mental health trust, as Sandra mentioned, or the GP, will it be an all-singing all-dancing system?
Mr O'Connell: I am not quite sure about the all-singing all-dancing, but it is intended to completely link up the system so that you have the data that you need when you need it on the system, which is the point of it, so we will do that.

Q441 Charlotte Atkins: It will not just be the summary, it will actually be the detailed record that we can access?
Mr O'Connell: The detailed record.

Q442 Charlotte Atkins: Can I ask Mr Shackman and Naomi as well, you both expressed concerns that the new systems provided by the national programme will not link together in the way that was originally planned, do you think that this will undermine this whole process we are discussing of bringing together the Detailed Care Record?
Mr Shackman: I have some difficulty, thinking about 60% of the country that is covered by the CSC LSP, because I cannot profess to understand what the Lorenzo system is going to look like. I understand that it is still being developed. It was supposed to be available from 2004 but has not been. I am merely stating what is in the public domain. We understand from CSC that it will start to be delivered by this time next year. I have been reading this week, and no doubt you have as well, the shenanigans (is as good a word as any) going on between iSoft and CSC and potential buyers and this, that and the other, and I do not know what is going on, but it surely cannot increase our confidence that the development is going to be successful. So certainly I have not heard of any firm dates for implementing clinical functionality effectively north of London but there again I am not part of the programme, I have no access to the detailed information systems, so there are doubts there. So far as the South is concerned, where Fujitsu is operating, presumably they can be in precisely the same position as BT in London, presuming that they can get either from Cerner or elsewhere the functionality necessary for PCTs and mental health trusts. My understanding—and Patrick will correct me—is that the Cerner product at present does not have specialised functionality to support community services and to support mental health applications. You will correct me if I am mistaken.
Mr O'Connell: It does have it but we are not using it. We are using Cerner for the acute space only.

Q443 Charlotte Atkins: Professor Fulop, I think your research was indicating some problems or some concerns about hospital trusts and the national programme being able to operate together?
Professor Fulop: Yes, and what I would say is that there is a lot of enthusiasm in hospitals for them to be able to link up and to link up with primary care and so on in their community. I understand there is less enthusiasm from GPs and also frustration that there has been a focus on functions, particularly Choose and Book, which locally they did not particularly see as a priority and saw as driven by other concerns than those to improve clinical care.

Q444 Charlotte Atkins: Mr O'Connell, do you think that people are right to be concerned about this lack of integration or do you think that this is something which will just progress and will work in the future?
Mr O'Connell: The integration does not exist today and people are operating. I think the integration will improve what is there already and I think as we move forward and we integrate these entire systems it will bring better healthcare to the fore.

Q445 Charlotte Atkins: So you think that integration has not be been sacrificed in terms of trying to just progress on the individual new systems?
Mr O'Connell: It is a lot of things, just like building a house, there is a certain order of precedence in order to establish things in terms of foundation and gradually working your way up and so what we are doing in London, for example, right now would be a proper profile to deliver the capability that we have signed up to do in the correct order to do that.

Q446 Charlotte Atkins: I suppose time will tell.
Mr O'Connell: Certainly.

Q447 Charlotte Atkins: We shall have to see how that actually works, but certainly a lot of people have expressed concerns that the Detailed Care Record is going to be a real struggle to deliver in terms of its electronic system. Do you share that or do you think that people are just scaremongering about that concern?
Mr O'Connell: I think there are two aspects to that. There is probably an operational aspect to it, which I am not really qualified to speak to, but from a technical aspect to it the capability will be there to share the records. I think it is like a lot of things, it may be in the 80/20 category in the sense that probably most of what people want will be there, but there is bound to be something not there that they want and, again, I think that is something that can be overcome so I think the system will probably—and it is a little bit outside my realm here—move forward to much better capability and will continue to improve as we go along. I am not quite sure if the Internet is a good analogy here because I have not thought it out before I showed up, but to some extent in 1990 if I was to look at the Internet I was not sure whether the Internet would be a good business tool or not, in 1995 I kind of changed my mind, and today it would be very hard to live without it. I think

the concept of putting English medicine on-line is a little bit like that because it is quite a complex task to do even though some things can be described somewhat simply, and I think that what you are seeing is that we are gradually improving our IT capabilities to enhance healthcare and it will kind of move in a profile like that—and I am not trying to make an analogy about timelines or anything, I am just saying that something as significant as this and so transformational as this will gradually improve so technically we are on our way and I think we are progressing very well in the sense of if you look at the record of what we have done, and I think that operationally it will probably enhance itself as it moves along.

Q448 Charlotte Atkins: Given the obvious potential patient benefits of the Detailed Care Record being accessible electronically, what can be done to speed up this whole process, because it does seem to be taking a very long time and I think patients and clinicians are likely to get frustrated over the time that it is likely to take?
Mr O'Connell: It is something that we have of course been thinking about as we think about progressing the issue and as how to go forward faster. We are looking at a few items right now with Connecting for Health and with the users about how to do that. There are a few tasks in particular, for example like the task of cleansing the data and migrating the data, which is quite an onerous task and a larger and more complex task than most people might have imagined on day one.

Q449 Charlotte Atkins: I think plenty of people imagined what a detailed task it was, that was one of the issues.
Mr O'Connell: I take that back. I was not here on day one so that was speculation on my part. It is quite a significant task and today much of that task is done with the local trust and a small amount of that task is done with the supplier. One of the things that we think we could do to go forward faster is to change the ratio and change the roles and responsibilities of who does what to insert it in the new system. If you take a look at the various IT departments that we have dealt with already, there is a variety of resource and a variety of expertise available, and one of the things that we could do potentially is take an industrial strength approach to the IT and the data cleansing and data migration and that might move it forward faster. In London for example there are 74 trusts. For each trust each time we install a new system it is the first time for that trust. For us it depends on where we are. If we are at the 37th trust it is our 37th time so what we try to do is take advantage of the lessons learnt so you have one group which does it 74 times and not 74 groups which do it one time, and some of the things that are part of those lessons learnt would be the data collection and data migration, so we are currently discussing that with Connecting for Health now in a very favourable and positive way, and with the trusts, to potentially alter the roles and responsibilities a little bit so that IT and data cleansing and data migration goes with the group which does it for a living versus the trust group.

Q450 Charlotte Atkins: I think what we learnt from Homerton Hospital was the fact that it had to be very much the clinicians in control in terms of developing the system rather than the IT specialists telling clinicians how they could actually use the system.
Mr O'Connell: That is true but I think there are elements to that in the sense that a supplier like BT could not and would not make any clinical decisions but in extracting the data from the place that it is at, getting a consolidated single place and then turning it over to clinicians, could be faster than the way we are doing it right now. In other words, everybody in their proper roles and responsibilities and to some extent IT with IT, but it is a lot of steps involved in order to get it to the point where a clinical person can say, "I would like it this way," or, "I would like the process to be like that." We might be able to move that faster than local IT staff or clinical people doing it part time with some clinical and some IT.

Q451 Charlotte Atkins: Would Professor Fulop like to comment?
Professor Fulop: Your point about clinicians being involved is absolutely key and I would add that the local trust needs support to implement it, it does not just happen, so they need resources to support project management, training, and so on, and also this issue that Alan mentioned earlier about changes in working practices. If we are really going to get the gains from this IT modernisation that everybody wants, it also means addressing how professionals work and manage to work differently and to my mind that is not happening yet and we really need to focus on those issues as well.
Mr Shackman: To my mind one of the reasons why you got some good vibes from the visit to Homerton is knowing a little bit about the background, the clinicians there were involved in the decision to go with Cerner in the first place. I know that there is a very enthusiastic core group of clinicians there who really wanted to make these changes happen. They may have been a bit frustrated through technical problems and such like but it is really good to hear that you were there yesterday and they seem to have climbed out of that. That is the key thing, changes at the coalface level have to be driven by some local people, so you have got to get them switched on to do it. Give them good systems—and that is Patrick's business—then find ways and give them the space to learn how to use them properly and make the changes.

Q452 Sandra Gidley: We heard earlier, and I think we are clear now, that even within the Detailed Care Record you have got a lot of different systems that have to talk to each other and there are the different elements of the health system. Has Connecting for Health done enough to set clear standards to ensure that that will happen? Patrick, you may be able to talk more as you have got more direct experience.

Mr O'Connell: From a technical stand-point and a delivery stand-point we have and I think we are all well-engaged at this particular point. As I mentioned earlier, they are well integrated into the customer engagement process and so the question about clinicals earlier, from a clinical stand-point, from a management stand-point, from an IT stand-point, from a migration of data stand-point, I think they are well-engaged in the sense of delivery.

Q453 Sandra Gidley: So from a technical point of view the speculation is clearly written, it does not keep changing and it has been clear from beginning to end where you are going on this?
Mr O'Connell: I am not saying it has not changed. The specification has changed from day one to day now. What I was speaking more of in the now sense of where we are to today is I think that Connecting for Health is fully engaged with the user community and the supplier community to roll out the capability on the ground, whether it be the mental health or the acute.

Q454 Sandra Gidley: That is not the question I am asking. I am asking whether the work done by Connecting for Health, the standards they have set, are clear enough to enable everybody to get on with it and deliver what is needed? Are the standards there which will enable the different parts of the system ultimately to join up with each other and talk to each other, because if they are not we might as well give up and go home now.
Mr O'Connell: I think that they are there today and the evidence of that is that we are rolling out capability on the ground in London for example.

Q455 Sandra Gidley: But you are not yet rolling out anything that can talk to anything else?
Mr O'Connell: No, but it is part of a sequence of events versus a lack of standards.

Q456 Sandra Gidley: Sorry, versus a what?
Mr O'Connell: A lack of standards.

Q457 Sandra Gidley: Can you explain that? I am not quite sure what you mean by that. Can you elaborate on that point?
Mr O'Connell: I was trying to answer your question in the sense that when you say we are not there now in terms of everything talking to everything that has to do with the fact that when you take the sequence of events of rolling things out, at a certain point they will.

Q458 Sandra Gidley: And you are confident?
Mr O'Connell: I am confident they will.

Q459 Sandra Gidley: What mechanisms are in place to make sure that the individual suppliers stick to what is happening?
Mr O'Connell: There are a lot of mechanisms in place but from a commercial stand-point in terms of the contract in place and from a practical stand-point, in our case in London for example, in order to make sure that they can all talk together there are two ways to do it, a relatively complicated integrated engine or a relatively simplified communication traffic cop, and each of our vendors, the three basic vendors have already modified their message formats—

Q460 Sandra Gidley: Sorry, modified their what?
Mr O'Connell: Their message formats. They have made their computer science stuff adapt to a common standard that we have to make sure that we can communicate, so it is already done.

Q461 Sandra Gidley: That was not Connecting for Health, that was pragmatism because it was not working, so you are saying Connecting for Health did not set those clear standards to start with?
Mr O'Connell: No, it had to do with the changing IT in the sense that on day one we had IDX which was a single vendor. Today we have three vendors and a best of breed and in creating three vendors, which was my decision to pursue that which was eventually accepted by Connecting for Health, one would have to do what I just did to make them talk together because I felt it was a better strategy, so we created a standard for these things to come together.

Q462 Sandra Gidley: Excuse me for labouring this point but if Connecting for Health had set very, very clear standards to start with you would not have had to do that, would you, it would have worked anyway?
Mr O'Connell: I think we may be speaking at different levels and at cross-purposes. I think the standards for single view are clearly set.

Q463 Sandra Gidley: I am talking now about how everything will work together.
Mr O'Connell: I think the standards for how things will work together are there and are clear. What I was speaking to (because I thought you were asking that) was a little bit how do I know when safeguards are in place and I moved into the implementation space and the fact that physically things have been changed to make sure that it comes together. So I think it may have been a "levels of discussion" issue more than it is not there. Sorry for the confusion.
Chairman: There was an issue that was put to us by one of our earlier witnesses that standards had not been agreed across the piece before the whole national programme was set up but there are other people we have asked that question, although we will have some more at some stage in this inquiry as well, so we do not have to labour it particularly now.
Sandra Gidley: I was just trying to—
Chairman: That is fine.

Q464 Dr Naysmith: A fairly quick question for Mr O'Connell. The N3 network provides fixed broadband connections across the National Health Service now. Will hospitals not also need wireless connectivity in order to take full advantage of detailed records systems?
Mr O'Connell: I think they can all probably take advantage of it with the current fixed system but we are currently in the process of trying to voice enable

the N3 system so that people can use it with either a fixed service or a mobile service and technically we are about there today and by the end of the year we should have that rolled out.

Q465 Dr Naysmith: Are there plans to provide this then?
Mr O'Connell: Yes.

Q466 Dr Naysmith: And they are fairly well worked out and they are going to just follow in sequence when the time comes?
Mr O'Connell: Yes, it was a matter of extracting more value out of the basic investment in capability that exists in terms of fixed service and now we are trying to move on to do greater things with it such as Voice Over IP which gives people the ability to use it with voice and wireless.

Q467 Dr Naysmith: Presumably that will involve lots more money as well? Was it a different contract?
Mr O'Connell: No, it is a levered circumstance versus a "from scratch" circumstance.

Q468 Dr Naysmith: Fine. A question to Professor Fulop. Your research shows that hospitals feel they are—and I quote from your evidence—at the "bottom of the food chain" because decisions were taken about the national programme and local service providers without their involvement. We have talked about that a little bit already but how do you think this could be addressed if we want to try and make sure that it does not happen in the future?
Professor Fulop: It means that Connecting for Health and the suppliers need to engage much more with local end users, as I have said, and I am pleased to hear that apparently in London that is happening more now because without it these systems will not work.

Q469 Dr Naysmith: You say the new NPfIT Local Ownership Programme will help to address the problem?
Professor Fulop: I hope so, although that was actually announced after we finished our fieldwork so I cannot say how that has gone down in the trusts.

Q470 Dr Naysmith: It has been suggested that it might just be a token gesture or a recognition of the problem without doing all that much about it. Is it a bit too soon to say that?
Professor Fulop: I think it is too soon to say. I would just say I very much hope that it is more than a token gesture.

Q471 Dr Naysmith: Do you know anything about this, Mr O'Connell?
Mr O'Connell: The NHS Local Ownership Programme, yes I do. From our perspective it is something that will help deployments of the capability to London.
Dr Naysmith: I suppose we could explore that further.
Chairman: Okay, the Summary Care Record.

Q472 Dr Taylor: The Summary Care Record—to me this should be the simplest thing in the world and yet we went to a demonstration of it at Richmond House just a couple nights ago and it was impossibly complicated. Somebody seems to have got the whole system confused between the Summary Care Record and the Detailed Care Record. My first question to Naomi is as far as you know has there been end user involvement in deciding what should go on the Summary Care Record?
Professor Fulop: What I can say is that from the perspective of the staff in the trust that we looked at, no, but I could not say there has been none from others. That is the most that I can say.

Q473 Dr Taylor: That gives an impression. We are told that the roll-out has now commenced. They do not call them pilot sites now, they are early adopters, which is a nice euphemism that does not tie you into anything. We are told that that roll-out has commenced but nobody seems to be able to tell us what the exact content of the Summary Care Record is going to be so how has the roll-out commenced? Do you have a clear idea of what should be on the Summary Care Record that you are actually about to implement?
Mr O'Connell: I guess the question to me is more along the lines of can I build what I am supposed to build in the Summary Care Record—

Q474 Dr Taylor: Unless you know what it is on it?
Mr O'Connell: Yes, we have a specification for what it is right now. We are putting that together and technically it works today.

Q475 Dr Taylor: Right, so what is the specification that you have been given for the Summary Care Record?
Mr O'Connell: I would have to get back to you on the specification itself in terms of data fields, you mean the data fields and the content of it?

Q476 Dr Taylor: Why is it not a single screen with demographic data, alerts, allergies, medical problems and current treatment? Why does it have to be any more than that, all of you or any of you?
Mr O'Connell: To be clear on the last question, you are asking what should it be, which is really a healthcare answer. I was saying that technically if healthcare has an answer we will build it.
Dr Taylor: Yes, that is very clear, you are not the person to tell me what should be on it.

Q477 Sandra Gidley: You said you had a spec regarding the data fields.
Mr O'Connell: Yes.

Q478 Sandra Gidley: I got the impression the other night that in the early adopter sites people were saying, "We would like this included, we would like something else included"—I do not particularly want to go in details—so are you having to adapt as you go?

Mr O'Connell: That is the point, yes, of the early adopter. Your early adopter is trying to work out the issues from ethical to practical of what really should constitute this summary record, so what are the essential or key elements needed to have somebody from the South who has a car accident in the North, you pull up this summary record to see what allergies he has, like allergies to penicillin for example, just exactly what should that look that and how that should be arranged, that part is the purpose of the early adopter programme to work out the details of the various communities of interest, come to an agreement and work their way through it. Some of them are theoretical, some are ethical, philosophical and practical and we are working our way through it right now so, yes, we have a spec, I expect it to change over time, at some point I expect it to steady up and then we roll it out.

Q479 Sandra Gidley: That is clear, so you are always expecting the data fields to change?
Mr O'Connell: Yes.

Q480 Dr Taylor: As far as any of you are aware has anybody actually defined what they mean by a Summary Care Record? To me a Summary Care Record is something short, possibly one computer screen. Has anybody defined this?
Professor Fulop: On the Connecting for Health website it says exactly what you said: "will contain any basic information such as current medications, adverse reactions and allergies. After that, each time someone uses any NHS health services, details about any current health problems would be added."

Q481 Dr Taylor: In the evidence that we have got from the Department of Health it expands on that tremendously and the demonstration we had again was more of a Detailed Care Record, as I would have seen it, so you have been told what fields you have got to have?
Mr O'Connell: At this point in time I would like to add I heard the earlier testimony before and just like "Secondary User Services" it gives a label that might not as best it could capture the value of the data in there. The word "summary", as you said, might sound like a very short thing but that may not be the best label because it is intended to be for an out-of-hours emergency circumstance so that you can get safe care if somebody does not have access to your detailed record, and so maybe that is why it takes a little bit longer to sort it.

Q482 Dr Taylor: What I am getting at is who has defined what "summary" means in these circumstances and who has decided what should go on it because that seems to me to be absolutely crucial? Would it be breaching commercial confidentiality to allow us to see the specifications that you have had for the Summary Care Record?
Mr O'Connell: I think that is something you would probably have to work with Connecting for Health on.

Q483 Dr Taylor: But it would be possible to let us see it?
Mr O'Connell: From a Connecting for Health standpoint if it is reasonable from their perspective it would be reasonable from ours.
Dr Taylor: Thank you.

Q484 Chairman: It may be the case Richard, as I understand it, that what you are looking at is the actual technical standards.
Mr O'Connell: Correct.
Chairman: That is the issue about what fields are in it in terms of what information would go on my Summary Care Record, which is probably something that we did see earlier this week in Richmond House and we can ask the question to see if there is any difference to that, Richard, if there is a conflict in evidence that we have received written or otherwise.
Dr Taylor: I am just trying to get at the exact content because the system we saw at Richmond House would have put off any doctor in an A&E department from even beginning to look at it because all you want in an A&E department is the basics.
Chairman: We will have a look at that.

Q485 Dr Taylor: Right, sealed envelopes; how far are you on the way with sealed envelopes?
Mr O'Connell: We are progressing on schedule and they should be ready next April/May.

Q486 Dr Taylor: So April 2008?
Mr O'Connell: Correct, April/May.

Q487 Sandra Gidley: You have not got the spec yet so how can you be on schedule?
Mr O'Connell: We have a spec for it as it stands today.

Q488 Sandra Gidley: We had heard in previous sessions that there was not yet a proper specification for the sealed envelope technology.
Mr O'Connell: It might be that the story is not over on what should go into a sealed envelope and what should not, and that is a different story.
Dr Taylor: Ah, what should go into it?
Sandra Gidley: No, I understood it was the technical spec.

Q489 Chairman: I have to say if it is stated that the sealed envelope is ready that is in conflict to what we have heard earlier in these evidence sessions. Our understanding is that the encryption, which is presumably the technical word, was not yet ready for really sensitive information on records being put into a sealed envelope.
Mr O'Connell: The patient sealed envelope specification exists and we are building to that. The clinical sealed envelope is not yet done, as I understand it.

Q490 Chairman: Could you tell us the difference between the clinical and the patient one, I do not understand that?

Mr O'Connell: I can speak to the patient in the sense that the patient sealed envelope is what the patient deems he wants to have not well-shared by everybody.

Q491 Chairman: Yes, it would be on a Summary Care Record but it would be encrypted it would be in a sealed envelope that may or may not be opened by anybody looking at the whole of the Summary Care Record?
Mr O'Connell: The contents of the patient sealed envelope is determined by the patient.

Q492 Chairman: I see, so what is the clinical?
Mr O'Connell: I am not sure but I believe the clinical is what the clinical person feels is appropriate or inappropriate or safe or unsafe to put in there.

Q493 Sandra Gidley: And how long have you had the spec, some time?
Mr O'Connell: It has been some time. I do not remember but it has been some time.

Q494 Dr Naysmith: Are you saying this is information that need not be shared with the patient? Are you saying that the clinical sealed envelope is something that the clinicians want to have on the record but need not be shared with the patient? If it is, it is the first time that I have heard of it.
Mr O'Connell: I would say that I am familiar with the patient sealed envelope but I am not familiar with the clinical sealed envelope.

Q495 Chairman: We might be in conflict, we might be talking about evidence we took on the Detailed Care Record earlier, but if that is not clear can we get back to you in writing about that?
Mr O'Connell: Certainly.
Chairman: I think it is important in terms of the Summary Care Record which is going to be the national record that is going to be sat on somebody's database. I think we are on to Sandra.

Q496 Sandra Gidley: Earlier we were talking about the Secondary Uses Service and we had quite a lot of evidence as to how it was probably useful to be able to extract names and addresses and refer back when it comes to pseudonymisation. Other people have raised significant concerns that the data is not anonymous enough. I believe it is currently pseudonymised by replacing the information that includes name, address and postcode, but other NHS systems use postcodes as identifiers in various work such as public health work on deprivation. Is there any way that postcodes could be removed and the system will still work? Patrick O'Connell, I believe your company is responsible for the anonymisation of data?
Mr O'Connell: We do both. We do the anonymisation of data, which is stripping out any kind of personal data, and the pseudonymisation of it, where you scramble the data, and mix other things in it so that even if you could read it you still would not know what it said, it would be hard to put it together. Postcodes from a technical stand-point can work however the community feels is the right way to make it work. So if postcodes are important to have I think we could fit those in. If postcodes should not be in there because you were concerned about inference attacks, then we will not put them in there.

Q497 Sandra Gidley: So this is a decision that you are working to rather than having any say over?
Mr O'Connell: Yes.

Q498 Sandra Gidley: Okay, that is fine. What have you actually done to test your pseudonymisation systems to make sure that patients cannot be identified? How do you test how robust that is?
Mr O'Connell: There is a lot of procedure to try to make sure that data is safe in an old-fashioned physical sense to a software sense to a hardware sense to a procedural sense, to continually try to penetrate the software yourself to see whether or not you can find holes in your own system. Every bit of time that goes along systems and counter-systems have a tendency to seesaw all the way up and so we are continually checking on a regular basis to make sure that we feel that it is safe.
Sandra Gidley: I think that is it really.
Chairman: Can I thank all three of you very much indeed for coming along and assisting us with this inquiry. Thank you very much indeed and we hope we will have the report out some time this year, I think my phrase should be at this stage.

Thursday 14 June 2007

Members present:

Mr Kevin Barron, in the Chair

Charlotte Atkins	Dr Doug Naysmith
Mr Ronnie Campbell	Dr Howard Stoate
Jim Dowd	Dr Richard Taylor

Witnesses: **Professor John Feehally,** President, The Renal Association, **Dr Gill Markham,** Vice President, The Royal College of Radiologists, and **Mr Frank Burns,** Former CEO, Wirral Hospital NHS Trust, gave evidence.

Q499 Chairman: Good morning. Can I welcome you to what is our fourth evidence session on our inquiry into the Electronic Patient Record? I wonder, for the sake of the record, if I could ask you to introduce yourselves and to tell us what position you hold? Could I start with you, Mr Burns?

Mr Burns: My name is Frank Burns. I am a recently retired chief executive of a large general hospital on the Wirral where I was chief executive for 17 years. During the course of my employment at the Wirral I was seconded for 18 months to draft an Information Strategy for the National Health Service which was published in 1998 under the title of *Information for Health*, and which has been subsequently superseded in terms of the implementation model by the National Programme for Information Technology.

Dr Markham: My name is Dr Gill Markham. I am a consultant radiologist now in North West Thames, I was previously in Liverpool for about 25 years, and I am Vice President of the College, who I am representing today.

Professor Feehally: I am John Feehally, I am a kidney doctor. I work as a consultant in Leicester. I have just completed a three-year term as President of the Renal Association, which is our professional society of kidney specialists in the UK, and I also chair a group called the Renal Information Exchange Group, which is a professional and patient group which has got itself together to try and ensure that the renal health community influences as much as it can and in the best possible way it can the whole information and knowledge agenda within the NHS.

Q500 Chairman: Welcome once again. Could I start by asking a couple of general questions? The aim of introducing electronic patient records is to improve the quality of patient care. To what extent do you think this has been achieved to date?

Mr Burns: By no means as much as it has the potential to improve the quality of patient care, but the fundamental requirement for electronic records, in fact "electronic records" sometimes misdescribes this technology, because the best of this technology is patient care management systems, not simply electronic means of recording what has happened to patients, the best of these systems actually support practising clinicians in their day-to-day work providing better care for patients; and where clinical management systems have been installed, and they have been implemented in various parts of the country, not as widely as we need them and not with the urgency with which we need them, there is very serious evidence of the capacity of these systems to improve patient care, but they have to be deployed at the operational level, they have to be functional at the operational level, they have to be tools which are used on a day-to-day basis by clinicians—doctors, nurses, community nurses, specialist nurses—right across the spectrum of care. There are very graphic examples of how information technology deployed in a clinical setting cannot just improve the quality of care but can dramatically improve the safety environment in which patients are cared for.

Dr Markham: My particular remit is the imaging aspect of it, but I also use the Electronic Patient Record in my trust. To give you an example, if I want to have a pathology report, that is immediately available. So, the patient benefit is indirect but it is safer availability, it is instant availability and accurate availability because you can go straight into the record and get it, but, as I say, it is within the trust that I have experience of that and, obviously, the imaging side of it, which we will go into later, I am sure.

Professor Feehally: There is absolutely no doubt about its potential. It is beginning to come in in some places, but in quite a lot of those places it has come in or is coming in, it is quite independent of Connecting for Health, it is initiatives taken locally by others either before Connecting for Health or, indeed, since it began but in spite of. We often think about it within an institution like a hospital, but for me the real gain is across primary, secondary, tertiary care within a network. To give you a single example, I was in my clinic yesterday afternoon. I saw a man in his sixties with diabetes who has kidney disease. He has a complex problem. I see him often. Three days before he was in the diabetes clinic. One week before that he was with his GP. I could not access blood tests from any of those. He is an articulate man who told me what had happened to him, but if he was not I would not have got that right, and that is transformed overnight if you get these things in, but we are not seeing it yet.

Q501 Chairman: Survey evidence has shown that doctors' confidence in the national programme has fallen sharply since 2003. Why do you think this has happened and what can be done about it?

Mr Burns: I think it touches on the points we have all three just made, that what clinicians want is functioning technology that will support the work that they do on a day-to-day basis. I think a lot of clinicians are frustrated, for instance, about the focus of Connecting for Health on the Summary Care Record. The Committee has heard enough evidence already about the delays with this programme. I do not think we need to repeat the fact that there is huge frustration about the fact that, despite the fact that Connecting for Health has been in existence since 2002, if you go round the NHS into the operational clinical services there is very little evidence as yet of the clinical systems that we are describing. There is lots of activity around the implementation and replacement of Patient Administration Systems, but these are not the same thing. Patient Administration Systems have existed in the NHS for many years. They are administrative systems, they support the processing of patients, they do not support the care of patients, and it is the elements of the technology that supports the care of patients which is slowest in coming forward. In many parts of the country, people have begun to despair of it as to whether it will ever arrive and I think a lot of clinicians are very frustrated about the focus on the national Summary Care Record, about the creation of a national approach to sharing information and the lack of priority that is currently being given to the development of the implementation of clinical systems at the clinical level and the sharing of information, in the way that my colleague describes, so that doctors and nurses, when they are treating patients, have a good, up-to-date, reliable, accurate picture of everything that is happening to that patient. Most patients come to harm in the NHS in the course of day-to-day care; they do not come to harm necessarily, to a greater extent, because their records are not available if they happen to turn up at some distant hospital, unconscious with no identification. I think the evidence for the benefit of the Summary Care Record has not been presented, and I think that evidence could easily be obtained. It is not a difficult thing to scope, in terms of the current NHS, how many patients are going to benefit in terms of remote need for emergency care. The real priority for the NHS, for the NPfIT, for Connecting for Health, in my view, and I think it is a view that is supported by most clinicians, is for Detailed Care Records at a local level, and I think it is the absence of progress with that that is creating the frustration you allude to.

Q502 Dr Naysmith: Do you think there has been too much emphasis on this emergency care?
Mr Burns: I do, yes.

Q503 Dr Naysmith: Do you think that is one of the real problems, concentrating on this record being available?
Mr Burns: It is not the only thing that NPfIT are pursuing. NPfIT can list some very creditable achievements, not least in PACS, which is picture archiving technology for radiologists. I am not here to condemn everything that Connecting for Health is doing, but I do think that the focus on the Summary Care Record is a misplaced priority. I think it is of less value clinically and less value to patients than the deployment of clinically rich functional technology supporting doctors and nurses on a day-to-day basis, and there is no sign of that being delivered to the NHS any time soon.

Q504 Chairman: Do you have anything to add to that?
Dr Markham: Just to say that Professor Feehally alluded to the fact that much of this had been present before, and we will no doubt come back to PACS in a moment, but an awful lot of PACS was available prior to this and in many ways it has muddied the waters, although it has rolled it out much quicker than it might otherwise have been, but it was in place in many places way before NPfIT.
Professor Feehally: To add to what Frank said, it is lack of progress which frustrates clinicians, but there has also been an appalling communication failure from the beginning. The early attitude was, "We are the computer experts. We will let you know when we need a little something from you, because we will roll this out and it will work", and they have gradually retreated from that as they have realised it is actually difficult, but what they have not done is really listened to clinicians and they have assumed that when we say, "This is difficult", or "This is complex", or, "This is quite sophisticated", we are a bit old fashioned or a bit Luddite or do not understand, rather than assuming we really did understand something very complicated we worked within for a long time, and we have used computers for 20 years in some ways, so it is a communication failure.

Q505 Chairman: Frank, would it be fair to say that out of the Detailed Care Record comes a Summary Care Record?
Mr Burns: Yes.

Q506 Chairman: This is putting the cart before the horse. Would you go as far as to say that?
Mr Burns: Yes, I would. It is true about clinical IT that all of the secondary purposes flow best from focusing on the principal purpose. The principal purpose is to support the care of patients, and if you give total priority to the principal purposes, which is supporting the care for patients, all of your secondary purposes will flow naturally from that. If, for instance, you had good, effective, supported clinical systems in hospitals—you already have them in general practice, it is in hospitals that there is a great black hole in terms of good functioning clinical systems—if you deal with that and focus then on technologies that can integrate the information in those records at a local level so GPs and hospital specialists who work in a partnership on a day-to-day basis can have a shared view and, as my colleague said, even specialists working in the same hospital can have a shared view of what is happening to a patient, I am not a technologist, I am not an IT specialist, but I am very confident that if you had

good, local Detailed Care Records, the technologists would not have too many problems in extracting the information that is needed for a national Summary Care Record, if there was a case for a national Summary Care Record. But bearing in mind that most people attend their local hospital if they have an emergency, the occasions when any of us fall over in a distant town and need emergency care are not all that frequent compared with mothers rushing to the local hospital with their sick child because they are not sure why they are crying. Most of this care is delivered locally, not remotely, and that is why the focus should be on delivering this functionality locally.

Q507 Chairman: I do not understand all the technical side of this, but in a sense for that to happen, for my GP to share records that are in my local district general hospital, they have to be compatible, and that is something we have not been very good at. The Patient Administrative System a decade ago was sharing no discharge notes at all with my local GP service, and I expect that was the case for the whole of the borough. It seems to me there has probably been an emphasis on making sure that, whatever systems are eventually installed, they are compatible systems so that you can deliver that. Has that been one of the major issues, do you think?
Dr Markham: To a degree, but prior to NPfIT there were systems that were set up locally—for instance access to specialist services. If you had a patient coming in with a head injury at night, then you could beam your images off to the local neuro-surgical centre for an opinion, and in some ways that has been made more difficult for NPfIT coming in. I suspect, although, again, I am not obviously a computer expert, these difficulties could have been got round in perhaps a slightly less all-encompassing way. The idea is very good, but I would entirely support what Frank Burns has said that the vast majority of healthcare is done in your local community. In the case of London or any of the conurbations, or even down in the South West, patients go to their local hospital, they may go to a specialist service in a hospital three miles down the road and that is the sort of sharing that we need rather than one end of the country to the other.
Professor Feehally: To repeat the answer in a different way, if at the beginning of this sorry process they had simply given local health networks some resource and said, "You will just simply resolve the question of the primary care computer system talking to the hospital computer system", we would all now be smiling, because there have been many other things we had not yet got, but that alone would have advanced the healthcare system, and that is what we wanted.

Q508 Chairman: John, you were talking earlier about clinical engagement in all this, and we have seen examples of where that has happened certainly for the good in my view. How do you actually get clinical engagement when you have got (I think the national figure is) 700,000 clinicians working inside the National Health Service? What happens? Where this has happened, how many people are really engaged with looking at the system that has been introduced and making sure it does fit their needs and the patients' needs in terms of that locality?
Professor Feehally: You do not need many champions. Where one has seen success there have been a small number of senior clinical leaders who have believed in it and have begun to demonstrate change, and then you take the clinical community with you. What you do not do, to use my specific example, I have on several occasions approached Connecting for Health at several levels saying, "Here I am; I represent the kidney world. We spend 2% of the NHS budget on dialysis and transplant. Chronic kidney disease is very common and it is a cardio-vascular risk marker. We are a big group. Can we please talk to you?", and they have not answered the email, not given me an appointment. I have simply never spoken to anybody. They have not wanted to talk to us. So at that level it is frustrating.
Mr Burns: I think philosophically there are a couple of approaches. The approach that preceded NPfIT where local health communities were, if you like, expected to source, procure, implement systems locally, there is a better opportunity for getting a critical mass. You do not need every clinician, but you need a critical mass of people, the leaders amongst the clinicians, as you do with any endeavour, and you can get a critical mass of local clinicians involved if there is some element of local choice of system. The more you scale that up the more difficult it is to achieve that, and you have to accept, and I accept, that if you accept the argument for national procurement, then there is no practical way you can achieve local clinical engagement. There is no point pretending there is a practical way, because there is not, and if the benefit of national procurement is greater than the need for local high input of clinicians, then you make the argument and you go on that basis, and I accept that. But if you do go on that basis, then you have to deliver quickly what it is that you are procuring nationally. If you say to doctors, "There are too many of you to involve you in the choices and the economics benefits nationally outweigh the argument for local choice, so we will do it this way because we will get it cheaper, because it is cheaper there will be more of it, because it is cheaper we can give you more sophisticated software, it will be better, then you have to deliver it, you have to come up with that; and if they are still waiting after five years, which is what the case currently is, then you have lost your way in making that particular argument. Then what you have got is not an argument about engagement, you have got a problem of disengagement because clinicians have disengaged because they see no evidence of what was promised in place.
Dr Markham: The way it was done with PACS is a very good example. The sudden cluster, as is now, was almost ready to roll out. People had been agreed, they were going the same way, they were going to connect up, and then it stopped on the basis of a national procurement. In practical terms what happens is you have perhaps a consultant radiologist

and a radiographer who have a particular interest in it in a trust or in a group of trusts and they are the ones that develop with the vendors what is required. They say, "This is the problem. This does not work. How can you make this work? This is what we want to do", and the work is very good and there is very close co-operation over a period of probably ten, 15 years as it developed, and that is why it was good.

Q509 Dr Naysmith: Was there any evidence of radiologists being reluctant to use the new system when it was being introduced or just before?
Dr Markham: You mean PACS?

Q510 Dr Naysmith: PACS?
Dr Markham: Absolutely not. That is one of the reasons for its success, because there were such strong drivers as far as PACS was concerned. We were running out of silver films, the disposal of dangerous chemicals was difficult, the paper films or the hard copy films used to get lost, you had to have people carrying them around the hospital in great big bundles, so to have it electronically—

Q511 Dr Naysmith: So there was not any need to convince radiologists that their system was out of date?
Dr Markham: Quite the reverse. We spent a long time trying to convince trusts it was a good idea to have it.

Q512 Dr Naysmith: You had to convince the trusts rather than the radiologists?
Dr Markham: Oh, yes. The radiologists were completely signed up right from the start. We realised the benefits it would bring. It was obviously the financial drivers that we had to convince, because it meant new machines, which, of course, were hugely expensive, but eventually that was gathering speed. Certainly in my own hospital I have been working with PACS for eight years, and two years before that in another hospital, and it was extremely successful.
Mr Burns: It would be almost impossible not to achieve a rapid roll-out of PACS given central funding.
Dr Markham: Absolutely.
Professor Feehally: And not just radiologists; other clinicians. We had a form of PACS in place for over a decade. It was absolutely fantastic, it works, and so there is never an issue about needing to persuade anybody. It was almost there in a way; it simply had to be rolled out. It was not a magnificent design achievement, I do not think.
Dr Markham: No, and in fact I was at a meeting earlier this week and it was said that PACS roll-out would have happened probably without NPfIT because there were such strong drivers.

Q513 Dr Naysmith: How do we get that sort of enthusiasm there obviously was for PACS to operate for other PAS systems? How do you get clinicians involved in customising their local system?
Dr Markham: We have already talked about the obvious advantages of communicating with general practitioners and within hospitals, but the frustration has been trying to get the software and the hardware to do what you want it to do efficiently, and also a very important point is the actual technical back-up when things are implemented. Inevitably with computers things go wrong, and you need someone who is knowledgeable who is there. Your home PC might crash and you just reboot it, but you cannot quite do that when you have got electronic systems in a hospital.

Q514 Dr Naysmith: You need the experts to talk with the clinicians closely on what is happening and what is required?
Dr Markham: Yes, and that has been in very short supply.
Mr Burns: It is availability and speed of implementation. If you want a PACS system, they are available; you can buy them off the shelf. You can say to clinicians, "Here, I have got some money. You have been asking us to put in PACS systems for the last decade and now we have got some money and you can have it in the next six months", so you get a huge surge of enthusiasm from the radiologists and the other clinicians because they know the technology is available, they know it has been funded and they know they can have it within the next 12 months. On the other hand, if you are waiting for the clinical management systems that support the work of diagnosis, treatment and therapy, the message to the clinicians is that we will be putting PAS systems in (which are not clinical systems) for the next two, three, four years and we are still developing. At least probably two-thirds of the country is still waiting for the clinical system to be finally developed, and the latest estimation—

Q515 Dr Naysmith: Does the same thing apply to Patient Administration Systems, or is that a different problem?
Mr Burns: No, the NHS has been putting Patient Administration Systems in for the last 20 years, and most hospitals have already got them and had them and embraced them. What they are getting is new Patient Administration Systems that are compatible with the clinical systems that have been purchased through the national clinical contract which they are compelled to have and must wait for, and that is the source of most of the frustration. The Patient Administration System is not the clinical system.

Q516 Dr Naysmith: But consultants at the Homerton were booking people into out-patient clinics months in advance.
Mr Burns: Yes. A Patient Administration System can help you book patients, but it does not help the doctors and nurses in terms of their day-to-day care of patients, the real purpose and benefit of this technology ultimately.
Professor Feehally: We have talked about engaging clinicians by giving them something better, but there is another point that some of us are concerned that we might lose what we already had. We have used

computer systems in kidney units for 20 years and, although they look a bit clunky, actually they have got all sorts of very bespoke functionality which we need to use in our every day clinical work. So part of our discussion with Connecting for Health was, "If you are going to give us something wonderfully new, do you understand what we already have so that we will even have that, let alone something better?" and they have never discussed that with us. So, we have been sitting with our so-called Legacy Systems (in the current jargon) thinking, "Are they even going to take this away from us, because it would be unacceptable?" We have never had those discussions.

Dr Markham: That has happened in many areas, that systems that were working have had to be removed.

Mr Burns: Certainly in my hospital we had a very sophisticated, fully functioning clinical system for 17 years. It is still the most sophisticated clinical patient management system in the UK, in my view, and, in my view, what is eventually produced by NPfIT will not be as sophisticated, which is the reason that in my trust, for issues of patient safety, we had to say that the first offering for NPfIT would have been a positive danger in that all our 6,000 staff have become familiar with using a sophisticated clinical patient management system and we have been offered something much less sophisticated.

Q517 Charlotte Atkins: Based on that comment, Mr Burns, I am assuming that you hold to your view in 2002 that contracting out nationally would be a disaster. If that is the case, can you indicate if there have been any successes, in your view, in the national programme?

Mr Burns: Yes, they have secured £12 billion, which is an enormous success, and it is the most fundamentally important thing about the national programme. There is huge resource available that was not previously available and, despite what was said at previous sessions about the lack of progress prior to NPfIT, the biggest obstacle to lack of progress prior to NPfIT was the absence of resources on the scale that are available to NPfIT. They have huge sums of money at their disposal which, if deployed in the right way---. I think there is a proper argument to be had for contracting nationally, but I think there is a way of contracting nationally using all the economies of scale and using all the purse-string muscle that comes from contracting nationally. I absolutely agree with that. I think they did a super job. I think what they might have done was contracted nationally a catalogue of products which could then have been picked from locally and the prices could have related to how much penetration the different suppliers achieved across the NHS. That would, if you like, combine the benefits of national contracting with---. It is a framework contract. It has been done in many areas. You contract nationally with a range of providers but they then have to compete in terms of how they present their products to potential users to determine what share of the market they get. I think that would have been a much more successful model, and I think we would be much further on if we had adopted that sort of model.

Q518 Charlotte Atkins: I think you argued that you wanted to make local chief executives accountable for delivering the new systems.

Mr Burns: Yes.

Q519 Charlotte Atkins: Do you think that would have resolved many of the delays we are experiencing now?

Mr Burns: From where I sit, and I have been a chief executive for a long time, the introduction of NPfIT and the central contracting and the contracting with local service providers to be responsible for implementation, for taking all the risk of implementation, completely removed from operational chief executives any sense of accountability for delivering this programme. Poor old Richard Granger gets blamed for everything to do with the failures of this programme, but that is because there is no other accountability in the system.

Q520 Charlotte Atkins: Is it too late to turn the clock back and bring in that accountability?

Mr Burns: No, I do not think it is, but it would require---. Everybody wants NPfIT to succeed. The goals and aims of NPfIT, my goals and aims in relation to rolling out functional clinical IT to the NHS, Richard Granger himself has said that you could not possibly embark on a ten-year programme on this scale without having to change tack over the course of the decade and I entirely agree with him. I think there needs to be some decisions made as to how to change tack to deal with some of the delays that they are currently experiencing, and one way they might do that is to use this current OJ tender that they are involved in. They are currently involved in a tender process with the IT supply industry to the NHS to identify a range of products that might supplement what they are currently contracted for, and if they found a way to make the best of those products available as a choice within the NHS (and that presumably would need some tweaking of the contract), then I think that might help move things forward. I will say one final thing and then shut up. If there was more focus on---. You could give accountability to the Primary Care Trust, for instance. Primary Care Trusts are responsible for the health of their resident population. They are a stable part of the structure of the NHS these days. They could be made responsible for the commissioning arrangements that will bring about the sharing of information from systems that are already in place, because there are many systems that are already in place that could share information and there is no focus or requirement or accountability for bringing information on GP and hospital systems into a single view at the local level, and you could stipulate that as an objective so people could be getting on with what they could be

getting on with whilst they are waiting for the delivery of the products that would come via the national programme.

Q521 Charlotte Atkins: We certainly hope that PCTs are now a stable part of the system?
Mr Burns: I am sure they do.

Q522 Charlotte Atkins: And I am sure that one of the advantages is that, of course, they are closely in touch with GPs, and I think that is one of the issues that we have been picking up along the way. Does anyone else want to come in on this issue?
Dr Markham: On the issue of the ambitiousness of the thing, I entirely agree that the roll-out certainly of PACS has been much quicker than it might otherwise have been. It was happening, and it would have happened, and it has certainly happened much quicker, but to give great big contracts to a small number of suppliers was always going to be a problem because not only do they have to supply the machines and the software but they have also got to supply the personnel for the back-up of the installation, and that was always going to be challenging. One thing that we have not mentioned yet but has been a challenge is the fact we have no unique identifier in England, and that is a huge difficulty because we have to be terribly careful, and this is one of the reasons why at the moment we cannot share images across the borders, because we have not got that unique identifier. They have in Scotland, I understand, but not in England.

Q523 Dr Stoate: Surely, we all have an NHS number. Why cannot we use that? That is a unique identifier: you are given it at birth; you keep it until you are dead.
Dr Markham: Apparently the technicalities of issuing them are too challenging at the moment.

Q524 Dr Stoate: One number per person up to 60 million. Can they not count to 60 million?
Dr Markham: If you have someone coming into A & E at night, for instance, badly mangled in a road traffic accident, you have to have that number issued instantly before you could image them—that is the challenge; it has to be like that—and you can get your NHS number, if they have not been imaged before, because it would be a bit like a grandfather clause. Babies could have it but people that are not in the system at the moment may or may not have it, particularly in my area of the country which has a high immigrant population. So the actual technicalities of getting it at two in the morning would be a problem, and there are other minor technical difficulties. I gather there is a push to get it approved, but, of course, all trusts have had their own numbers which they have used and they are reluctant, unless they have a central directive, to change to a new identifier.

Q525 Dr Stoate: Can you briefly explain how Scotland has managed to achieve it and we have not?
Dr Markham: I am not in Scotland, but apparently they have. It is called the Community Health Index. The Chief Medical Officer, so I understand, has decreed in the middle of last year that this is what should be used, and I understand it is working well from my Scottish colleagues.

Q526 Dr Stoate: I just do not understand what the difference is between a Scottish unique identifier based on a patient and an English unique identifier.
Dr Markham: What they have used in Scotland is the date of birth with four digits after it, and they are assured that that is unique. What is more, when England does get one, which we sincerely hope it will, then it will not overlap, so there will not be a conflict of people who go across border for healthcare, but that, I understand, is the problem.

Q527 Chairman: Can I ask a question, Mr Burns. You said earlier that PCTs are a stable part of the structure these days. NPfIT has been around for quite a while now, and we have had not just the restructure of Primary Care Trusts but particularly the restructure of SHAs. We have now got the LSPs that are delivering in the new restructured SHAs. In your view has that been one of the problems of getting cohesion with in terms of the national programme, that there has been this restructuring inside the National Health Service, particularly at SHA level, or it did not matter?
Mr Burns: I do not think so. I think the reasons for the slow progress are the reasons that have been discussed. It is to do with the national contracting model. My point is that I have a fundamental view that there needs to be a genuinely local approach to the development of clinical IT, because that is where most healthcare occurs. There needs to be some local accountability for ensuring that patients have reliable records and for ensuring---. PCTs at the end of the day are responsible for commissioning healthcare. They are responsible for commissioning healthcare from providers who are competent, who employ competent staff and who have competent and up-to-date systems running their organisations. If it was the PCT, for instance, that was responsible for managing the public debate about information sharing, as I have said in my evidence, this Committee has spent a lot of time discussing security and I think it has spent so much time discussing security because of the plan to build a clinical database at national level; I think that is the only reason you have been having the debate, because they have gone for a national model with the Summary Care Record. If they pursue a local approach to development of a Detailed Care Record, which would resolve the problem of local access for emergency records, I think the local debate would be entirely different because you would be able to explain to people why their own GP needs to share information with a specialist at the hospital to which they are being referred and why those two individuals need to share information with the Macmillan nurse, the nurse specialist, the respiratory care nurse, whatever the professional, because they can understand the context, because

the context is for their own care in the local healthcare system, and in that context I think the public would be much less concerned. In fact, our experience is that the public expect that we do that and they are quite appalled that we do not, and the one thing that the public do constantly get absolutely sick and tired of is ricocheting around the local healthcare system from the specialist hospital to the general hospital to the GP to the nurse specialist telling them the same story time and time again and finding doctors relying on them, as was evidenced before, to give them information about what happened the last time they saw a doctor. It is a complete indictment of the lack of progress with support in the clinical process with information technology. So, I think if the discussion about access to records out of hours, shared records was all in a real world context of a local healthcare system, I do not think you would have had the debate that you have had about security. It is because somebody is wanting to do this through a national debate that you then have to have a national debate about security, and if you have a national debate about security, then you find yourself talking to national experts on security who, in my view, could spend 20 years in a locked room and never come up with a solution to perfect security.

Professor Feehally: Two comments on local accountability if I could. Firstly, I am not sure PCT is the right level. What it has to be is a local health community which is big enough to reflect where people with chronic conditions are looked after, which is primary care and often a number of hospitals over quite a wide patch—that is where you need to get the accountability that they will work together to solve that—but I absolutely agree with the point about people's understanding of the necessity of this as opposed to the risks of this. I will leave you a single example. In Salford, where I know they have put in a clinical management system, which they have done themselves, nothing to do with Connecting for Health, they started in diabetes and they now have a system across the whole of primary and secondary care for everyone on the diabetes register, everyone on the coronary heart disease register, everyone on the chronic kidney disease register. They had patient engagement while they designed it, they asked everybody on those registers if they were willing for their data to be in and there were no refusals; so that makes the point exactly. If people understand this is about their local healthcare, it is completely self-evident that they would want to be on that record, whereas if they think their data is going to some vague national space where somebody they do not know might use it, they get sometimes anxious. That is a very important point.

Q528 Chairman: I assume, on that basis, that you are largely in favour of using information technology for chronic disease management. That is one of its great potentials.

Mr Burns: Absolutely. Given the amount the NHS has to spend on chronic conditions, in that sense it is its greatest gain, both at the individual clinical level and in terms of the use of NHS resources, by far the greatest gain.

Q529 Mr Campbell: Mr Burns, you have touched on Detailed Care Records, but can I press you a little bit further. You said, instead of having electronic patients record, we should have detailed electronic patient care management systems. Can you explain what that actually means?

Mr Burns: Yes. I will try and give you an example. In my own hospital, for instance, my own former hospital—I was there a long time—we had a system whereby, for instance, if a radiologist reported something sinister on an X-ray she could use the system to automatically alert the relevant clinical nurse specialist, who would then take steps to make sure that patient was seen in the chest clinic. So, this is the technology actually not just recording what has occurred but helping in a proactive and positive way the proper management of that patient. Another area, if you said to me, "Which is the single biggest clinical benefit in my view of proper clinical management systems?", I would say electronic prescribing systems in hospitals, which are as rare as hen's teeth at the moment in the NHS, but the Department's own evidence to you gives you some very graphic statistics about the amount of harm that comes to patients from prescribing errors or poor prescribing or prescribing where there are contraindications for prescribing. When you have paper systems the doctor literally, with what is in his own or her own head, writes a prescription. If you have got an electronic prescribing system that has some intelligence attached to it and you write a prescription for something and that system knows that the patient has got diagnostic results that suggest that that prescription might be contraindicated, then the system will tell the doctor, or can tell the doctor, or the system can say, "This medicine should not be prescribed to patients with these contraindications", or the prescribing system will automatically compute the dose for prescribing for children where body mass is important and many, many errors are made. I wish more people would spend more time looking at the website of the National Patient Safety Agency and look at the detail of the adverse incidents that occur in the NHS, a huge number of which, in my view, relate to poor sharing of information, the absence of information, the misreading of information. A huge amount of that could be eliminated by the use of proper clinical management technology. All that is different from simply providing a record of something that happened historically.

Q530 Mr Campbell: That is all local stuff, and I understand where you are coming from, but then again, if we look at the element of NPfIT which is furthest from even getting started along with the local, they are not on the planet at the minute. How do you get them brought together?

Mr Burns: Yes. What I have just described, very inadequately, because I am not a doctor, and I am sure my colleagues could give better examples, is exactly what the clinical staff in the NHS are looking for—systems which actively support their care of the patient, not just things that passively record what they have done to the patient. But even the passive recording and the instantaneous availability of what has been done to a patient to everybody else that is looking after that patient is part of the process of providing safe care, but it is the absence of those systems at the moment, especially in the hospital setting, that is creating the clinical cynicism and disengagement, in my view, but I defer to my medical colleagues here.

Dr Markham: Perhaps another example is, for instance, if I do an ultrasound scan I see a liver which looks abnormal. Now, this actually might be normal for the patient. If I had access to a blood test, or if I knew something in the past history, I could instantly look at that and say, "Yes, okay, that is relevant. This does need further investigation", or I could say, "Oh, that is because the patient is slightly obese." I would have access to the information that would tell me that. In other words, it is information that is there that might not originally have been thought to be relevant but I can get access to the information that way. Does that answer your question?

Professor Feehally: Let me give you another example, a simple one. It would be great if I could access the GP system and when the patient sits in my clinic know what medicines they are actually taking and know about the blood test result from last week, but even better would be the patient sees me in the clinic, I need to adjust the blood pressure medicine, I make the dose change on the computer so it is immediately in the GP's surgery, but, further more, that patient needs a blood test in two weeks to ensure that the change in blood pressure medicine does not upset the kidneys. I put that on the computer. At the GP's surgery when they open up the system the following morning there is a flag that says, "Mr Smith: blood test 14 December". It will happen. It is moving from information through to clinical management. That is what you are after.

Q531 Mr Campbell: That is what we are hoping for and we are hoping at the end of the day we can work locally and nationally, but the indications are that it is not quite happening at the moment. I do not know whether it is teething problems. Will it happen?

Professor Feehally: It will happen more quickly with local accountability. I am absolutely sure of that. If the local health community for the last five years had known they had some opportunity for resource to do the things they were wanting to do anyway, as Frank said, if we had seen a bit of the 12 billion, I think there would have been real local progress already. Not to the level I have described perhaps, but something which generated momentum and excitement and expectation amongst the clinical community.

Mr Burns: There is no doubt that the contracts that NPfIT have led have the intention to deliver those sorts of systems, but whether they will be as sophisticated by the time they are delivered, because they are being delivered over an extended period of time and requirements will change in the meantime. I think the real fear is that there is a frustration that what we have described is not yet available and looks to be many years away in some parts of the country, and that is not an overstatement, and there is a secondary fear that when it arrives, because it is being provided to hundreds of organisations—it has to be a common system for hundreds of organisations—if it is not quite what people want, it will take another three years to get any fundamental changes made to the configuration or functionality because it is being implemented over such a large-scale.

Q532 Mr Campbell: Is that the problem? It is such a large scale. It is too big?

Mr Burns: Yes, I think so. There is a counter view, and they have the counter view, there are many other people and it is laced through all the evidence you have that many people think that the schedule of it was too ambitious. It is an impractical scale on which to implement something as complex as supporting clinicians in their day-to-day work. That is a common view. It is not the only view; there are other views that if contracts on a national scale---. I think that is a legitimate view but it is undermined if what you are contracted for is not delivered very quickly and is not very good when it is delivered.

Q533 Dr Naysmith: What sort of conversations do you have with Richard Granger?

Mr Burns: I have never had a direct conversation with Richard Granger.

Dr Naysmith: I think that is a pity.

Q534 Chairman: Can I ask you a related question? You were on this system—you have now retired but it is still your hospital, the Wirral—that your clinicians are very happy with and obviously we have not seen it, or any evidence of it, but it is managing patients, it is good for patients as well as good for the clinical staff who are working there. Did anyone ever ask you whether NPfIT would be compatible with your system or your system compatible with NPfIT?

Mr Burns: No, but given that the model they went for---. The fact is all this conversation started on the basis that they went for a national contract which was bound to leave them with huge problems of inter-operability between the large amount of computing capacity that was already in place, despite what is being said to the contrary, and the systems that were secured. That was always inevitably going to be, and they must have known that and they must have factored that into their calculations and timescales and all the rest of it.

Q535 Dr Stoate: I am very interested in looking at the level of detail required for you to do the sort of job you are proposing. You are seeing someone in the renal clinic with diabetes and many other complex health problems and you are suggesting that you have access to a significant chunk of the record. Are you saying you want to see exactly the

same record that the GP has in front of him when you see your patient in that clinic? All I am looking at is the level of detail you need.

Professor Feehally: I cannot see any reason not to really, because you merely add complexity by excluding bits, and it will be multi-screened. I will not go to the gynaecology page because it will not be a particular issue for me, but I cannot see why at the local level one should not share all the information. The notion that the primary care would withhold a bit from me would be as odd as the fact that I might not know there was an orthopaedic operation last week on that patient. It seems to me that open sharing of information for those involved in direct clinical care from first principles would be right.

Q536 Dr Stoate: I happen to agree with you. I am a practising GP and I would be delighted for you to get involved in adjusting somebody's dose of medication, because at the moment what happens is that you would write me a letter, I would get that letter probably a fortnight later, by the time it has been typed in your hospital department. It gets scanned in by one of my receptionists and then shredded and ends up on the patient's record as effectively a photograph. I have then got to read that photograph manually, find out what you suggested, enter that manually onto the patient's record and then take the action a fortnight later, which actually is prone to so many steps of error it does not bear thinking about.

Professor Feehally: It is self-evidently the right way to go. I do not think there is any doubt about that.

Q537 Dr Stoate: The question I want to ask now is how close are we realistically to that? Is the programme even heading in that direction or are we miles off course?

Professor Feehally: I think it is heading in that direction. I am aware that, for example, the clinical manager tool, which is one of the interim solutions, which is the one that has been put in in this Salford application I described, does pretty much most of those things. I have seen it in action just as an observer and you can get that kind of information and you can talk to each other in that kind of electronic way. I think there is the potential to do it, but it is back to this problem of national solution rather than getting people to do things locally: because if we were in the same health community we would self-evidently want to engage and make it happen. At the moment, in so many places, people still have this helpless sense of waiting for the solution to be given to them to then implement. That is the way it is done.

Dr Markham: There is a good example of what is happening at the moment. There is a lot of effort being put in to a common request form for Choose and Book and in this there is an argument about what questions should be filled in by the general practitioner and what will be needed. The good example is MRI imaging. It is becoming clear that we need to have some knowledge of the renal function of a patient. If we had access to the general practitioner's records or, indeed, the records for the local hospital, we could look it up ourselves when we needed it rather than relying on the general practitioner going through his records and putting it down on a national request form. So, that is a good example of where this huge amount of work is going on at a national level for this, which would not be unnecessary.

Mr Burns: There are examples, it depends what degree of integration we are looking for, but we have to work on the basis that a move---. If this is an incremental thing, I suppose it is part of the philosophical debate here about whether you go for big bang national solutions or incremental growth from local systems, but there are places in the country where they are uploading to a different information system from GP systems and the local hospital systems on a 24-hour cycle so that GPs and hospitals in that community can see that integrated information, and there is local agreement amongst the clinicians about what the clinicians usefully want to see from the record of the general practitioner. There has been a local discussion about what the local GPs would like to see of the hospital record and what the specialists would like to see of the GP's record. Some people would disagree with my colleague about the need to see absolutely everything, and, in fact, it may well be that that would make the debate about confidentiality a bit more problematical if, for instance, social care records or family histories or stuff in the GP record that could usefully stay in the GP record was available outside, but all of that can be agreed locally. The debate could be had locally with the community about what should be on the shared record. It would give the community a greater sense of influence over that process. There are structures in place for those debates at a local level, the Local Overview Scrutiny Committee, where you get some democratic influence on these decisions, and we have done that on the Wirral. There was a debate, the Local Overview Scrutiny Committee was involved, there was an agreement or an explanation about what would be shared and why it was being shared. We did develop a publicity campaign in the local community and virtually nobody objected.

Q538 Dr Stoate: You talk about expert prescribing systems which actually we have been using in general practice for years.

Mr Burns: Indeed you have.

Q539 Dr Stoate: Why is it then so difficult for the hospital simply to replicate what GPs have had on their desks for a long time? What is the problem?

Mr Burns: I do not know. The processes are different.

Q540 Dr Stoate: Why? When I prescribe a drug, lots of menus come up, but one of the menus is the interactions, which you cannot get past—you have to okay the interactions screen before you are allowed to proceed—and if it is a high level interaction, for example, Methotraxate or a complicated drug, you have got to go through

several steps before the machine will allow you to prescribe because of the level of interaction. That is not complicated. Why is it different?
Mr Burns: One of the difficulties is that most of the prescribing in hospitals is done by doctors in training, not by fully qualified people, so there are safeguards that you need in place to support that, but electronic prescribing actually provides greater safety. It has always been the most difficult nut to crack.

Q541 Dr Stoate: But why? I still cannot get round why.
Mr Burns: It is partly to do with the leadership, and my two colleagues here might not agree with me, but it is partly to do with the resistance of senior hospital clinicians to the introduction of changes to their working processes that fundamentally affect them directly and require them to, if you like, action the prescription, and understandably so. As you know—you are a doctor and I am not—you can do a lot of harm with drugs, and, therefore, it takes an awful lot of persuading for a community to see its clinicians move away from a tried and trusted system to one where they are relying on a computer.

Q542 Dr Stoate: It has been tried and found wanting, because the current system—
Mr Burns: The current system is a disaster.

Q543 Dr Stoate: The National Patient Safety Agency will tell you that there are hundreds and thousands of mistakes each year.
Mr Burns: I agree.

Q544 Dr Stoate: So, the current system has been tried and found wanting?
Mr Burns: There has not been enough will, either managerially or politically. It is not a priority of NPfIT, and it should be one of the first things that are rolled out across the hospital service (electronic prescribing), but there is not the managerial or political will, and I think there are also issues about the numbers of systems that have cracked the particular way in which hospitals need to prescribe.
Professor Feehally: As you might expect, I am still an enthusiast of such systems, and some of those points may be true in some trusts and also a simple one which comes back to money. There are so many things we would have loved to have done over the last decade in IT development in hospitals for which there was also no resource, and there is still no resource because it is sitting nationally. I have no doubt at all that with the dispensation of some of that resource locally you would have seen a lot of change in growth.
Mr Burns: It is interesting that the Department of Health evidence in which it extols the importance of using IT and the importance of the work that NPfIT is engaged on quotes directly the benefits of electronic prescribing. As far as the hospital side is concerned, electronic prescribing is the very last in the list of things that are going to be delivered by NPfIT, and there are people who fear they will never ever be delivered?
Dr Markham: Can I come back to one of the problems which I think may be behind this. I have alluded to it before. It is the lack of back-up of IT staff within trusts. The PACS system has just been rolled out across my trust and we have had three people who have been across three different sites with about 20 different consultants, let alone hundreds of radiographers trying to use the new system, and they are extremely stretched; whereas I think in general practice you have got much more direct access to the people that are sorting out the system. Certainly when you sit there and something does not work, you ring them up on their mobile and you find that they are at the trust four miles away, and that has been a big barrier to convincing staff at the hospital that this is definitely the way to go and this is how they should do it. It really is quite frustrating when you know all these wonderful things that you could be doing but your brake is the lack of IT back-up because of the lack of staff and the expertise available, I suspect.

Q545 Dr Taylor: Anybody listening today and reading a lot of our evidence would think that the only good thing NPfIT has done is to produce 12 billion. I want to try and explore the ways in which it has delayed things. Is it fair to say with electronic prescribing in hospitals that many hospitals were on the verge of doing this quite some years ago and that this is one of the things that NPfIT has delayed?
Mr Burns: I would not say that. To be fair to NPfIT, I think introducing electronic prescribing into hospitals—take it from me, I have been there—is a really difficult challenge, because there is so much nervousness around switching prescribing to electronic systems. It is worth the effort in persuading people, because the systems are so much more reliable and safer, but it is very difficult and I do not think it would be fair to say that we would have wall to wall electronic prescribing in hospitals if it had not been for NPfIT. I think that would be unfair.

Q546 Dr Taylor: At Homerton we learned last week that, although they have got a pretty good system, that was the one thing they still did not have. Going on to the radiology front, I know that CT scans have been available at the local neuro-surgical unit for 20 years plus. Did you say that that was being jeopardised or put back by NPfIT in any way?
Dr Markham: There is no doubt there is a difficulty. The arrangement for the clusters, which was NPfIT—these are the areas in the country that have had the providers and they are the areas that have been rolled out—London is one, the South of England is another, the East is another, and that side of things going nationally has jeopardised things that were already in place. For instance, apparently there was a thing before I was in the South of England called the Shire's Consortium, and that was a very co-operative area in the South of England which was ready to go on PACS, communicating between each other, and that was stopped because they had to go on to the NPfIT system. It has rolled out very quickly, and I think parts of the country

that were not as well organised as that, I think it has speeded up with the availability of the finance, but there is no doubt there have been instances. For instance, only just now Truro can now communicate with Plymouth and back, whereas before they could not communicate quite as easily, but that has stopped for a while before it has got going again.

Q547 Dr Taylor: Coming back to PACS, because we have talked quite a bit about it, it has been available since the early 1990s.
Dr Markham: Yes.

Q548 Dr Taylor: So where has the delay come on that?
Dr Markham: Part of it was computer technology. It very much developed in line with computer technology and the storage available, and the acquisition of the images and the storage of the images, if you like, did not roll out as quickly, but it was very much financial and convincing people who had machines that produced hard film that they were going to have to ditch all that and go electronic. That was a big financial investment. Once the advantages were realised, once the radiologists convinced the trust that this would be a great advantage, and the clinicians, because they are now entirely enthusiastic, they have got their work station in the clinic and they can see the images and they can see the reports and that is great, but it took a lot of convincing, I would say it started to roll out towards the middle late nineties really.

Q549 Dr Taylor: I think it was the intention that PACS should be available nationally. Would that have been a good thing?
Dr Markham: You mean connecting up nationally?

Q550 Dr Taylor: Yes?
Dr Markham: Yes. There is no doubt it would be useful. It is a question of where your priorities are, but, as one of my colleague said before, the vast majority of health interactions are relatively local and, yes, you do get people going down to the South West for their holidays and their care is maintained back at base in Newcastle, or wherever, so there will be instances where it is useful, but what has happened at the moment is, largely because of this unique identifier, you cannot transfer images like that; and there is an enormous industry at the moment with people burning CDs, putting the images onto CDs that then get sent to the hospital that might be two miles down the road and then they find they cannot open it because the technologies are not compatible to open it, or there is some problem or other, and then they have to ring up and say, "Can you tell me over the phone what the report was?" All that type of thing is, in my mind, much more important than the relatively small number of people who will be going from one end of the country to the other.

Q551 Dr Taylor: Is the roll-out of PACS pretty well complete now or are there places that still—
Dr Markham: Yes, the North West and the West Midlands is delayed, because there were some contractual problems initially, I believe, but I think about 70/75% of the country is now covered. The full potential is not there just yet. One of the difficulties that was perhaps mistaken at the beginning was that, although the PACS image thing was national, the radiology information systems were not and the interface between those has been challenging. So, although the images were okay, you were trying to interact with your previous films and your previous demographics, and that is still a problem in many places and many places have a radiology infrastructure that does not match.

Q552 Dr Taylor: Have old films been archived digitally?
Dr Markham: Many have, yes.

Q553 Dr Taylor: So the old X-ray departments and stores of X-ray films in the cellars and things are gradually going, are they?
Dr Markham: Gradually going is the way to describe it, yes, absolutely, and the vast majority of previous images are not accessed after about three years; so inevitably we will get less and less.

Q554 Dr Taylor: Obviously PACS has changed the way radiologists work. Has it changed the way other clinicians work?
Dr Markham: We believe so, because they, again, have instant access to the images. A patient can go from A & E, a film is taken and immediately, without the patient having to come back again, the image can be there for the doctor to look at. My colleague will obviously be able to tell you better, but certainly our clinicians are very enthusiastic about it.

Q555 Dr Taylor: Have you got the ready availability of X-rays in all your clinics of any of your patients all the time now?
Professor Feehally: It works. It makes a clear and unequivocal difference. It improves patient care.
Jim Dowd: I would refer to the questions on PACS, but I think they were covered more than adequately in the early part of the session and so I will not delay you any further.

Q556 Chairman: I questioned you (I am talking to Frank Burns now) about the issue of what happened on the national organisation, as it were, versus a local Detailed Care Record in many circumstances. I know you have retired now and I do not wish to upset you in any way, but if you were in charge of Connecting for Health tomorrow what immediate changes would you make to the organisation of the national programme?
Mr Burns: I am not ducking that question, but I think a lot of this depends on the nature of the contract that has been struck. If you are asking me what my wish-list would be, that is a different question to what is practically possible, given that there are contracts in place with the LSPs and with software suppliers. I suspect and I hope that it would be possible---. Without that knowledge about what

the contracts allow for, certainly in some parts of the country that depended, for instance, on hospital system software that is not yet developed, not yet available, may not be deployed in terms of the clinical functionality until we are into the next decade, if that is the realistic position (and it looks to be the position for some parts of the country), then I would think it absolutely imperative that some options are made available to those parts of the country, that some way is negotiated, either on an interim or on an entirely permanent basis, to give parts of the country with excessive delays in the availability of clinical functionality and resources—. The resources are all locked up in NPfIT, and that is the problem locally. Nobody can do anything because NPfIT has the money. I would look for a way of making resources available in those communities that have got an unacceptably long time to wait for clinical systems and try and find a way of giving them choices of clinical systems. There is a supplementary contracting process going on, as I alluded to before, where NPfIT is identifying IT suppliers with systems that I think are described as "step-in systems", so they have systems, if you like, on the shelf if they have problems with current suppliers. I would move from "step-in" to "alternative" in circumstances where the delivery of clinical functionality is unacceptably delayed. I would certainly want to look at why—. There are parts of the country where they have procured a system that is up and running that does have decent clinical functionality but does seem to be taking an age to be implemented, and you would certainly want to have a good hard look at implementation timescales in those parts of the country where potentially decent systems have been procured, and there certainly are parts of the country where that is the case. I think the other thing I would do would be to make PCTs, as they are accountable for the health of their populations, accountable for commissioning arrangements to allow information sharing electronically between the organisations that they contract with for the care of their residents. In other words, I would introduce a local focus on the sharing of information and, if you like, remove any obstacles to the procurement of technology that maximises inter-operability between existing system and allows information sharing between existing systems. I think the structure of the contracts makes that very difficult currently.

Dr Markham: If I had a wish, the unique identifier, because until that is in place---. For instance, there is a trust down the road with extra capacity. They could do some of our reporting if we could send the images. We cannot do that until we have a unique identifier, and also the trust would need to be mandated to use that rather than using something different; so that would be a practical step forward.

Professor Feehally: I think something that has begun to happen which has been almost stealth-like is worth commenting on, because for so long from our perspective we were told that the national programme would deliver everything and we would have a system that would replace everything. Now, as you have heard, within the last few months there is a tender out for so-called additional services capacity, which are effectively interim systems which will be compatible with the final solution, which is a recognition from them that they cannot do everything. That is fine, but they need to be talking to people like us about what are going to be in those interim systems and people like us need to be helping them to get the functionality right. So, I think my single wish really is communication with clinicians over that particular thing but, in general, that they come down from the mountain top and we really engage and they begin to learn to help us understand what they want to do, because we have not got it yet.

Q557 Chairman: Could I thank all three of you very much indeed for coming in and helping us with this inquiry. I am not sure when we will be reporting to the House and the Government, but it I hope it will not be too long.

Witnesses: **Lord Hunt of Kings Heath,** a Member of the House of Lords, Minister of State for Quality, **Mr Richard Granger,** Director General of IT for the NHS, and **Dr Simon Eccles,** National Clinical Lead for Hospital Doctors, Department of Health, gave evidence.

Q558 Chairman: Good morning and could I welcome you to what is the second half of our fourth session on taking evidence in relation to the Electronic Patient Record. Could I ask you for the sake of the record if you could introduce yourselves and let us know what position you hold.

Dr Eccles: I am Dr Simon Eccles and I am a Consultant in Emergency Medicine at the Homerton Hospital in Hackney. I am acting Clinical Director for the National Programme for IT and I am one of the national clinical leads for secondary care.

Lord Hunt of Kings Heath: I am Philip Hunt and I have ministerial responsibility at the Department of Health for the National Programme for IT.

Mr Granger: I am Richard Granger and I am the NHS IT Director.

Q559 Chairman: Welcome. I have just got a few questions to ask to open this session up in relation to the Summary Care Record. You will have seen no doubt some of the evidence that we have been taking, both written and verbal evidence, in relation to this inquiry and we have heard a number of different answers about what information will be included in the Summary Care Record. Could you tell us definitely what will be included in the Summary Care Record?

Lord Hunt of Kings Heath: Can I ask perhaps Dr Eccles to take that in detail. In basic terms it will start off with information from the GP practice

regarding medication, allergies and adverse reactions. The expectation is that it will grow richer in time but I think perhaps Dr Eccles might like to give a more detailed response perhaps about the uses it is put to.

Dr Eccles: The information on the Summary Care Record when it first starts—as you know we are starting in Bolton at the moment—contains centrally held, specific demographic information on the patient, current address details, date of birth, contact numbers, the NHS number (which means you can uniquely identify individuals), contact preferences (including things like preferred language) and their consent status for the record. The initial upload from the GP summaries of clinical information is medications, allergies and adverse reactions. That upload is by implied consent. The next upload of information, following a discussion with the general practitioners, will be a summary of key medical information—past medical history, important procedures or operations undertaken. What that minimum information set contains is being derived at the moment by a group headed by an A&E consultant in Bolton using GPs, patients and others to derive what is that most helpful list. That is going to be a part of the evaluation process: Does that work? Is that the right list? The next stage—and we are still in 2008 at this point—is the capacity to take discharge information from hospital settings, whether that is in-patient discharge summaries, clinic discharge letters, or emergency department discharge summaries. So what the GP believes are the most important things wrong with you; medications and allergies; and, every time you have been in contact with secondary care the information exchange between GP and secondary care, what I hope, as an A&E consultant, is the most helpful block of summary information. If I have a critically ill patient in front of me that is what I would look for in the notes now, so that is what we are going to provide.

Q560 Chairman: Is it intended to support scheduled care, unplanned care, or both? What is its intention?

Dr Eccles: Its primary role is supporting unscheduled care so when a patient appears at a setting where they are not currently known and their main records do not presently exist—that would be emergency departments for the sake of speed; GP out-of-hours centres where records are currently sketchy (and there has been some recent publicity of some unfortunate occurrences as a result of poor information); walk-in centres; ambulance personnel and others would have access to this information. I can also see it being used during the transition phase in hospitals where you cannot get the patient's main record. To have access to that summary would be very helpful. And, of course, it would be used where patients transfer over geographical distance, so if they are on holiday elsewhere in the country that is the only record you may have.

Q561 Chairman: What about the issue of Secondary User Services and the Summary Care Record?

Lord Hunt of Kings Heath: Clearly the information in anonymised form that becomes available could be extremely helpful in auditing quality and in enabling research to be undertaken into areas of illness. We of course understand that it has huge potential for researchers in the future. It clearly has ethical and practical considerations too, and we have had two working groups, one which has published looking at the technical aspects, such as anonymisation of data, and a second one that will shortly be published on some of the ethical considerations. There is a rich mine of information which, if used appropriately, could have a huge benefit in terms of understanding our knowledge about the quality of care but also in terms of research into future developments, and I think that secondary use is a terminology which I know has been commented upon. It is not a word I am very comfortable with. I think that treatment goes alongside research. One of the great strengths of our National Health Service has been the quality of its research base, it is why so much R&D resource is spent in this country, and I think the potential positive benefits that have been defined under the terminology "secondary use" really do go hand-in-hand with effective treatment and care.

Q562 Chairman: Are patients currently in the early adopter schemes made aware of that?

Dr Eccles: It is indeed referred to within the leaflet on—I am going to seek confirmation. Unfortunately, I have not got it with me.

Q563 Chairman: It is important to have a leaflet!

Dr Eccles: It is important, if I tell you it is in the leaflet, to make sure that it is.

Q564 Chairman: I will take your word for that.

Mr Granger: The information in the Summary Care Record is not feeding into the secondary usage service; it is sourced separately. At the moment they are isolated.

Q565 Chairman: Summary records could be used for purposes of research?

Mr Granger: Eventually.

Q566 Chairman: That is why I asked the question. The other thing, Simon, you said earlier about the adverse reactions, prescriptions, allergies and everything that will be in it. All that information will only be added to the record with explicit patient consent and patients will be able to see what is added; is this correct?

Dr Eccles: Let us be clear on what is happening. The implied consent, the automatic update, is purely medications, allergies and adverse reactions. The reasons for particularly taking those fields is that it was felt from widespread medical and patient consultation that they are the lifesaving fields. Indeed, according to the National Patient Safety Agency, they are the second largest cause of adverse events to patients. The next step, which is the GP-derived summary of important health information, we are recommending is done in consultation with the patient and the patient is shown what is proposed

to be sent up and agrees that that is the case. We will be evaluating that model and that is an independent evaluation from University College London: Are we picking the right information? Is the process by which we are gaining patient consent the right one? Is it too cumbersome or is it too stringent or is it too lax? We think it is the right blend.

Q567 Chairman: If you add some information about that patient in that area at a later stage will that have to be consented as well?
Dr Eccles: What we would hope in that early consultation is that patients will usually—and that certainly seems to be the evidence we are getting at the moment—give their express consent "I am happy for you to continue to add information to this record unless as my GP you think it is clearly of a sensitive nature, and I have outlined to you that for example sexual health issues I wish to keep separate from this, but otherwise if I come in and see you and you diagnose me with diabetes we do not have to have the whole conversation again; I perfectly accept that that goes up to the record." That is how we are expecting those conversations to take place.

Q568 Chairman: Could I ask you what access I will have as a patient to my Summary Care Record if I agree to have one?
Dr Eccles: This is the biggie. This is the purpose of HealthSpace and it is one of the biggest benefits of the Summary Care Record. You as a patient will be able to see your record and everything that is on the Summary Care Record for yourself via a secure website called HealthSpace.
Lord Hunt of Kings Heath: Can I add to that, the great advantage of HealthSpace is alongside having access to your Summary Care Record there will a whole host of information about health, and my own view is that it has huge potential in helping people take control of their own health. More and more people are interested in health issues and we think this HealthSpace has very exciting potential. Having access to your own Summary Care Record as well will add to the importance of this and I believe the use of it by patients.

Q569 Dr Stoate: I wanted to ask Simon about the logistics. You have talked about effectively sitting face-to-face with patients and there are going to be 2,000 patients on average per GP. You have then got to sit down with the patient, discuss what the implications are about building the record, you have then got to make some judgment as to what gets uploaded, you have then got the logistical problem of actually sifting through the GP record and somehow moving the data from the general GP record into some uploadable form. All this is pretty resource intensive. Have you considered literally the pros and cons of how you are going to do it?
Dr Eccles: My colleague Gillian Braunold thinks of little else on a day-to-day basis I am reliably informed.

Q570 Dr Stoate: She needs to get out more, does she not!
Dr Eccles: We could not do this without her. You are absolutely right that we need to make sure that the logistical process is as straight forward as possible. That is part of the reason for this minimum data set that is being gathered together at the moment by GPs, by patients and by A&E staff in Bolton, in conjunction with all of the early adopter PCTs and the potential early adopter PCTs. So it is not just Bolton. We are asking all of them to give us the list of what we should automatically pull from the GP record into what we have got on our demonstrator programme. It is quite a clear screen that says this is what we are going to send up, if it is okay with the patient. You print a copy of that out and give it to the patient, "Read this at your leisure and see if you are happy with it." They have a 16-week timespan in which to contemplate that as a patient, approve it and then come back to their GP and say, "Yes, I am happy with what you plan to send up," or, "Take some items out," or, "Why have you not mentioned the back pain . . . "

Q571 Dr Stoate: I am just going to stop you there. That is now two consultations with the GP both of which are quite detailed so that is half a year's average GP contact time for a patient just on that one issue. I am very concerned and I would like to know what work you have done on how you are going to say to a GP you have got to do half your annual consultation with that patient on this one issue.
Dr Eccles: I do not think we will, I really do not. The majority of patients will either be given that print-out or will request it from the receptionist staff at the front, who will hand it to them in an envelope without a consultation. For most they will look at it and say, "That's fantastic," and will sign it off again without a consultation.
Lord Hunt of Kings Heath: It is also worth making the point that we have the evaluation being undertaken by UCL and clearly the whole purpose of that is to learn lessons from the early adopter sites so that can then help us feed into the next stage of rolling out the programme.
Dr Eccles: As Gillian just kindly pointed out to me, the reason we are doing it this way is that the group we want to get first, and most importantly, is those patients who have the largest body of disease because they are the ones for whom it will be most helpful for out-of-hours settings where an acute or chronic exacerbation of their existing condition at the moment results in our starting again from scratch and amending a carefully described plan of treatment that the GP and the hospital spend ages getting right and we in A&E, through—I would like to point out—no fault of our own, adjust that for the emergency and change it for the patient. We will catch them because they have many more than just two consultations a year. We are using diabetic clinics and we are using nurse practitioners, who are seeing patients for all of these conditions, to have those conversations. I do not think the burden will be that high. I do not know that for certain and that is what we will be evaluating.

Q572 Dr Naysmith: You will be very well aware, I am sure, about the concern there is about iSoft's Lorenzo system. When do you expect it to be widely available.

Lord Hunt of Kings Heath: Perhaps I could ask Mr Granger to answer the details of that.

Mr Granger: We expect within the next couple of weeks the first live running of Lorenzo Version 3 software to be working in Germany in Aachen. And we expect the first live secondary care versions of Lorenzo to be available next year in the NHS in England. Also on the topic of iSoft, there has been a lot of speculation regarding the corporate structure that will support iSoft in fulfilling its NHS obligations. The situation at the moment is that the organisation with whom we have a contract, which is not iSoft, it is in fact CSC, is in the latter stages, which I hope will conclude satisfactorily, of ensuring appropriate funding and management control to take the now largely completed code and to test it and get it into a state of readiness for putting it into production. I understand that an associated transaction involving an Australian company, IBA, is also near to satisfactory conclusion with iSoft and IBA. I would hope that those three companies will be making an announcement about that in the next few days. Should that fail, we have third party resource present now to take control of the NHS delivery components on a step-in basis under our contract, which will force CSC to step up to the plate of ensuring properly financed and managed completion of the Lorenzo product for the NHS.

Q573 Dr Naysmith: The question was not so much about when you will have a prototype ready but when it would be widely available to those areas which are depending on it?

Mr Granger: It will start to be rolled out next year. One of the challenges in healthcare IT is that it is pretty easy to get a good solution working in one hospital if you throw enough money at it, but when you come to re-tender that solution, it often ends up being unaffordable. The sites of excellence that the NHS had pre-2003 have all faced that challenge. They have run independent tests in many cases and the costs have been unaffordable. One such example is the Wirral where on re-tendering their very good local systems have had to go with a national solution, and indeed one with an American software supplier. In the Homerton their contract was transferred to BT for the same reasons—that it is difficult to sustain excellence even on a limited basis locally. We will start rolling out the Lorenzo product next year. I expect there will be some difficulties with the product in the early sites and it would be misleading to suggest otherwise. It will, through the last part of 2008 and over the next few years, then be rolled out across the rest of the sites that want it.

Q574 Dr Naysmith: Are the on-going delays with Lorenzo your biggest problem? I know you have got lots of other problems.

Mr Granger: I think the biggest problem is finding time to manage a Programme which is subjected to so much negative examination.

Q575 Dr Naysmith: Is that not because it is not working?

Mr Granger: No, I think it is because there is a lot of mythology being generated by people who would like to see it fail.

Lord Hunt of Kings Heath: If I could comment on that. Clearly taking over responsibility for this programme at the beginning of this year I have been struck by the degree of negative comment and clearly it is a feature of many IT procurement programmes, but I think if you look at what has been achieved over the last few years, particularly if you look at some of the developments that have had a real impact on quality of patient care such as PACS or the start of the electronic prescription service, or getting broadband connection for the whole of the Health Service, or a quarter of a million staff with their own email address on the NHS system, or the quality management system to enable information in GPs to be properly assessed, or the work we have done on the Summary Care Record, it is a very solid body of achievement. Now you are right, there are also challenges. We know that the Summary Care Record is later than we would wish but that was because of the extensive debate there had to be with clinicians about what should be in it. We know the challenge of Patient Administration Systems, particularly in hospitals with existing systems, as you have inferred, is a particular challenge, and we knew that was going to be the case. However, in terms of where we are, I strongly believe that we have a very strong foundation on which to go forward. If I can look back because, as you know, I have responsibility for IT—

Q576 Dr Naysmith: I want to ask another question related to this one which will enable you possibly to say something else. The Millennium system seems to be much further advanced and seems to be working much better. If it is successfully implemented and Lorenzo is further delayed, will you allow hospitals outside London and the South to implement the Millennium system instead? Would that be a possibility?

Mr Granger: Yes, definitely. One of the reasons that, unlike a number of other organisations, we did not choose a single solution from a single supplier where we were able to have some contingency within our resourcing arrangements was to deal exactly with the risk of supplier failure. Perhaps the best example of that is in the picture archiving arena where we initially chose an innovative product from a company called ComMedica to implement in the North West and West Midlands. Unfortunately they missed nine key milestones and their contract was terminated by CSC and they were replaced by the contractor GE that was already serving the south of England. We will by the end of this year have got most hospitals in the NHS running digital imaging systems. It is important to note that when they were being bought locally with 16 different systems being procured, most of which were not compliant to the standard that enables images to be read on competitors' systems, in five per year were being put

in. We do five some weeks now, so the procurement model does work and it does deal with supplier failure.

Q577 Dr Naysmith: It is interesting in the session just prior to this it was said quite clearly that there was a system up and running in the Wirral which is at least as sophisticated as what you are trying to put in nationally now and possibly more sophisticated. That was also happening at the Homerton which we saw last week, so what is happening in this national procurement programme is seeming to be blocking local initiatives which have been working extremely successfully, and perhaps this concentration on the national model and also on the summary patient record, which seems not to necessarily have been the most important thing, seems to be delaying progress rather than making it. Finally, Philip and then I will let you come back, if we have got large areas of the country which are waiting for a system to come in and it is not coming in because it has been consistently delayed and other parts of the country have successfully implemented useful local management systems, which everyone tells us is what is more important than being able to deal with the odd problem that happens when you are on holiday in Cornwall, this is going to be a real disaster for the whole thing, is it not?

Lord Hunt of Kings Heath: I wonder if I could make some general comments and then ask my colleagues to comment on the specifics. The two things I would like to say is that I do not think we should underestimate the potential of the Summary Care Record in everyday clinical practice and not just in the circumstances as you have described. The more general point is that I look back to many years' experience with the NHS's approach to IT and the fact is that at the beginning of this decade, if one looked at what has happened in the NHS, it simply was not making sufficient progress. There were these islands of excellence. I am enormously admiring of Frank Burns's contribution to that in the Wirral but the fact is as a whole the NHS was under-investing, it was developing systems that could not be integrated, it was very patchy in its approach, and I think that national approach that we have taken was absolutely essential in terms of ring-fencing the resource, giving it the priority and ensuring that the NHS did move in step. Clearly there will always be issues that individual organisations will think, yes, we might have done better, but I do think you have to look at the NHS as a whole. The way IT had been in the NHS over 20 years simply would not have done the business and that is why I am convinced this approach has been the right one, alongside a contracting regime which does transfer risk to the local service providers, which again is, I believe, a model of what ought to happen in public sector procurements that has not always happened with previous procurements.

Mr Granger: I have just a couple of things to add. The Summary Care Record is going to be the first port of call for the 115.5 hours a week when the GP practice is shut, so I think it is quite a useful instrument to have regardless of whether you stay in one place or move around beyond your immediate place of domicile. In terms of the excellence that has existed in islands in the NHS, I said in 2003 that what we were about was trying to get that implemented in more places, and that remains the challenge. So where we only had 50 sites in the NHS with digital imaging over a ten-year period, we have now probably got less than 50 sites that do not have it. So it is about trying to build off those islands of excellence, all of which have problems with affordability, the standards they use and the extensibility of what they are doing onto a national basis. So you can do very, very good work with very good clinical engagement at a local level but every time those installations have come up for contract renewal there have been serious affordability problems.

Q578 Dr Naysmith: It is not surprising if all the money is going into a national system.

Mr Granger: If you look at, for example, the Wirral, maybe you should go and look in detail at the cost of replacing that system through local procurement. It was entirely unaffordable. The same was true of the Shires procurement when that was running on a regional basis and that was also true in Blackburn and Bradford. So a number of data points show that you cannot afford to buy these rich systems in every NHS site because you do not get any economies of scale from the supplier community. So it is not about all the money being spent nationally. It is about the unit costs being too high if things are bought locally.

Q579 Dr Naysmith: Just finally on this, all the evidence suggests that if you do it locally you can engage the clinicians much better and this is something that is not happening everywhere with the national system. What do you say to that point?

Dr Eccles: "You are quite right" is the one-line answer to that, but there is the problem we have just heard outlined. I am a committed fan of the idea of a national programme, despite having just agreed with you that a system that a local hospital goes out and buys for itself will always be loved much more than one that is apparently given to them by the Government, however generous that may apparently seem. Why am I a fan of a national programme therefore? Because we were not getting on with it in the NHS. You have seen what the financial figures for the NHS have been like over the last year. Without a national programme with separate Treasury funding I do not think there is a cat in hell's chance that we would be upgrading the IT systems to the point we needed to get to had we done it on a one-by-one trust-by-trust basis. What I find fascinating working at the Homerton with the Cerner product, and it works and it is part of our day-to-day function (you have come and seen it) is when I bring groups of clinicians from anywhere else in the south of London to have a look at the Homerton system, their answer is: "I want it. I want it right know. When can I have it? That is fine, we will take that product please". It is a question of trying to get that clinical message back through the management structures of the trusts and then

through the Strategic Health Authorities. Do not strip off those clinical functions. Do not see this as an IT project, "Do not see this as simply a patient administration problem. This is better patient care and this is saving doctors' time and effort, they do like the product. Give them the whole of that". That is what we thought we were doing, that is what we were trying to do. Understandably, local hospitals reconfigure it to suit themselves and occasionally make a decision that I would regard as flawed, that they are going to just take the Patient Administration System, the pure IT only project and not the much wider clinical benefit programme that I think they should.

Q580 Chairman: Could I just ask, you were the Minister responsible for the national IT programme from 1999 to 2003 and then you have some respite. You are now six months into your second phase, what have been the positives and the negatives coming back in again and looking at the programme over two years on from when you left it?

Lord Hunt of Kings Heath: Respite including heroic stewardship of the Child Support Agency and its IT programme. I think I know a little something about some of the challenges of big IT programmes and I would draw a distinction because what it does seem to me in drawing parallels is that the way the national programme has been developed has very much emphasised ensuring that as much of the risk is transferred to the private sector as it ought to be and, secondly, "derisked" in terms of not going for heroic dates when everything has to go live, that it has been very, very carefully planned and executed and I think those are very much to the credit of the IT team. I am absolutely convinced that without that strong national direction the NHS would be nowhere near where it is at the moment in terms of progression. There is nothing to suggest from the history of the NHS that left to its own devices it would have invested sufficiently in IT, nor would it have dealt with the need to ensure that there was integration. It is on integration that so much depends in terms of patient safety and quality. A lot of the programmes are proving to be very successful indeed. I have mentioned them already and I think that they are being used by clinicians on a daily basis. There is a lot of enthusiasm in parts of the NHS in terms of their use and implementation. I would say there are four major challenges. There are the two programmes that we have already discussed, the Summary Care Records and the Patient Administration Systems particularly within hospitals, and clearly those are major challenges. I am sure that it was right to spend more time preparing the ground for the Summary Care Record. We will see the results of the evaluation but I believe that was time well spent. We have seen too many IT programmes in the past where an over-ambitious target has been set, it has been introduced too quickly, it has not got ownership amongst the people involved, and the technicalities will often not be right. On the Patient Administration Systems, this is a huge challenge. It was never going to be easy for hospitals to change from their current multi-faceted systems, if I could call it that, to the new systems but again it is working through. We are seeing systems delivered quicker and the next two or three years will see a huge advance. The two other areas that I would identify as really major areas for my own attention are the issue of clinical buy-in that Dr Naysmith referred to and the issue of local commitment by the leaders of the NHS. On the clinical buy-in we now have a very good programme. In the National Programme a lot of clinicians are involved. They have an essential role to play. Equally, the Committee may recall that going back to the beginning of the national programme I invited Dr Peter Hutton to chair a group to encourage clinical buy-in and I believe that did very good work at the beginning. I met with the Academy of Royal Colleges a week ago to discuss establishing a joint group which I will co-chair to ensure that we do get buy-in at the senior level. Locally we need individual NHS trusts to do the same and I think that then comes to the issue of getting strong management support for IT and for implementation of the programme. David Nicholson, the newly appointed (some months ago now) Chief Executive of the NHS has made it absolutely clear that IT is to be one of the top priorities for the NHS over the next few years. We have now given a clear and explicit responsibility to Strategic Health Authorities in terms of their accountability for local implementation. In all the meetings that I have been involved in and David Nicholson has been involved in engagement with chief execs of the local NHS organisations, we have emphasised that this has to be one of the most important areas of responsibility that they are involved in. I think the big change that I have noticed in the four-year gap has been the much stronger buy-in by senior managers, both nationally and locally. We need to make sure that clinicians locally are also brought into the process.

Q581 Chairman: When you look at the whole history of the National Health Service over the last 60 years and its culture as an institution, why was that not one of the things that was done in the early days? It seems to me that would be something that would be so obvious particularly when it was going to be a national programme?

Lord Hunt of Kings Heath: I think that if you look back, one of the problems of IT historically is that many senior managers in the NHS did not give it the priority it deserved. That was one of the reasons why we went for a top-down national programme. I make no apologies for that because I come back to my earlier point, I do not believe that unless it had been driven and driven hard from the centre we would have made the progress that we have. We have moved into a new stage of the programme where it becomes ever more important that there is local ownership, and I think now is the time that we really do need to get the managerial buy-in. I am confident that we are now getting it.

Mr Granger: The Programme was initially led by a doctor—Professor Sir John Patterson. The clinical aspects of the Programme were then led by another

doctor—Dr Adrian Halligan. We then set up a panel of national clinical leads including three doctors. The specification exercise involved hundreds of doctors whose names were in fact made available and the organisations they represented to the PAC last year, so it is not the case that there has not been clinical and medical leadership of the Programme. The challenge has been getting people locally interested in something which was in the future. They get most interested in it when it becomes disruptive when a product is about to be delivered; when training is required and when staff rosters need to be altered and so on. The challenge is getting them interested early enough. I think one of the pieces of evidence you received contains a complaint from a specific group of doctors that it is impractical to make seven days available over a two-month period for input to design. The continuous paradox that we face is getting people that are caring for patients involved early enough with the disruption that causes to their lists. I think it is difficult. Undoubtedly, at a small scale you can achieve that more readily with local installations. What you cannot then achieve is ubiquity of local installations because you only get installations in a limited number of sites, so the 105 community hospital and community PAS systems we have put in you do not hear a lot about. What you hear about are the difficulties we have in the acute sector getting that level of clinical engagement. You do not hear about 10% of GP systems replaced. You do not hear about the dozens of sites every month where we roll out picture archiving systems. You only ever hear about the problems and those problems are most severe where the clinicians are most busy managing against their whole set of targetry. Getting those people involved early enough is going to be an on-going problem.

Q582 Charlotte Atkins: When we visited Homerton Hospital last week I think what we were very impressed by was the clinical engagement, but that was clearly developed very much on an incremental basis because this has been developed over a number of years. I think the other thing was that clearly the trust had been contracting directly with the system supplier so there was much more of a management buy-in and also development of a system which would reflect local needs. How is that going to be replicated when you have the national programme because inevitably there is going to be one-size-fits-all kind of approach?
Mr Granger: You saw two systems at the hospital Simon works at. You have also seen a PACS system.

Q583 Charlotte Atkins: Yes.
Mr Granger: So it is interesting that you can put a PACS system in on a standard product in every single site in London now and you have a PAS system which was bought locally, and the same would be true of University College Hospital, but both those contracts now in fact are run by BT. So you come back to this paradox of the necessity of strong local leadership and management ownership, which David Nicholson is addressing through the NLOP Programme of putting targets for this activity on to trust and Strategic Health Authority chief executives with a necessity of buying things at a higher level in the NHS in order to make them affordable. So we have to do both; it is not an either/or. The Homerton has now transferred its contract to BT so that it can get some economies of scale and have the systems managed on a professional basis with the relevant levels of resilience and so on. This is also part of the problem of doing thing locally, as those trusts that endured the Buncefield Oil Depot fire and no IT systems for two weeks through a locally procured systems (with significant data loss) can probably testify to you.
Dr Eccles: The big thing I hope you saw at the Homerton was that this was seen as a clinical project. It was led by their clinical staff. It was chief executive level decision. This was not run by the finance director and the IT department as an IT project for cost savings.

Q584 Dr Naysmith: This is what we are particularly worried about because Mr Granger was saying that the other two areas we were talking about—the Wirral and so on—were unaffordable and what worries me is this very issue that it is was not finance driven, that it was clinically driven, and therefore you have got a system that actually works with clinicians being involved on a hands-on basis with the system. I am worried that with a national programme you will get a one-size-fits-all which means therefore you will not get a clinical buy-in and you will also not get the hands-on approach which we saw at the Homerton.
Lord Hunt of Kings Heath: Of course you probably will not get the systems because you hit then the unaffordability issue which we faced back at the start of the programme. Mr Granger has already referred to the Shires and the programme in the West Midlands where there was clinical engagement. I met many of the clinicians involved and they were very enthusiastic but you ended up with a situation where it simply was not affordable. There is no easy answer to this. There has clearly got to be a balance between the benefits of a national programme in terms of the value for money but also the strength of a national contracting process aligned with doing as much as possible to get local buy-in to it. There is bound to be a tension there.

Q585 Dr Naysmith: There is bound to be a tension but are we learning the lessons from Homerton, not just in terms of the clinical buy-in at a hospital level but also clinical buy-in at the GP level, because what we saw there was that they could not work electronically with the GPs?
Dr Eccles: With regard to the first of those, yes, I think we have been learning the lessons, as you rightly point out, from the Homerton both within London on its patch and indeed across the whole of the South where that particular Cerner product will be deployed. Myself and Michael Thick, the Chief Clinical Officer, have been round many of the live sites with Cerner having those discussions. What we have seen is where there have been elements of that

that have not gone as well as they could have done, that is usually because those lessons were not followed even though they had been very well-described. The second point I want to make relates to what you described as the one-size-fits-all. I do not want the impression that the product simply arrives in a box and that is exactly what it looks like and there you are. That is not how it works. There is a huge degree of local tailorability to it. What matters is that, underlying it, the architecture of how tests are ordered and patients' details are moved around the hospital and the coding that applies to the disease process, are stored in a very clear, logical way and is then compatible with GP systems at the Spine and elsewhere. However, on top the layer that you look at can be tailored hospital-by-hospital and eventually group of clinicians by group of clinicians to the sort of view that they wish to have. That is true both of the Lorenzo product and of the Cerner Millennium product.

Q586 Dr Naysmith: But each of the hospitals under the national system will be working through a local service provider rather than dealing with the systems people direct. Will that lead to a lack of buy-in and also a system which is not as well-tailored to their needs as we have seen with Homerton and other hospitals? Clearly we want a national programme which is cost-effective but there is no point it being cost-effective if it does not work properly.
Mr Granger: I think we have some hard choices to make. I think you have been to see the Veterans' Administration. Did you have a discussion with them about the degree of variability they allowed between sites? Because the answer was none.

Q587 Dr Naysmith: Absolutely and what is more there is no option but to buy in.
Mr Granger: But that has given them a system which has a lot of very useful clinical information at the point at which decisions are made. If we would like to indulge ourselves with 200 rich local systems across the NHS we not only cannot afford them, we will forever be locked into information not being moveable between locations. There has to be a balance struck between standardisation and localisation, and, unfortunately, some of the desire for local variability is simply not affordable. When we computerised Social Security in this country there were 600 or so local offices in the DSS many of them did things differently. There is now one national Social Security system in fact for the UK not just for England. It is quite interesting to imagine that we are going to allow every group of clinicians and every group of managers in every NHS trust to do everything as they so choose.

Q588 Dr Naysmith: No, I do not think we are saying that at all. I think what we are actually saying is if this is going to work we have to have proper clinical buy-in and we all know, do we not, that doctors can be pretty difficult characters and doctors have a huge amount of power in the NHS, and if we are not going to get them buying in then it is not going to work properly. You mentioned the Veterans' Administration. Yes, of course we saw the system but I do think the Veterans' Administration is somewhat different to the National Health Service one because being ex Services they are more likely to be compliant around their records so I do not think there is a direct comparison there. What we are concerned about in the Committee, given that we are putting so much money into this national programme, is that it works. That means we have to have proper clinical buy-in and we cannot cut those corners.
Dr Eccles: And we are hitting the tipping point that I think will make the critical difference. Lord Hunt and Richard Granger have made the point that it is extremely hard to get good clinical engagement with a piece of paper talking about an IT system. It is exceedingly hard. It is very hard for the NHS to release people. It is very hard to get people excited about it. What you tend to get is the people who are very interested in IT, which is fine, but the people I want to get engaged are the people who loath IT because if it works for them it will work for everybody else. As soon as you have begun to get the systems rolled out in the enthusiastic early hospitals, at that point everybody switches on that this is real, it is going it affect them, they can go and see it, they can see it at a neighbouring institution and at that point if that is going to come to my hospital I want to get involved in the committee that is designing it for my hospital and tailoring it and I want to be part of it. We have to get past the point of visibility to get the bulk of clinicians engaged. It has been my job for the last couple of years to try and get doctors engaged with an idea. They are very enthusiastic about the idea. They are not necessarily enthusiastic about giving up huge amounts of their time to fine-detail Excel spreadsheets to make it work. Now that they can see it, it is much, much easier to get people enthusiastically engaged, and they are enthusiastic. In secondary care we have overwhelming support for getting this in. People want it but they want it to work for them, and you are quite right on that.

Q589 Dr Naysmith: With Dr Eccles involved I hope that we have some chance of making it work.
Lord Hunt of Kings Heath: If I can comment on that. Clearly one of our strengths is that we have a huge network of clinicians who are involved. I do not disagree at all with what you are saying about the need for local clinical engagement, I understand it fully. I just think that in terms of the history of the National Health Service that experience shows that the best way to do it is to start with a national programme, get the investment in, get the clinical engagement. I am convinced that we have got the architecture right. If you are saying we need to do more with clinicians, I agree with you. I do believe that the renewed drive, the priority, the targets that have been set for Strategic Health Authorities will absolutely require chief executives to do that. I also think that, as Dr Eccles has said, the more clinicians are using some aspects of the new system the more champions we have. Of course there is this question

of where do you reach the tipping point, where do you get the momentum that really does get that critical buy-in.

Q590 Dr Stoate: As a practising doctor I know exactly how clinicians think. Clinicians are all in favour of progress; it is change they cannot stand! You might think that that is facetious but actually it is true. You will get buy-in to the point where it starts to disrupt the way they do things and that is when it starts to clash. Choose and Book is a great example. I think most GPs in principle are very happy with Choose and Book. If it interferes with the way they do their work and if it clunks along and causes them problems, they get angry with it. It is not the principle; it is the practice they have got problems with, and those are the issues we have to smooth out. What I wanted to talk about was this dichotomy between central and local buy-in, if you like. I understand the point you are making, Lord Hunt, about the fact that we have to with economies of scale use a central system to drive progress, that is fine, and we also know that clinicians like local systems. GP systems now have been decentralised to the point where GPs can choose their own supplier. How much further do you intend to go as part of this programme in decentralising as much as you possibly can? Do you have anything in mind that you are going to further decentralise?
Mr Granger: One of the interesting things about the decentralised GP systems is the paradox of the excellent support that they give to you as a GP in the building in which you deliver care and how incredibly useless they are in all other contexts. So they are not very useful for you as a GP in the patient's home; they are not very useful for you as a GP when you are doing a session for an out-of-hours service provider; they are not very useful for your patient when they are anywhere else; and they are not very useful for 3.3 million patients when they change GP a year.

Q591 Dr Stoate: So why have you let GPs have different systems?
Mr Granger: We have been trying to walk a difficult path between real inter-operability between competing suppliers who talk the talk about information exchange between their systems and then deliver systems which are fundamentally incompatible with the previous versions of their systems and with their competitors' systems.

Q592 Dr Stoate: I was going to ask you about that because you have put in this RFA compliance that they all have to meet the specifications, and presumably they all do, and yet the point is that none of them is compatible with each other and if you migrate from one GP system to another you lose unacceptably high levels of data.
Mr Granger: I think we are coming to a point with a variety of key information around the issuing of prescriptions, around the making of bookings, around the verification of demographic data where we are using HL7 Version 3 standards which means that if the other countries in the UK want to step on to the arrangements we have they will be able to because these are international standards. They are not English standards, so that is dealing with a number of real-time information exchanges. We are also at a point now where the GP-to-GP record transfer programme, which along with RFA pre-dates the establishment of a national programme, we are getting to a point where we are getting good information transfer between competitor heterogeneous GP systems. We had some difficulties with the GP contract in 2003 and the national programme running in parallel and the interpretation of the words "choice of system". We bought a choice of system but we did not buy the fact a GP could have any system they so chose. I think we are finally getting to the end of that problem by having a number of compliant systems, but it is no different to the hospital sector where the greater variability of systems and the cost of testing those systems militates against serving the interests of people who want information to move between GP practices.

Q593 Dr Stoate: I am not disagreeing with you; the point is why have you allowed this to develop knowing, as you do, that you will cause yourself some more problems?
Mr Granger: We are trying to strike a balance. We recognise that a lot of GPs do not want to change the system they have got because it supports them very well and is delivered by people who understand what they do. At the same time we want systems which support their patients in multiple locations.

Q594 Dr Stoate: You have not got that, so how will you get that?
Mr Granger: We are getting there with that. If you look at the work that TPP have been doing, for example, where we have now got 10% of GP practices properly hosted in professionally run data centres—

Q595 Dr Stoate: Is that your vision then, to have hosted data for GPs?
Mr Granger: Yes, and that is exactly what EMIS is also pushing towards.

Q596 Dr Stoate: That is your vision for the future, is it, for GPs?
Mr Granger: Yes. I do not think having servers sat in GP practices with a whole pile of maintenance problems, and difficulties accessing, information on them out of hours, serves the way people wish to be cared for.

Q597 Dr Stoate: Are you confident that will actually work because the connectivity between GP practices and anything outside the building is not very reliable at the moment?

Mr Granger: Is it not?

Q598 Dr Stoate: No. At the moment, for example, Choose and Book is, to say the least, slow. If I had to run my entire clinical system using some sort of broadband connection as they currently are, I would have real difficulties.
Mr Granger: 10% of GPs in the country now do that and I do not hear them complaining about the speed of performance of their TPP applications or their network connection. If you take some of the legacy GP applications there are some problems with the way they have configured their system to operate Choose and Book. This is not a Choose and Book problem and not a network problem. It is a legacy application configuration problem.

Q599 Dr Stoate: In summary, you want to go down the route of more uniformity eventually so that these systems have effectively less choice but more compatibility, is that what you are aiming for?
Mr Granger: Yes.
Lord Hunt of Kings Heath: What you have really described is the same discussion that we have had before, the trade-offs here. There have had to be some trade-offs with the GP community and you see some of the downsides of that, which is the variability. I think it very clearly illustrates the debates that we are seeing but in the end we have to have a system that really works together rather than the problems that you have described.

Q600 Jim Dowd: By nature, I am slightly more optimistic than some of my colleagues. I want to look at the position when the system is in and working and obviously it must then become a permanent feature forever more beyond that. The contracts only have a ten year lifespan. What do you imagine will emerge after that? The system will obviously need upgrading, it will need improvement, it will need software new releases, *et cetera*, who is going to be responsible for that and how is that going to work?
Mr Granger: I would say we will be in quite good shape because we have based the core national applications on the dominant global database supplier, Oracle. And we have based the applications on standards which are becoming dominant global standards. In terms of local provision we continue to have contestability so we should not have the problem of having to effectively bribe the market to compete because we will not have a monolithic national standard. With the central systems where we have got one supplier there have already been numerous upgrades and that is just business as usual. Because we are operating to international standards in terms of the messaging structures and applications and so on, we should well be able to run healthy competition there. Because of the adoption of these standards and, which was not without pain having had to set up an international body for data standards, for example, SNOMED CT, we will be in a position where the systems we are using will be similar to the systems being used in other jurisdictions. If you look at what is going on with the regional health organisations in the States, which are effectively pilot operations at the moment, they are going to step up to those standards when they start doing things on a more robust and industrial scale.
Lord Hunt of Kings Heath: I was just going to say what is really exciting is we are clearly going through the pain barrier at the moment, it certainly feels painful, but, as we know, the more clinicians engage, the more benefits they get and the more enthusiastic they become. By 2010 the health service will have made a significant advance and, of course, the momentum will be there and it will not want to stop there because people will increasingly see the benefits. I believe that alongside the national infrastructure that we clearly will need to develop and take decisions on in due course, we will also get the essential enthusiasm at local level in terms of using these systems. There is not much point in doing this unless we can see at the end of the day improved safety and quality for patients, and patients will increasingly see a really fantastic service as a result of all these changes.
Dr Eccles: I would take a slightly different line from my two colleagues, which is we will have got used to it and in consequence we will be complaining about it bitterly, that it takes up to three seconds to get a CT scan from the neighbouring hospital and you have to sit there and wait for ages looking at the egg timer and how disgraceful is that.

Q601 Jim Dowd: That is irony, is it?
Dr Eccles: As broadband gets faster and faster you still keep complaining it is not quick enough and we are going to be where the patients will expect their records to be instantly available whenever they change GPs and if it takes two days they will be complaining about the two days rather than the three months it takes now. On Dr Stoate's comment that we like progress but we do not like change, we are going to see the innovating hospitals, the innovating individual clinicians, taking the systems we have got and sprinting into the distance with them designing generation after generation ahead. And some of their colleagues will be sticking with exactly the core product they have been supplied with and will not change a thing for the next ten years after that.

Q602 Jim Dowd: Is not the danger that that takes us back to exactly the position we are in now and trying to escape from?
Dr Eccles: No, absolutely not. If I take a transport analogy that we are moving everyone to either Mondeos or Vectras, and we will get there in ten years' time and everyone will have them, at the moment some have vintage Bentleys and an awful lot have rickshaws. We have got to get to a common level and that common level is actually world class. There is not another country that will be in the state we will be in at that stage, we will be ahead of the game and the NHS, I think, can genuinely be proud of the change in quality of care it can provide as a result. Moving forward from there is easy, that is a good thing. We have got everybody on to an

electronic environment using a common coding set across the whole of the NHS with free movement of patient data with permissions as appropriate. We can do research off that in a way that no-one else, except possibly Sweden, can at the moment. That is absolutely brilliant. If some people start innovating from there others will copy them. Yes, there will be one or two who will stay where they are at that point but that is a hell of a long way ahead from where they are now.

Q603 Jim Dowd: It was put to us today that there is a philosophical divide here as much as anything else insofar as we should have just waited to see what worked elsewhere and utilised that rather than attempting to—
Dr Eccles: Why would we want to be last?

Q604 Jim Dowd: --- rather than attempting to create the international standard to which others will aspire. I accept there are probably irreconcilable differences and you will not be able to say which is right unless, of course, it does become world leader. Can I just test that for a moment from the taxpayer's point of view. The experience so far has been a reduction in the number of suppliers and participants. You said earlier, Mr Granger, that it is possible—I will not say highly likely, one has to be very careful about this—that as Millennium works and Lorenzo does not we might wind up with simply Millennium everywhere as regards the hospital-based EPR systems. Is there not a danger that we will have a reducing number of participants, people able to supply and support the system and, therefore, the ability for the taxpayer to extract maximum value from any upgrades or changes in the future will diminish?
Mr Granger: That is a risk. Of course, there are no prizes for the NHS not having already fallen into that trap. Nobody says, "Oh, it is quite good actually that you recognised that in January 2003 when you published a procurement strategy that you were not going to immediately become reliant on one supplier for everything". Of course, the Department of Health in 2002 was full of large corporates walking up and down the corridors talking to people, imploring them to just turn the whole lot over to one supplier and, indeed, to TUPE out around 20,000 frontline IT staff from NHS trusts to one supplier. We did not put our head in that particular noose. I do not think we will end up in a situation where we have the Millennium product across the whole country but we do have difficulty attracting the interest of competitor patient record suppliers. One of the other major suppliers has told us that because of the variability in the NHS they are just not willing to supply to us. It is a company called Epic who have some good systems but they say they are not willing to work with the NHS while there is this degree of self-determination amongst frontline clinical groups because their experience with Kaiser Permanente has been that you have to have a sufficiency of standardisation in order to be able to put the same software in across multiple institutions. Else you end up with incompatible datasets and an inability to move information to serve patients between primary and secondary care and, indeed, tertiary care. There is a danger there but I think we have mitigated that as much as we can.
Lord Hunt of Kings Heath: To put it bluntly, we are developing a world class system and we need world class suppliers to work with us. The situation ten years ago was that we were doing basically a cottage industry which would not have the capacity or, I suspect, financial strength to be able to support the NHS in the way that we wanted for the national programme. I also think that the contractual arrangements have allowed us to transfer risk to the local service providers and that is a big contrast to many other public sector procurements on IT where the client in the end has accepted the risk and then often had to pay considerably more amounts of money to make fixes to get the system right because they did not get the specification right in the first place. Clearly, I think the contractual arrangements that we have established put us in a much stronger position and we want to continue to do that.

Q605 Chairman: Can I just ask you about the NPfIT Local Ownership Programme. You have given the responsibility for that to the SHAs to implement but the contracts are actually held by Connecting for Health. Is this not responsibility without power?
Lord Hunt of Kings Heath: Mr Granger might want to talk about the details of the contracting process, but I do not think so. Obviously we expect the local service providers and other contractors to work closely with a Strategic Health Authority. They well understand that accountability has been transferred to the chief execs of the Strategic Health Authorities. David Nicholson and I have stressed to the NHS the importance of taking this seriously. If there are problems they will be dealt with. I think it has been a very good thing to have done to get that buy-in at the regional level. It will also ensure at the local level, with the chief executives of the trust, that there will be the absolute right, strong engagement that we need for the next phase of the programme.
Mr Granger: Out in the NHS,in the SHAs in the north of England, the Midlands and the east of England, the six SHA CIOs—chief information officers for the Strategic Health Authorities—meet with CSC directly, with procurement contract experts and, indeed, technology experts present. They recently dealt with some contractual issues around the achievements and milestones on Lorenzo on a collaborative basis. The same thing has always gone on in London with a CIO for the Strategic Health Authority London—originally there were five SHAs, if I remember rightly, and now one. In the south the three SHAs recently appointed an individual with responsibility for managing the implementation of key systems there for Fujitsu and she, in fact, is leading the re-planning exercise for release one of the Cerner product with changes to the functionality that have been requested by frontline clinicians. We already have SHA personnel dealing day-to-day with key contractual management issues in collaboration with CFH people and frontline staff from trusts.

Q606 Dr Taylor: Can I go back for a few moments to clinical buy-in because it is marvellous to have enthusiastic national clinical leads, to have enthusiastic local champions and, Lord Hunt, you said huge networks of clinicians involved. We seem to have a knack of picking on the clinicians who do not feel involved. We have had one this morning from the Renal Association who feels distinctly uninvolved in that he has tried to get involved and failed. I would take exception really to Richard's comment that critics want the system to fail; certainly the medical critics do not want it to fail. If I can quote one or two bits out of the Renal Association's evidence: "We are therefore strongly supportive in principle of the development and establishment of electronic patient records" but then they give a litany of complaints: "Connecting for Health has failed to assure the renal community that its strategy respects clinical need as well as technical solutions; failed to develop an understanding of specific IT needs of ours and other specialist health communities; eschewed opportunities of early wins by demonstrating benefit in chronic disease management; and threatened the survival of specialist clinical software suppliers who understand well the needs of the healthcare community". They are not alone, we have had other evidence from groups of clinicians who feel distinctly disengaged with the system.

Lord Hunt of Kings Heath: If I could make a general comment and ask Simon Eccles to comment on the details. Medical organisations are many and varied and they are not backward in coming forwards. Inevitably, in any major programme such as this you are never going to be able to satisfy every specialist group to the degree that they would think necessary. My role as minister back in 1999, 2003 and now is to make sure that the programmes we have established do allow for considerable clinical engagement and the submissions that are put forward are considered and then to make sure with David Nicholson that people out in the service understand the importance of clinical gains at local level. I am not going to say that this is perfect, nor indeed do I think it would ever be possible to meet all the needs that every specialist body produces, but I do think that what has been achieved, starting with the work going back to the start of the programme and more recently with the clinical champions and discussions with various bodies, is a very good foundation. I want to improve on that and that is why I have agreed to establish a high level group with the Academy of Medical Royal Colleges, which I will co-chair, to make sure if there are concerns they are heard by me and we make sure that we do engage as much as possible. Perhaps I could ask Simon Eccles to talk about the specifics of how—

Q607 Dr Taylor: You have actually answered that and I want to move on to Detailed Care Records. Surely the real priority for improving patient care is to have the Detailed Care Record readily available at local level. We have been looking at security and somebody this morning repeated that security is really only a problem because of the widespread nature of the Summary Care Record. Why have we focused so much on the Summary Care Record, which from our demonstration at Richmond House a week or so ago looked to be merging much more into a Detailed Care Record? Why do we not keep the Summary Care Record as a single field with the demographic, the allergies and the crucial things, and then really work to develop the Detailed Care Record which nobody yet has been able to tell us exactly what it will be? That is what I want to know, what exactly will the Detailed Care Record be? Are you actually working pretty hard to get that available because this is what will improve patient care?

Dr Eccles: Yes, it will. They both will. The Summary Care Record is a subset of the Detailed Care Record. It is not one or the other. All the information in the Summary Care Record will have come from, and be contained in, the Detailed Care Record.

Q608 Dr Taylor: Are you saying the Summary Care Record, by definition, has to come first?

Dr Eccles: No, no, they could come in either order. They do not hinder each other's development. The Detailed Care Records for an individual patient are currently held electronically in over 70% of GP practices and on paper in each of the hospitals in which they have been seen. If they have been seen in the emergency department they will have a separate record, in maternity they will have a separate record, paediatrics has a parent-held record in addition to their own records, sexual health will have their own record and mental health will probably have their own record. Those comprise your and my current Detailed Care Records and, as you will be familiar with, as I am, they do not always appear in front of the clinician who wishes to see them at the time at which they wish to see them. It is those records we are replacing with Cerner Millennium, iSoft Lorenzo and the GP systems of choice. In addition, in London they are using a separate community system and those are being done slightly differently in different areas depending on the needs they are getting from those. We need to ensure they all integrate with each other, that the information contained and entered into a detailed record once can be used many times in other areas for the care of that patient and can cross those boundaries from primary care to community care to hospital care. When relevant an extract goes to the Summary, so if you have only got one bit you have got the most relevant stuff.

Q609 Dr Taylor: Who are you talking to about the design, particularly when one is thinking of common clinical standards so they have got to be all the same and easy to understand? Who are you actually talking to about the design?

Dr Eccles: Lots of clinicians. I mean lots of clinicians.

Q610 Dr Taylor: Specifically, are you talking to the Royal Colleges?

Dr Eccles: Yes. You have taken the lid off that can. Yes, indeed, we are. My colleague, Ian Scott and I, as the national clinical leads for hospital practice, and Gillian Braunold and Mike Pringle for general practice, have met with all the Royal College presidents, we have met with most of the specialist association presidents and we have a national advisory group to which every specialist association is invited to send members. They do not always come but they are certainly invited. For example, the Choose and Book specialist reference panel has representation from just about all the specialist associations. We have certainly consulted at a national level as far as we conceivably can. I chair a clinical reference panel representing all of the different types of health professional as well as large numbers of patients. There are 26 people on there, to make sure we are not just dominated by the medical professional, for example, learned though we are, we have got to make sure this works for allied health professionals, for nursing staff.

Lord Hunt of Kings Heath: That is why I am going to form this group with the Academy to make sure at that senior level they are content with the degree of involvement and buy-in. As you have heard, there is a huge network of discussions that are going on at the moment.

Dr Eccles: We are doing that equally down at local level for the design and tailoring of the product. There are two big products for UK use. They have got large numbers of clinicians, over 2,000 clinicians, involved in the design, the build, the test and so on of those products at that level. You mentioned specialist systems, renal systems for example, and the Chief Clinical Officer, Professor Michael Thick, was due to meet the Renal Association pre-dating this panel. But in some large hospitals in the South of England, for example, there are over 70 databases held by specialist clinicians, in some cases several databases held within one specialty, because individual consultants cannot agree on the right database to use so they are using their own. At some point we are going to have to agree best of breed here in conjunction with those specialist associations, what we should feed to the manufacturers of that system: "Here is how to make sure it is compatible with ours so that data will flow out of the national system into your database". What I hope is that our system will be sufficient to manage the day-to-day running of patients with renal disease to a high standard. It may not collect every data field that renal clinicians want because they have got some pretty detailed stuff that is not relevant to others, but we let them know how to get that information out of our system. By doing those two aspects I think we will fit the needs for specialist systems.

Q611 Dr Taylor: So are there enough people like you who are going to engage with all of these specialists, the Royal Colleges?

Dr Eccles: That is a very unfair question to ask me! Some would argue I am unique and I would have to disagree.

Q612 Dr Taylor: Sorry, let us tie it down. How many people are there, and I do not mean just like you but equivalent, who are trying to engage with the specialist associations and the Royal Colleges?

Lord Hunt of Kings Heath: We have got about 250 clinicians who are working with us.

Q613 Dr Taylor: Okay, fine. I will move on.

Lord Hunt of Kings Heath: What I would love to see is more local champions of the programme, that is where it is clear from our discussions we want to see more emphasis given in the future.

Dr Eccles: We need to divide the question into, not "You have not spoken to me about the design of the system", but "Have you spoken to people like me about the design of the system?" We may not have spoken to each individual renal consultant but have we spoken to a sufficient body of opinion to get it right?

Q614 Mr Campbell: Do the organisations know the names of these people? Are they given the names of these people, the organisations and the health authorities and trusts?

Lord Hunt of Kings Heath: I am not aware that this is anonymous information, it ought not to be. I will certainly check up because clearly they ought to know.

Mr Campbell: They might not know, that is the problem.

Q615 Dr Taylor: We saw very clearly at the Homerton the enormous importance of the enthusiastic senior clinician right at the top. What are you doing via, I do not know, Strategic Health Authorities, whoever, to try to make sure that there is one such figure in every major hospital who will take it under their wing and convert everybody to it?

Dr Eccles: This is part of the Local Ownership Programme. It cannot be for us centrally to go and start pointing a finger saying, "You are going to be the champion for this hospital" or, indeed, "Send the name of your champion and we will send them files of information". Individual Strategic Health Authorities need to speak to the acute trusts in their patch to identify their champions locally. They must be locally derived champions, if you see what I mean. What we have found is this varies. We have done huge amounts of work centrally to try and encourage leadership. We have a leadership programme being organised by Connecting for Health, we are working with the British Association of Medical Managers to develop leadership here specifically around the Programme and we are talking to trusts. When one discovers a trust which, having put in their Patient Administration System, we ask them, "What was your clinical engagement strategy" and the answer is, "We chose not to tell the doctors", I despair of that.

Lord Hunt of Kings Heath: There are clearly lessons that are being learnt all the time, particularly with the introduction of Patient Administration Systems in hospitals. One of my aims is to ensure that we learn the lessons both good and bad and that is then translated into the roll-out of the programmes.

More generally, if you look at where the health service is going, the introduction of much greater patient choice, given that effective IT programmes assist patient choice and the perception of patients as to the value or success of a particular institution, it has got to make sense for senior management to engage the clinicians because if you have an institution where the clinicians have not been involved the one thing you can be sure is that when the Patient Administration System is introduced it is not going to work very well. Part of the reason for placing responsibility fairly and squarely on the National Health Service is to get that kind of commitment from senior management and it really is a no-brainer that within an NHS trust you want to have a senior respected clinician who is champion of the programme.

Q616 Dr Taylor: What do you say to the critics who say because delivery of the Detailed Care Record is so slow it leads to loss of interest and then loss of engagement?
Dr Eccles: I go back to the answer I gave to Charlotte Atkins earlier. While the product is invisible and coming at some point in the future it is relatively hard to get people enthusiastic. As soon as it is in the neighbouring trust it is much, much easier. Taking a slightly different topic of PFI hospitals, trying to get clinicians involved in the design of a new hospital build, whether it is PFI or anything else, is really, really hard but as soon as the foundations start going in the clinicians all flood in saying, "Well, how is it going to work then?" and it is too late by that stage. What we are hoping is that by having some trusts ahead early and by having worked so hard to get clinicians involved in the design up until now, when it is visible we will have no difficulty in its development which we have got carrying on for the next five or six years.

Q617 Dr Taylor: Are you going to insist on more use of the NHS number? Will that go on the Summary Care Record?
Dr Eccles: Yes.

Q618 Dr Taylor: Is that going to be widely used and unique so it can cross boundaries? We have heard there are problems with crossing to Scotland and crossing to Wales at the moment with the NHS number.
Lord Hunt of Kings Heath: If I can make a general point, having the NHS number as the unique identifier is critically important. It is going to be one of the unseen but huge advances that we are going to make. That is not just in terms of administration but also in terms of patient safety.

Q619 Dr Taylor: Is that included in the demographic bit of the Summary Care Record?
Lord Hunt of Kings Heath: That is my understanding, yes.
Dr Eccles: Absolutely, yes.
Lord Hunt of Kings Heath: On the Scotland and Wales issue, would you care to comment on where we have got to?
Mr Granger: It is currently an issue for devolved administrations as to what indexing arrangements they choose to have. We now have, and have in fact had since mid-2004, an online database with demographic details for the NHS in England. That is already accessible to about 7,000 locations. It has been accessed 319 million times since it went live and about 50,000 frontline NHS workers use it every day. The issue is not about having a highly robust online database which, unfortunately, had to replace a batch system that was rather quaintly implemented in the late 1990s by somebody who submitted evidence to you in defence of antiques, I think. That is not the issue. The issue is getting the plethora of departmental systems to support that indexing arrangement and, indeed, the GP systems reconciling different demographic information that is held locally and nationally. The GPs who use the electronic prescription service or Choose and Book experience that requirement today. We want to know that we have got up-to-date demographic information. We will have to migrate to a properly reconciled unique identifier, it is not something we can do on a big bang basis. Because our demographic information is passing around the NHS in England already on HL7 message standards it is relatively straightforward for other countries in the UK, or elsewhere, who adopt those international standards to exchange demographic information with us with the appropriate protocols. The challenge is their adoption of the standards rather than our systems.

Q620 Dr Taylor: Will that number be different from the current NHS number?
Mr Granger: No.

Q621 Dr Taylor: How close are we to rolling out electronic prescribing, which seems to me to be the single most important thing to improve safety?
Mr Granger: We are already rolling it out and as of last Friday 4,824, ie 56%, of GP practices and 4,397 community pharmacies, ie 42%—

Q622 Dr Taylor: It is hospitals I am really aiming at.
Mr Granger: Okay.

Q623 Dr Taylor: We know GPs are doing a lot of it.
Mr Granger: In terms of e-prescribing systems in secondary care, that is going to come in over the next two to three years. The software already exists in the Cerner application. The initial implementation of Cerner has not put e-prescribing in although the software is built and works in hundreds of hospitals.

Q624 Dr Taylor: Are any hospitals doing it already?
Mr Granger: Yes, with local systems.

Q625 Dr Taylor: With their own systems?
Mr Granger: Yes

Q626 Dr Taylor: Will they have to pull those out to put the new in or will they be able to keep those?
Mr Granger: No. The Winchester system is planning to interact with the Cerner system.

Q627 Dr Taylor: Is it just a handful that is doing it now?
Mr Granger: Yes.
Dr Eccles: Part of the reason for going slightly slowly with this was we had huge clinical engagement on e-prescribing, and quite rightly, because it has got to be standardised. It is really an area where we cannot have local variability. We have absolutely clear critical safety. I do not know if you are aware—I was not until I started doing this programme—just how differently pharmacists, general practitioners and hospital-based doctors look at the same prescription for the same medication to the same patient. We have very different ways of describing the same thing. We can all have our unique view but we have got to make absolutely certain that we end up with the same product being taken by the same person with the same expectations on the part of all of those different professionals.

Q628 Dr Taylor: I am fearfully disappointed really because I was involved in trying to implement it about 12 years ago and it was at that time that we did hit on exactly what you have said, the different perspectives from the pharmacists and the prescribers.
Dr Eccles: We will have it sorted.
Lord Hunt of Kings Heath: If one thinks "What is this all about", number one it has got to be about improved patient safety: here is the clear, real winning goal that we must go for.

Q629 Mr Campbell: Just on that point of safety of patients and dependability of the system, we have been told that when clinical records are remotely hosted, the loss of the hosting centre or the network for more than a few minutes could lead to loss of life. So both the hosting and the network need to be available virtually all of the time. Is there any evidence of this?
Mr Granger: Yes, there is lots of evidence of it. Unfortunately, there are some members of the commentariat who seem to have trouble finding their way to the service availability data that we publish on our website. You may have received evidence from people who do not like looking at published service availability data. I think you had Patrick O'Connell from BT come and give evidence. BT run both the network and the core national messaging systems and there is a very strong body of evidence from the published service availability data for both those pieces of national infrastructure that not only do they work but they have the level of reliability and dependability which is appropriate to the task. We have not had any major network outages since we replaced the old NHS network. The last time there was a significant network problem was when the Royal Victoria Hospital suffered two routers failing as a consequence of them being plugged into a dirty supply rather than a clean supply during a generator test about two months ago. The last time there were any service problems and there were some performance delays, it was taking more seconds than was appropriate to get messages transferred on the Spine infrastructure in January last year, the last time there was a major upgrade, which in fact increased the level of reliability and number of back-up platforms that we used. There is some scaremongering about this which ignores the published data. I think we have been singled out for special treatment here because people do not compare what we have implemented in the NHS with anything else. They just have some abstract "It can't be good enough" set of comments. I would like them to look at the reliability of our core systems and network against other pieces of civil infrastructure. If they have got some evidence that it is wanting on that basis rather than just scaremongering then I would be very happy to go back and review the contracted levels, which the suppliers do meet.

Q630 Mr Campbell: Can I just read this out to you: " . . . .a power failure at the CSC centre last year. 80 Trusts (72 PCTs and 8 hospitals) lost access to records systems when servers failed and back-up systems could not be made to work". That is the evidence we have been given. Was that just a one-off or could this happen all the time?
Mr Granger: That is one part of the country, one set of systems. Three levels of back-up failed, no data was lost and the back-up systems that the trusts had in place meant that care was not disrupted. This scaremongering that this could have a serious clinical safety issue is completely wrong.

Q631 Mr Campbell: So nobody could lose their life here?
Mr Granger: No, not in that situation.

Q632 Mr Campbell: In what situation would they lose their life if it failed?
Mr Granger: I cannot envisage that situation. I do not know if you have received advice from somebody on some strange interaction between a locally run anaesthesia machine, for example, and a Patient Administration System, but that is a bit of a fantasy because it does not exist, or an intensive care system interfacing to a PAS system. The critical systems for patient safety that are run off generator backed-up power supplies in hospitals are a different kettle of fish from systems that contain information that is used for administration and care of people generally not on a real-time basis where frontline doctors have work-arounds and can revert to paper and undertake activities that do not necessitate these host systems.

Q633 Mr Campbell: So the view that somebody's life is in danger is scaremongering?
Mr Granger: Yes.

Q634 Mr Campbell: I would accept that.
Dr Eccles: Absolutely. People's lives are in danger by lack of information. If we do not know that their potassium is high then we do not know to bring it down and their life is in danger, that is absolutely

clear. That is far more prevalent right now than it is in the hospitals that have the systems that we are putting in place.

Lord Hunt of Kings Heath: If you look at the National Audit Office report or the National Reporting and Learning System run by the NPSA, they continually show issues due to medication errors and misidentification of patients. There is no doubt in my mind that the outcome of the National Programme for IT will be to have an appreciable reduction in those incidents. Overall I have no doubt whatsoever that this is going to lead to enhanced patient safety.

Q635 Mr Campbell: I just want to nail it and make people aware that they are not going to die. We all know about computer failures, at least MPs do: the Child Support Agency, Child Tax Credits, "Sorry, the system has gone down", and in that case it might be somebody getting mixed up with their money but in your case somebody might die and we need to nail this is not going to be the case before people start to back off from all of this.

Mr Granger: If I can just add a couple of things. The failure that CSC suffered last year led to them being punished to the tune of £3 million. The allocation of that penalty around the NHS in the areas of the country that were affected by that was determined by the Strategic Health Authority CIOs, so that is part of this Local Ownership Process working. Since then CSC has doubled the amount of resilience that they have, so they are now running off four data centres rather than two. The specific difficulty that happened was because there were some engineers in Japan altering some microcode on a back-up platform but they have now ensured that specific failure cannot happen again. The probability of that happening is lower. The thing that is important is recognising the vulnerability—these are civil systems that have been bought on a budget and there can be failures with them. The back-up arrangements that the NHS have locally to deal with this type of failure, people keeping paper copies of things, keeping local electronic copies and having clinical procedures, mean they are not real-time dependent on this information. I will just point out to you that it is estimated by my colleague, Professor Michael Thick, our Chief Clinical Officer, that 40% of patients arrive for outpatients' appointments without their records being present using a paper approach. We have got vulnerabilities with computer systems and their reliability, which are the bane of my life, and we have problems with paper as well. The same is true, for example, of picture archiving systems. Lord Hunt and I visited Basingstoke before Easter and the trust there estimated 20,000-30,000 studies had been re-shot in the year before they put their digital system in. That was 20,000-30,000 sets of radiation and costs applied to patients unnecessarily because the information was not available. There are problems with the analogue world as there are with the digital world.

Q636 Chairman: Do you have a comparator in terms of databases in the UK? I know there are different levels of resilience that evolve but what is the comparator with the one you are implementing for the national patient record?

Mr Granger: We asked CIOs and frontline clinicians in the NHS during the specification process what levels of resilience did they want. They had some degree of tolerance for planned downtime, and I can let you have a note on the details of this, and a low degree of tolerance for unplanned downtime. The computer vendors, frankly, had trouble getting their head around what the NHS wanted because the systems that had been put in nationally in the NHS previously defaulted to not being available when it was dark and all maintenance being done at the weekends. As soon as you started to introduce systems which people have a use for in an A&E department the vendors had to get their heads around the fact that they could not do their upgrade work on a Saturday night because we would quite like the system to be available then. Undoubtedly, if money were no object we would have bought another level of resilience and even lower levels of non-availability. I will let you have a note on the performance over the last year of all the key systems that we run and that is the information which is, indeed, on our website.[1]

Q637 Chairman: The last issue is about patient privacy. We had some evidence given to us that the Summary Care Record and possibly the Secondary Uses Services could be challenged, or are likely to be challenged by European law. Do you think that is a serious risk?

Lord Hunt of Kings Heath: I certainly hope not. We have taken advice from the Information Commissioner and from our own lawyers and we are confident that what we are doing is within the law.

Q638 Chairman: Your lawyers believe that, there is no gap between what laws we have here in the EU and Europe?

Lord Hunt of Kings Heath: Obviously part of their review has been looking at European law as well as domestic law. I am very happy to write a note to you about these aspects if you would like me to.[2] The bottom line is the advice that we have received and the advice from the Information Commissioner is that we are acting within the law.

Q639 Chairman: I would be grateful for that note. Some critical parts of the NHS, clinical IT, are going to start keeping things as images and test results and they are going to be centralised. Of course, individuals can have the right not to have their tests centralised but in any way as you see it now, or in the future, are you likely to turn round and say to these individuals who have not had their tests centralised that the National Health Service cannot treat them because they are not on this system, the non-consent would then say that we cannot do that?

[1] Ev 141
[2] Ev 123

Mr Granger: In particular, section 10 of the Data Protection Act and an individual's right, due to the level of distress they experience, to not have information processed is rather difficult in an environment in which we want to have a health service that is safe and efficient and, therefore, necessarily processes a number of pieces of information electronically. Pathology results and picture archiving are probably the two test cases and friction points around this. If an individual is so distressed that they do not want an x-ray to be conducted electronically, I think ministers would need to decide whether it was indeed in the public interest to maintain wet film processing, a 19th century technology, for these distressed individuals.
Lord Hunt of Kings Heath: Clearly we continue to engage in these kinds of discussions but I think there has to be some reality here and the reality is that we are moving much more into a non-paper based system.

Q640 Chairman: I think that most GP practices now have got records held electronically, have you any evidence that people can opt out of the electronic local record in their GP's surgery and they can tell them they want theirs to be paper based?
Mr Granger: It would be impossible for somebody to be registered with a GP in the NHS without there being an electronic record because we would not be able to pay the GP. Whilst I am sure there are a significant number of philanthropic GPs, there has been very, very good take-up with our payments system under the new GP contract.

Q641 Chairman: In as much as the Detailed Care Record is held in a GP's surgery there is no opt-out there under any circumstances, would that be a fair analysis?
Mr Granger: Yes.
Lord Hunt of Kings Heath: Of course there is a requirement on clinicians to keep records and that is in the public and patient interest.
Chairman: Could I thank you all very much indeed for helping us with today's evidence session.

Supplementary evidence submitted by the Department of Health (EPR01A)

1. The Health Select Committee is conducting an enquiry into the NHS electronic patient record, which is the cornerstone of the NHS National Programme for IT (the Programme). The Committee has taken or received evidence from the Department of Health (the Department) and a wide range of other witnesses.

2. The Department submitted written evidence in March 2007. Departmental officials also gave oral evidence on 26 April 2007 and are due to return, with the Departmental Minister, on Thursday 14 June 2007. In advance of this next session, this note provides additional Departmental evidence relating to some of the issues raised during the Committee's enquiry.

TERMINOLOGY RELATING TO ELECTRONIC PATIENT RECORDS, DETAILED CARE RECORDS AND SUMMARY CARE RECORDS

3. In particular, this note aims to provide greater clarity on the differences between Electronic Patient Records, Detailed Care Records and Summary Care Records. The terminology often used includes references to:

(1) Electronic Patient Records (EPR): EPR is a catch-all term covering the patient data held in digital form by computers. The Programme is delivering a number of EPRs. A Summary Care Record (SCR), Detailed Care Record (DCR), Diagnostic Test Order and Results, PACS images and all other clinical data held in computers are examples of EPRs.

(2) Detailed Care Records (DCR): At present patients have many Detailed Care Records. These include a GP record, usually held electronically but often supplemented by paper records. Where patients have visited a hospital or clinic, there will usually be an electronic patient administration record; a separate written clinical record in their local hospital; a separate paper record if they have been pregnant; a further separate paper record if they have received mental health treatment; another separate paper record if they have been treated in the sexual health clinic; and a separate record if they have attended Accident and Emergency (A&E). Each of these records will be repeated for each hospital or clinic the patient has attended. In addition the patient may have a community record if receiving long term care in the community (eg, physiotherapy or care of leg ulcers).

The Programme has a clear objective to reduce this duplication of diverse records by providing a patient centred electronic Detailed Care Record that spans these areas. As a minimum, this would be within a hospital but there are real benefits when providing a consistent record across a local health community and across the boundaries involved in care pathways for a patient.

The overall objective is a single detailed care record for an individual patient that is accessible by the GP and by community and hospital care settings. Local Service Providers (LSPs) have chosen to deliver this vision by integrating systems, eg, in London the GP system InPractice will be integrated with the Cerner hospital system and Rio Community system. Initiatives such as GP Systems of Choice support this level of integration.

(3) Summary Care Records (SCR): A subset of the detailed care record held by GPs and Secondary Care will be made available nationally and this is the Summary Care Record. By late 2008 it will be capable of holding a patient's current medications, allergies, significant past events from the GP detailed record and all discharge letters from hospitals from A&E, Outpatients and Inpatient visits. The precise content of the SCR will be determined by a clinical reference panel representing the views of clinicians.

The Reasons for Having Both Summary Care Records and Local Detailed Care Records and the Differences Between Them

4. The NHS Care Record Service (NHS CRS) aims to establish an electronic health record for every person in England by 2010 to support the NHS in delivering better, safer care. The NHS CRS comprises two distinct yet integrated elements:

(1) Detailed Care Records—created and managed locally by different providers of NHS services including the GP, Acute Hospital or Community Hospital;

(2) Summary Care Records—held nationally on a centrally managed database (the Spine) and populated by contributions from the Detailed Care Record.

5. The two records fulfil different objectives:

(1) The Detailed Care Record will contain the full clinical notes for each patient, recording each care event. This reflects the current arrangements but, in future, records can be shared amongst a locally determined health community that is on the same IT system. Typically, as a minimum, this is at GP practice level or hospital level but can span Strategic Health Authorities (SHAs) or other local health communities as agreed between the NHS and suppliers. The Detailed Care Record aims to be patient centred and the specification includes functionality to support clinicians in delivering safer and better patient care, for example to support electronic prescribing, to provide decision and knowledge support and to provide access to digital images stored on PACS systems.

(2) The Summary Care Record will contain those elements that are important in supporting care in unscheduled events and/or the transfer of care between providers. It will contain details of medications, allergies, adverse reactions and significant aspects of a person's care. The patient's Summary Care Record will be available (subject to the appropriate security controls) to any clinician who has a legitimate relationship with a patient from any healthcare location in England connected to the secure NHS Network.

6. The introduction of the Summary Care Record is essential because:

(1) Even after full implementation of the National Programme there will always be providers of NHS care who do not have locally integrated systems, for example out of hours service providers, private sector providers of NHS care or hospices etc. In these cases, the Summary Care Record will provide an invaluable tool in ensuring that joined up patient care is as extensive as possible. Provided that healthcare professionals are on the secure N3 network, have a smartcard and a legitimate relationship with the patient they will be able to access the Summary Care Record.

(2) The Summary Care Record will facilitate joined up care at a local level in advance of local detailed records becoming integrated. The Summary Care Record is being implemented currently across a number of early-adopter sites, with national rollout following from 2008 after the evaluation of experience in the early-adopters.

7. The Summary Care Record will also provide additional benefit for patients who wish to play an active role in managing their own care and treatment as it will enable them to have access to their own Summary Care Record—either through HealthSpace or by requesting printouts of their record. This is a new service, enabling them to become partners in their own care and helping to ensure transparency and accuracy of records through empowering patients.

Structure and Coding in Records Supplemented by Free Text and Documents

8. Some existing, legacy EPR systems duplicate the paper-based document style approach to note taking. These act as a passive repository of documents but the underlying electronic system does little more than pull together all the documents relating to one patient.

9. The Programme has adopted a much more structured approach which organises and codes the data entered into the EPR. This approach ensures individual items of data (such as diagnoses) can be entered once but then used many times throughout the record. This is fundamentally more difficult but provides significant benefits in terms of:

(1) improved patient safety by ensuring consistency of information and alerts when eg. a diagnosis does not fit with a prescription;

(2) significant time savings for clinicians and their patients, as significant amounts of information will not need to be recorded again and again (as now);

(3) improved access to information to report, assess and improve community health;

(4) allowing decision support systems to operate effectively by applying rules.

10. To deliver these benefits clinicians will need to adopt the new approach to record keeping. This will need a cultural change in the practices of health professionals which should not and could not be led by an IT programme but must be seen as a significant improvement to patient care and therefore owned and led by the NHS.

11. Free text can be an important part of clinical recording where it is used appropriately. Conversely, coding of care events ensures they are recorded unambiguously and allows improved decision support and safer transfer of care. This is a question of balance, but the right balance is not struck currently as people use free-text because it can be easier for them than codification. However, unless they are the only person caring for the patient, it leads to systemic inefficiency across the NHS and raises issues of patient safety.

12. An Information Standards Board, which operates independently, authorises the use of coding and terminology within the Programme. It does so only after rigorous peer review and safety assessments.

13. There is no intention to remove free-text from patient records which, used correctly, is vital to enrich the record. To ensure clinicians have the maximum choice to support their individual ways of working, the Programme is promoting diversity of input, for example keyboard, speech and handwriting recognition when these are shown to be reliable.

14. In answering a question from the Committee on the computerisation of hospital notes, Dr. Gillian Braunold said:

> ". . . we would change the way we work; that we would only need to send each other actions, instead of sending each other information that we share on a Detailed Care Record. That for me is the Holy Grail of what we are about. It is really about changing the effectiveness and the efficiency of how we work."

Recording and Sharing of Patient Information

15. There are three key issues relating to patient confidentiality and the introduction of the Summary and Detailed Care Records:

(1) should patients be required to have a Summary Care Record and/or Detailed Care Record;

(2) should information on the Records be shared and;

(3) how should any choice be exercised, explicitly (by opt-in) or implicitly (by opt-out)?

16. Both the law and professional regulation require adequate records to be kept and the law provides only one legal route for patients to object—Section 10 of the Data Protection Act 1998 in cases where the patient can show that substantial distress or damage would be caused.

17. Patients do not therefore have an automatic legal right to choose whether to have medical records. The complexity of modern healthcare and the reliance of clinicians on electronic systems means that, though this is a matter of local clinical judgement, there will be little opportunity for patients to request that information is not entered into Detailed Care Records—this is no different from now. However as a matter of policy, the Department's Ministers have determined that patients should have a choice in respect of the creation of Summary Care Records.

18. There has been much debate on the relative merits of the opt-in and opt-out approaches in relation to the creation of Summary Care Records. The Department concluded that the opt-out model was preferable on the grounds that the alternative approach would:

(1) take considerable time to implement and therefore delay the delivery of the benefits associated with having a Summary Care Record;

(2) disadvantage the most vulnerable members of society who may benefit most from the new record but may not be provided with one for a considerable period, or who may be difficult to contact to gain consent;

(3) require everyone to take action when, based on the experience of other countries who have implemented similar electronic records, only a very small minority will request not to have a Summary Care Record at all;

(4) potentially result in complaints and litigation where health outcomes would have been improved if a Summary Care Record had been created.

19. The NHS has always operated on an opt-out or implied consent basis for sharing information about patients. This is in line with the NHS Confidentiality Code of Practice and the Care Records Guarantee. What will change with the introduction of the new systems is that when patients request that information is not shared, it won't be.

20. The approach taken therefore allows patients to opt-out of storing and/or opt-out of sharing medical information on the Summary Care Record. It is supported by a comprehensive communications programme to ensure that people have the information in time to determine their preference about a Summary Care Record. The Ministerial taskforce (including the BMA, the Society of Emergency Medicine and various patient organisations) unanimously supported the Department's approach.

21. It is stressed that the assumption of implicit consent (ie the opt-out approach) relates only to the initial setting-up of the Summary Care Record and the inclusion of medication, allergies and adverse reactions. The next stage of adding the patient's significant medical history will occur only after a discussion between the patient and their GP and therefore requires explicit consent (ie opting-in) unless there is a lawful basis for recording information without consent, eg when a patient lacks capacity. The inclusion of future health episodes will continue to be for discussion between patients and clinicians.

22. The result of the approach taken is that patients may choose whether to have a Summary Care Record; may choose what is in it; may restrict who may see it; and may view it themselves through HealthSpace, a website with registration and access controls. Patients will need to register to get access to their HealthSpace record, which will provide them with access only to their own Summary Care Record, including visibility of their participation options. HealthSpace will also allow patients to view any personal data that they have chosen to keep private.

23. Evidence from Scotland, Hampshire and our Early-Adopters is that only around 0.25% of people object to having a Summary Care Record.

24. University College London (UCL) has been contracted to conduct an independent evaluation of the Summary Care Record Early-Adopter Programme. Their team is led by Professor Tricia Greenhalgh, Professor of Primary Health Care UCL who is also a practising GP. The evaluation commenced formally in May 2007 and will run for one year. The aim is for the final report to be published in the summer of 2008. In the meantime, any emerging findings will inform the continued implementation of the Summary Care Record under the early-adopter phase as well as the subsequent national implementation, scheduled to begin in 2008.

Sealed Envelopes

25. Patient sealed envelopes provide the mechanism whereby patients can restrict access to the parts of their Summary Care Record they consider to be particularly sensitive. Patients will be able to request that parts of their record are either "sealed" or alternatively "sealed and locked." These procedures form a level of access control deployed at the direction of a patient, not the NHS. Although the coordination of sealing decisions across multiple IT systems and the Summary Care Record is new and challenging, functionality which is analogous to sealing is already in many of the new systems being deployed. For example TPP/ System One, a GP IT system being deployed by CSC, has functionality called privacy markings. It is therefore wrong to characterise the functionality as new or untested.

26. Sealed information will be recorded on Summary Care Record and system users will be aware that some information has been sealed. However, access to the sealed information from outside of the team recording it will be obtainable only with the patient's consent; in exceptional circumstances (eg child protection or serious crime investigations); or if it is permitted or required by law. Only those users with the necessary privileges will be able to gain temporary access to sealed information without the patient's consent. A privacy officer will be alerted to the temporary access by any user and patients registered with HealthSpace will receive a notification when access permissions are changed or when temporary access is gained.

27. Sealed and locked information is not transmitted to the Summary Care Record and cannot be accessed outside of the team that recorded it. Users who do not have permission to access the sealed and locked information will be unaware of its presence.

28. Sealed information will be available to the Secondary Uses Service (SUS), but will not be disclosed in an identifiable form. Sealed and locked information will not be available to SUS.

29. NHS Connecting for Health has specified the functionality required to provide a uniform service for the sealed envelopes across the NHS and the link to the Spine. The Spine elements of this will be in place in 2008. Sealing functionality in the LSP systems will continue to be upgraded with successive software deployments until it meets the required specification. NHS Connecting for Health is now working with suppliers to agree implementation plans.

System Security

External system security

30. The new systems will be protected by state of the art security measures capable of providing far greater protection than has ever been the case previously. The NHS patient database (the Spine) will reside within a fully private network known as N3. The Spine system and database can be accessed only from within this private network. Should an attacker somehow gain access to the NHS private network they

would then have to break through three separate layers of tiered architecture—each tier being protected by twin firewalls (of different manufacture) to access the database. The firewalls are supported by intrusion detection systems and other multiple security measures, which monitor network traffic routinely and raise an alert on the detection of suspicious activity.

Avoiding misuse of the systems

31. There are four distinct levels of controls to protect against the danger of data theft by a legitimate user.

(1) The first control is provided by all users needing to have a smartcard. Smartcards are secure tokens that, together with a password, confirm the identity of staff and determine access rights to information in line with the highest level of government standards. They are issued only when satisfactory evidence of identity and residence is provided in person by the staff member, for example by the production of a passport and utility bill. Smartcards provide a unique digital identity that enables the system to know precisely who each user is.

(2) The second control is that staff will be able to access only information that is relevant to their role within the healthcare team, so a receptionist will see information about an appointment, but will be unable to look at detailed clinical records.

(3) The third control is that the system will not permit anyone to access clinical information unless they are registered within the system as working in a team that is providing the individual patient concerned with care or are checking the quality of care provided—a new and powerful safeguard referred to as a legitimate relationship.

(4) The fourth control is provided by the staff who oversee compliance with the security processes. A record is kept within the system of who has done what and if an irregularity is suspected these staff will be alerted automatically and will investigate the incident.

32. The Department has produced what it believes is the most comprehensive privacy statement of any public service in the form of the NHS Care Record Guarantee for England, setting out twelve commitments the NHS makes to patients in order to protect their confidentiality.

Secondary uses of the data (for research and analysis)

33. The NHS uses patient information for many purposes other than the provision of care and treatment, for example for research, audit, management and public health surveillance. The Secondary Uses Service will enable data from the full national patient database to be accessible to healthcare professionals, whenever and wherever it is needed.

34. Confidentiality will be protected through the use of sophisticated anonymisation and pseudonymisation processes, either removing patient identifiers or replacing them with codes. Patient identifiable data would be used only where there is consent or a legal basis for disclosure.

35. The Committee received very strong evidence, both oral and written, that the use of patient data for research provided overwhelming benefits for patients of the NHS. The key points made were that patients should have unique identifiers; that explicit consent cannot always be obtained in advance; that data is required at an individual level; but that individual identity is of no interest. All parties to this evidence stressed that good information governance is a prerequisite, including the optimum anonymisation as appropriate to the case. The Department supports this evidence and two expert groups are providing advice:

(1) The Care Record Development Board has established a Working Group to report on the policy and ethical issues around the use of information in the National Care Record Service to support research and other secondary uses of information in compliance with the Care Record Guarantee and the secure and ethical use of patient records. The Working Group is chaired by Professor Sir Robert Boyd, Greater Manchester NHS Research and Development Director, and includes representation from key stakeholders including patients, groups representing patients, the BMA, the Academy of Medical Sciences, the Wellcome Trust and the GMC. The report of the Working Group is due shortly.

(2) A UKCRC expert group chaired by Professor Ian Diamond, Chief Executive of the Economic and Social Research Council, is advising NHS Connecting for Health on maximising the benefits of the NHS Care Record for research. It commissioned four simulations to show in detail how the design of clinical trials; large observational studies; and surveillance of the effects of treatments could draw on the NHS information infrastructure. It reported recently.

The two groups have cross-group representation and have held joint meetings.

DELAYS TO THE PROGRAMME

36. The aim of the programme has been to deliver new systems which are fit for purpose and which support the delivery of key benefits without compromising patient safety. The Programme also has to be responsive to changes in policies and priorities, and to technological developments, all of which are inevitable over a 10 year period. The approach is necessarily flexible.

37. The following are examples of products that have been delivered:

- Quality Management and Analysis System (QMAS)
- N3 broadband implementation—19,687 connections
- Bowel Cancer screening
- Technical development of Picture Archiving and Communications Systems (PACS)
- Deployment of 95 PACS systems
- Technical development of Choose and Book
- Technical development of the Electronic Prescription Service (EPS)
- Deployment of 4,832 EPS systems
- Deployment of 27 Acute Patient Administration Systems
- Infrastructure for the NHS Care Record Service, including Personal Demographics Service (PDS), Security and Authentication Systems and Messaging Systems.

38. Many thousands of systems at local and national level are operating effectively every day. Whilst some elements of the Programme are delayed against the original timetable, substantial new systems have been added and many delivered on time and ahead of time. Key examples of additions to scope are:

Reason	*Product*
Improving Patient Benefits	— The choice element in Choose and Book; — Option to nominate dispensing location in EPS; — Patient medication record within the EPS; — Payment by Results — PACS
Improving the benefit to clinicians and other professional users	— Payment by Results — PACS
Making the system more convenient and easier to use	— QMAS for GPs to record, clinically code and manage their patients' medical conditions.
Improving clinical safety	— Bowel cancer screening — PACS
Improving organisational efficiency	— NHSMail — Payment by Results

39. Introduction of the Summary Care Record was deferred by around two years against the original plan. This was due partly to its complexity and partly to the need to secure consensus from the medical profession on its contents. Although the implementation of the Summary Care Record itself was deferred, work continued on the necessary infrastructure.

40. The Spine was launched in 2004 and the central database, known as the Personal Demographics Service (PDS), has become crucial to the effective running of the NHS. The PDS was deployed on time and to budget in July 2004. The number of enquiries made of the PDS service in an average week is in excess of seven million with over 250 million enquiries handled to date. The NHS Summary Care Record is now very advanced in the first early-adopter sites within Bolton Primary Care Trust (PCT). A further five PCTs have plans in place to begin the Public Information Programme as a preliminary to implementing the Summary Care Record. The early-adopter phase will provide evidence and experience to support the full implementation of the Summary Care Record.

41. Although the Programme is the largest single IT investment in the UK to date, it is not a single monolithic system due for delivery or go-live at one point in time. The Programme comprises a range of new and existing systems, introduced incrementally and meeting the Programme's objectives over time. For example:

- over 80 versions of software from existing IT suppliers have been through the compliance process for use within the NHS, resulting in significant improvements in the quality and reliability of the software involved;
- existing NHS systems have been utilised to deliver new functionality;
- the LSPs' plans are all based on delivering incremental improvements;
- new systems are deployed in phases agreed with the SHAs.

Distributed Versus Centralised Databases

42. There has been an assumption, on the part of some commentators, that patient data for an individual is held on a single central database. In practice, the Programme uses a combination of distributed and centrally managed databases, depending on the nature of the application.

43. Centrally managed databases allow greater scope for sharing data and for the application of consistent controls on the use of the information. The NHS Care Record Spine is an example of a centralised database, designed to serve clinicians across England by providing access to the patient's Summary Care Record. However, such databases are always designed for resilience and, in line with best practice, the data is actually held across multiple databases and data centres.

44. The detailed records exist on distributed databases. These are smaller database deployments that involve databases managed by existing IT system suppliers and LSPs. The key to ensuring interoperability is the consistent application of standards and demonstrations of system integration compliance to support information sharing.

45. As with the centrally managed databases, LSPs are required to design for resilience and to have multiple databases and data centres. The existing system suppliers are working towards similar standards.

46. The approach takes into account the nature of the application, for example locally used or requiring national access; technical constraints such as resilience and business continuity; and the clinical need to access information at either a detailed or summary level.

Department of Health
12 June 2007

Further supplementary evidence submitted by the Department of Health (EPR 01C)

Note on Compatibility with European Law

I promised to write with clarification on whether the summary care record and the secondary uses service are able to satisfy the requirements of European law in respect of data protection.

I can confirm that our legal advice, and the advice of the Information Commissioner, is that the various elements of the National Programme for IT are designed to enable users to be fully compliant with the Data Protection Act 1998, the domestic legislation that gave effect to the European Directive on Data Protection.

You raised the question of some possible future challenge over compliance with European legislation. It is my understanding that this possibility has been mooted in relation to a draft European Working Document rather than to existing European law. The Working Document is currently out for consultation and the Department of Health, along with numerous other UK bodies, have responded with suggestions for clarification and amendment.

If this document remained unchanged and was accepted as the interpretation of law that the European Courts adopt in the future, there would be questions about our compliance. Essentially the Working Group has suggested that it may be difficult to provide electronic health records with a robust legal basis under the European Data Protection Directive and that member states should consider providing such records with a clear basis in domestic law. This applies equally to existing electronic health records and should not be seen as an issue originating with, or exacerbated by, the summary care record or other new developments.

Working Documents are issued for consultation purposes. They do not represent agreed legal interpretation and have no legal weight attached to them. We expect that the Working Document will be amended to better reflect the realities of team based modern healthcare and to allow for the impact of UK domestic common law of confidentiality that runs alongside data protection requirements. The Information Commissioner is represented on the group that is drafting the Document and his staff are confident that the final document will not require any significant change to UK practices.

Lord Hunt of Kings Heath
Minister of State for Quality,
Department of Health

29 June 2007

Supplementary evidence submitted by Professor Brian Randell (EPR 20A)

Introduction

1. At the Committee's second evidence session, Dr Richard Taylor asked Professor Brian Randell to provide a short note describing where independent technical reviews had previously helped major projects to succeed. This supplementary evidence has been prepared in response to that request.

Examples of Independent Reviews

2. In 1998, the project to develop the New En-Route air traffic control centre (NERC) at Swanwick was three years late, over budget, and facing continuous scrutiny by the press[1] and by the Parliament. Mrs Gwyneth Dunwoody MP, as Chair of the Transport Committee, called for an independent review of NERC, and this was carried out by DERA (now QinetiQ)[2] and Arthur D Little. The review reported that the project was likely to succeed if a number of technical and management recommendations were implemented.[3] One conclusion was that the Chief Executive Officer had such a powerful commitment to the success of the Project and this "very likely inhibited more open discussion at such meetings on project problems and possible Operational date slippage. This in turn stifled debate and helped reduce the effectiveness of the review meetings". The recommendations were followed and NERC came into service in 2002; it has proved very successful in operation.

3. In MoD there is an Annual Major Projects Review, which is published. It would make sense for all of the major programmes across Government to be included in an Annual Major Programmes Review similar to the MoD Major Project Review. This would get the facts about those programmes into the open on a regular basis for scrutiny and debate.

4. In the USA, the Office of the Undersecretary of Defense introduced a programme of independent project reviews in 1999 (the Tri-service Assessment Initiative). A status report[4] states that "As a direct result of the assessments conducted to date (19 since inception), Project Managers are implementing relatively low-cost post-assessment recommendations and realizing high returns."

5. A report by Jack Ferguson, director of Software Intensive Systems for the US Department of Defense[5] describes their independent expert programme reviews.

> At the DoD, our large development efforts face problems with the lack of software management expertise and of real data on the causes of problems. To address these issues, we are implementing independent expert program reviews (IEPRs) at appropriate points in the system life cycle. The Defense Science Board Task Force on Defense Software made this industry best practice its top recommendation. IEPRs leverage the scarce technical talent resident in government and industry to help DoD program managers better understand risks, problems, and best practices. Independent expert teams provide a comprehensive assessment of the programs, identify risks, and make recommendations for management and risk mitigation. Participation in these assessments is voluntary; program managers request assessments and control assessment report distribution. The review team and program staff jointly establish assessment scope and initial issue areas. They also establish a follow-up review schedule to evaluate actions taken as a result of the assessment. To date, 42 such IEPRs have been performed. Besides significantly reducing the overall risks on the programs reviewed, the IEPR results are giving the DoD stronger experience based insights that help software-intensiveısystem programs as a whole. Based on generic, systemic issues found across the assessments, IEPRs give feedback to DoD and senior acquisition managers, identifying recommended changes in policy, education, and training. These findings let us base risk mitigation and process improvement decisions on real data rather than anecdotes. They also provide information on the unintended consequences of well-meaning policy directives.

6. The MITRE Corporation and the Software Engineering Institute (SEI) in the USA both frequently review major programmes for the US Department of Defense. The SEI's publication on lessons learned from independent technical assessments[6] contains the following summary.

> All of the assessments summarized in this paper were on large scale, DoD (or related government agency) programs. All of the programs were in actual or perceived difficulty. Some of the recommendations were for substantial restructuring or cancellation of the effort. With this in mind, we look to some of the root causes of the problems uncovered, and attempt to compare and contrast them to similar works in the non-defense world. In doing this, we find that there are more similarities than there are differences. The most significant drivers to failure on these systems continue to be management and culture related, just as they are in commercial systems.

[1] http://news.bbc.co.uk/1/hi/uk/politics/75220.stm
[2] http://www.qinetiq.com/home/case—studies/aviation/swanwick—air—traffic—control—centre.html
[3] http://www.publications.parliament.uk/pa/cm199899/cmselect/cmenvtra/586/586mem01.htm
[4] http://www.stsc.hill.af.mil/crosstalk/2000/11/baldwin.html
[5] IEEE Software, July/August 2001
[6] www.sei.cmu.edu/pub/documents/01.reports/pdf/01tn004.pdf

> Technological failings, while they exist, also have a strong management flavor, as they tend to cluster around failings in the systems engineering process. There are no technology "silver bullets," and anyone promoting any technology as a panacea should be viewed with suspicion. A recent Defense Science Board report states: "Too often, programs lacked well thought-out, disciplined program management and/or software development processes. . . . In general, the technical issues, although difficult at times, were not the determining factor. Disciplined execution was.". There are numerous examples as to how this lack of disciplined execution manifests. Some deficiencies are related to human nature. Self-interest leads people to primarily consider their tenure on a job, cleaning up problems left for them by their predecessors and often not considering long-term consequences of short-term decisions. There is also a tendency to try to place blame on other organizations: customers and program offices cannot hold to a set of requirements; contractors don't live up to their obligations; vendor's products don't live up to their performance and capability claims. It is obviously someone else's fault. This is all a case of lack of discipline. We find that in programs in trouble, there are NO innocent parties. All stakeholders involved participated (at some level) in creating or abetting failure.

7. According to Dr Robert Charette (who was chief designer of the IEPR process referred to above), the US National Academy of Science and Engineering routinely carries out reviews of troubled programmes and makes recommendations to help them to succeed. Dr Charette has taken part in many reviews, including the post-Challenger shuttle review for NASA,[7] and he is willing to provide personal evidence to the Committee if you request him to do so. Dr Charette is also author of a recently-published article reviewing American and other efforts to develop national healthcare IT systems.[8]

8. I and other members of the UK Computing Research Committee have participated in many independent project reviews for public-sector and private-sector organisations. The systems reviewed include large (several million lines of software), distributed (many scores of processors), information systems processing large quantities of real-time data. Many have involved complex supply chains, with suppliers in the UK and overseas—mainland Europe or the USA—with complex, multi-party (including multiple government agency) procurement organizations. Several have had challenging programmes, with multiple deliveries and complex integration activities to carry out prior to delivery. On several occasions, these reviews have occurred late in programmes. Whilst there are more opportunities and alternatives for improvements early in a programme, our experience is that it is usually still possible to identify courses of action which significantly improve the likelihood of successful project outcome.

UK Policy

9. The Information Tribunal has recently ordered the Office of Government Commerce (OGC) to publish its Gateway reviews of the ID-card programme. In response to the decision, the information commissioner Richard Thomas said: "Disclosure is likely to enhance public debate of issues such as the programme's feasibility and how it is managed". It seems likely that the same ruling would apply to NPfIT.

10. On 3rd April 2000, the Committee of Public Accounts published its Session 1999-2000 Thirteenth Report entitled "The 1992 and 1998 Information Management and Technology Strategies of the NHS Executive". This report concluded (paragraph 39 & 40)

> "Evaluation of the success of IT projects is essentially to identify lessons learned and avoid the same problems in future. We have previously expressed our concerns about the failure of the NHS Executive to evaluate important aspects of the 1992 Strategy in its reports on the Hospital Support Systems Initiative and Read Codes. .... The Executive assured us that they are committed to evaluation of ongoing projects .and of the 1998 Strategy. But they have yet to develop their plans in detail. We expect the Executive to produce a programme for these evaluations, and to let us see it as soon as possible".

11. Hence the Committee of Public Accounts recognised as long ago as the year 2000 that evaluation of projects while they were still in progress is a potentially valuable act. In response, the Department of Health commissioned two reviews of direct relevance to the Health Committee's enquiry. Between August and October 2001, Professor Denis Protti, School of Health Information Science, University of Victoria, Victoria, British Columbia, Canada was commissioned to review "the state of progress of Information for Health". His report (the Protti Report) contains many pages of detailed recommendations. It was undoubtedly critical. In response, in 2003, the Department of Health commissioned a report from the PA Consulting Group (Core National Evaluation of the Electronic Records Development and Implementation Sites). This report also made a number of important recommendations.

[7] Such reviews by the National Academies of Science are routinely published, and play an inportant part in restoring public confidence in troubled projects. An Assessment of Space Shuttle Flight Software Development Processes, R. Charette (Chairman). Commission on Engineering and Technical Systems, National Research Council, (National Academies Press, 1993), 194 pp. [http://books.nap.edu/openbook.php?isbn=030904880X]

[8] R Charette, "Dying for Data: A comprehensive system of electronic medical records promises to save lives and cut health care costs-but how do you build one?," IEEE Spectrum, vol. 43, no. 10, pp 22-27, 2006. [http://www.spectrum.ieee.org/oct06/4589]

12. Between April and July 2003, the Department of Health commissioned a review "The Public View on Electronic Health Records", conducted by the Consumers' Association and the researchers they commissioned: Research Works Limited (qualitative) and BMRB International Limited (quantitative). This report's findings are fascinating and its recommendations are most interesting.

13. The difficulty is that Connecting for Health appears to have largely ignored the recommendations made in these reviews. If they have not done so, they should be invited to explain to the Health Select Committee which recommendations they have implemented and how they have implemented these recommendations.

CONCLUSIONS

14. The Health Select Committee may wish to address two issues: (a) having independent timely information, which can only come from a thorough independent review; (b) monitoring that the Department pays attention to the review report, through a continuous programme of Health Select Committee scrutiny of the Programme. In this context, it may be worth noting that the House of Commons Work and Pensions Sub- Committee (Report HC 311-I Published on 14 July 2004) (paragraph 26) says:

> "We recommend that, as formal evidence to Parliament, the Department should present an implementation assessment for each major IT project. We envisage that such an IT Implementation Assessment (ITIA) would be similar to a Regulatory Impact Assessment (RIA) that is currently required. An ITIA should set out in some detail the Government's justification for embarking on the IT programme, including purpose, timings, costs, IT requirements and major risks."

15. In many ways the review recommended by Professor Randell, on behalf of the 23 academics, would produce an independent IT Implementation Assessment similar to that proposed by the House of Commons Work and Pensions Sub- Committee, which together with the Department's response may move the National Programme for IT genuinely forward.

16. Please let me know if you would like me to provide the Committee with any of the reports or other documents referred to in this evidence.

Dr Martyn Thomas

May 2007

Supplementary evidence submitted by BT (EPR 51A)

1. BT was awarded the contract as Local Service Provider for London in December 2003 to design, deliver and operate the integrated local patient record applications and systems for all care settings in the capital. BT is progressively replacing and updating networked IT facilities in NHS hospitals, clinics and GP surgeries and working with NHS staff to ensure they are able to make the best use of national applications being introduced as part of the NHS National Programme for IT.

2. BT is now making good progress in London and has delivered significant capability to more than 50 out of 74 Trusts, particularly to Primary Care Trusts and Mental Health Trusts. At the end of March, BT completed the rollout of Picture Archiving Communication Systems (PACS) to the remaining 21 trusts in London, where PACS is now in use in every hospital in London, every day.

3. Whilst BT has been deploying valuable capability across the NHS, progress in delivery to Acute Hospitals has been slower than was originally anticipated. BT has therefore taken steps to improve its Acute clinical application delivery. In agreement with NHS CfH and NHS London, and following a strategic review of its suppliers, BT made significant changes to its subcontractors in 2006, which included the replacement of IDX with the Cerner Millennium solution.

4. This switch to Cerner together with a strategy of providing an integrated solution employing Cerner (Acute), InPractice (Primary Care) and RiO (Community and Mental Health) removes risk from the delivery strategy by moving away from a "single vendor" strategy, and uses products that the NHS has deployed and "trusts" in the field.

5. The execution of this revised strategy is proving successful. In particular, great progress has been made in Mental and Community Health care settings, with half of all London's Mental Health Trusts having had new IT systems installed. Two trusts in London (Newham and Homerton) deployed upgrades to their Cerner systems late last year. There are plans to go live at Barnet and Chase Farm later in the summer and two further deployments are planned later this year. Comprehensive plans have been agreed with NHS CfH to continue this programme of work across all care settings in 2008 and beyond.

6. A key element of BT's strategy has been to install products initially as "standalone" deployments and then to integrate them with the Cluster-wide solution. Each of BT's key suppliers is modifying its product to facilitate integration, which is planned to commence in 2008. This may also allow some integration of legacy systems and products. BT will ensure these applications are seamlessly integrated to support the vision of a "single view" shared patient record across acute, primary and mental health settings.

7. BT is committed to:

— working in partnership with NHS London and Trusts;

— continuing the level of deployments across all care settings, with a definite pathway for acute deployments; and

— ensuring the integration of a shared patient record across all care settings.

British Telecommunications
6 June 2007

Supplementary evidence submitted by BT Health (EPR 51A)

Figure 1

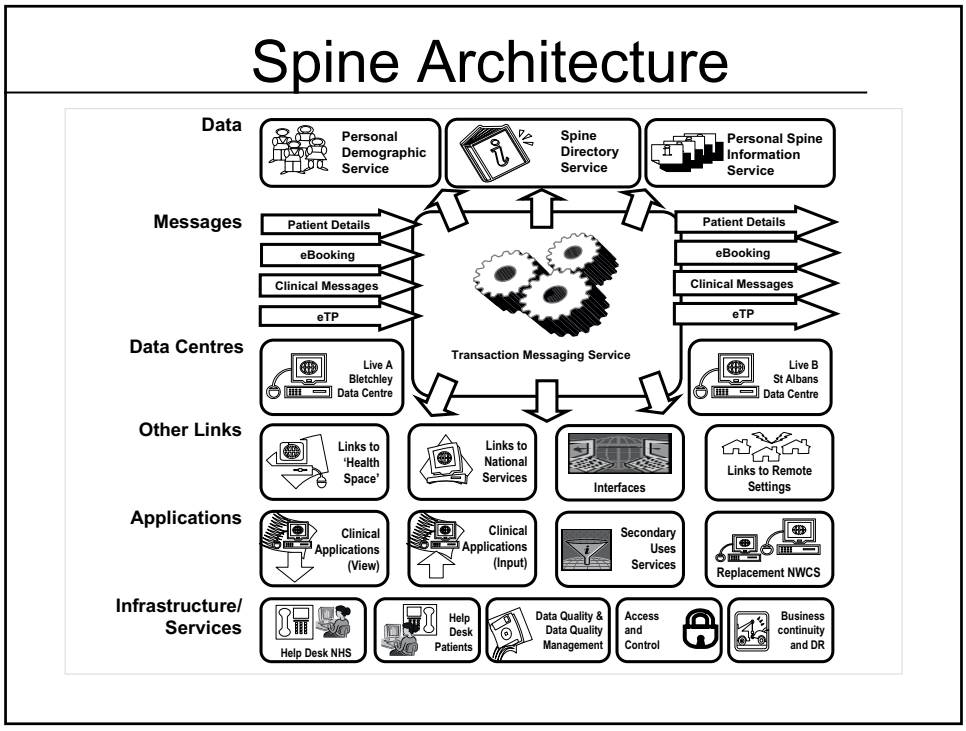
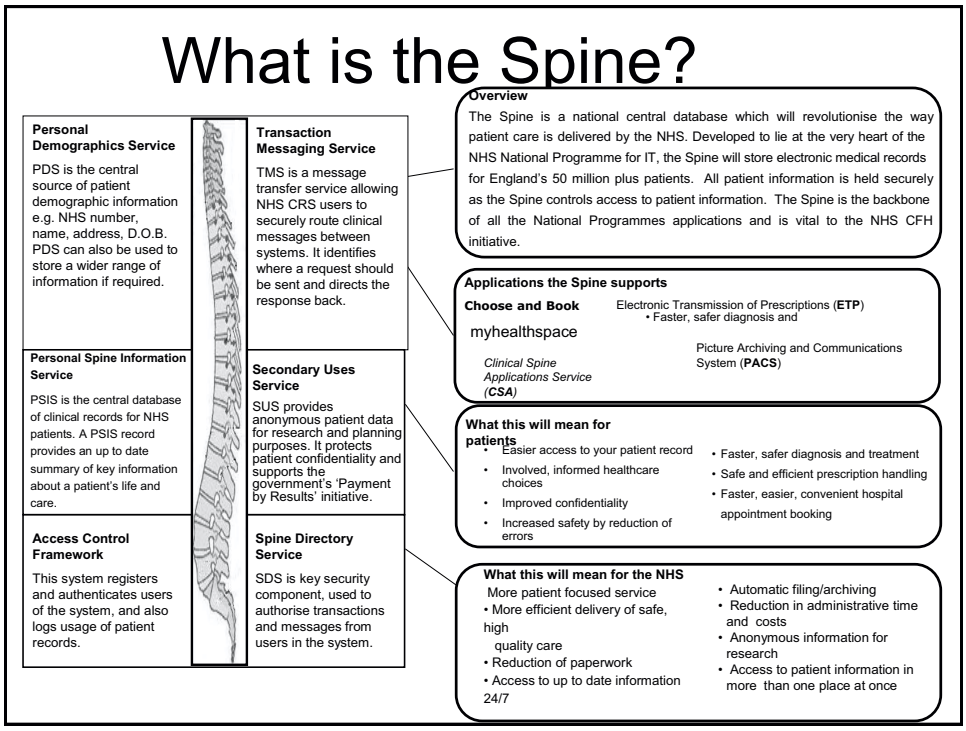


Figure 2



BT Health

June 2007

Evidence submitted by Dr Paul Cundy (EPR 73)

Background

In advance of my oral evidence session with the Health Select Committee on 26 April, I outline further consideration from the Joint General Practitioners' IT Committee (JGPITC). The JGPITC is a committee jointly constituted by the General Practitioners Committee of the BMA (GPC) and the Royal College of General Practitioners (RCGP). It has membership of roughly equal numbers from the GPC, the RCGP, GP computer system user groups, in addition to observers from NHS Connecting for Health (CfH) and the British Computer Society. It is the senior committee mandated by the GPs of the UK to deal with, and advise upon, GP IT matters.

I would like to make clear that the views expressed in this document are not necessarily those of the either the British Medical Association, or the Royal College of General Practitioners.

99.97% of all GPs now routinely collect clinical data on a wide variety of chronic conditions. Some GPs have approaching 20 years experience of using exclusively electronic records. Possibly 50% or more of all GPs now consult "paperlite"", that is without the use of paper records.

GPs are by far the most experienced users of IT systems in the NHS, they are the NHS's experience and evidence base in the use of electronic records. In addition, GP have driven the use of IT systems in healthcare and continue to be amongst their strongest advocates. It would be incorrect to describe the GPs as against the National Programme for IT.

Some of the main areas of concern regarding the Summary Care Record (SCR) are set out below.

Clinical Engagement

It is accepted that clinical engagement has been poor until recently, as stated in the recent National Audit Office report, but the assumption has been that this was due to error rather than a more active process. As far as GPs are concerned, the evidence we have attached in appendix 1 suggests that the National Programme, as it was then known, actively decided not to engage with the relevant representative, and therefore accountable, bodies. I would like to make clear that the information contained within appendix 1 is intended for the Select Committee's consideration only.

Consent

It is self evident that patients should control what happens to their information. Every body or organisation external to CfH has come out in favour of the "opt in"" or explicit consent model. Despite this CfH, presumably under political direction, persists with the lesser "opt out"" model. Even the programme's own internal ethical advisors stated: "the only way to demonstrably satisfy the requirements of the common law of confidence is through an opt in process (sic)"". Our committee considers this persistence in ignoring all calls for the "opt in"" approach to be very worrying and in the long term more damaging for the SCR. We believe it is far better to build an SCR slowly and on the basis of absolute and enduring trust.

We are very concerned at CfH's insistence that section 10 of the Data Protection Act 1998 should remain the exit justification for patients who do not want a SCR. We believe this is counter to Lord Warner's verbal assurances and also all ethical, professional, moral and legal principles.

A False Sense of Security?

Many of the theoretical protections promised by CfH for patient data have yet to be actually delivered and their scope and specification is being downgraded as technical difficulties arise. We have serious concerns about another potential problem in that the protective technologies promised for patients 1) are not yet in place even though data is being accumulated and 2) may never be in place.

Sealed envelopes and Role Based Access controls have both been heavily watered down since first being proposed and we believe that they will offer very little of the initial protections promised.

We also have proven evidence that security controls are being "worked around" in various places in the NHS.

If significant changes to the privacy protection arrangements occur, patients and GPs need to be made fully aware so that they can re-evaluate their position. If, for example, Social Services staff were ever to be granted access to the SCR, I believe that many patients would want their records withdrawn.

The Summary Care Record

The Summary Care record shows signs, even in the early adopter pilots, of rapidly becoming far more than merely just a "Summary" care record. This "scope creep" will create great concern amongst GPs whose records necessarily contain large amounts of contextually sensitive information.

Whilst some argue for a widely available "summary" record to assist in unplanned or emergency care the records being created under the Early Adopter Pilots will be far more than just summaries, indeed they have the potential to become nothing short of an ongoing finely detailed event by event accumulation of the entirety of the locally held GP record, in short a mirror copy.

Thus far all debate has been about the concepts and issues of a "summary" record. The public information campaigns are focused on this aspect yet the records being created are not summaries. I believe this is yet another area of considerable concern firstly because the public have been misled and secondly because of our experience of electronic patient records (EPRs) as day to day tools.

It is assumed by protagonists that the SCR will improve safety. I know of no evidence that the SCR per se will improve patient safety. GPs know from their day to day use of their local computer record systems that they are not the panacea, they are not fault free. It is possible for computer records to be just as inaccessible and just as confusing for the user as any paper record. Prescription errors occur with computer systems just as they do with paper based systems. The experience from within general practice is that these risks are mitigated by the concept of there being a "guardian" of the record; an agent or agency that is responsible for the maintenance of the record. It is recognition that electronic records are dynamic and require ongoing management.

The SCR has no such person or organisation indeed I do not believe it is possible for the SCR to have one once it becomes a multi-contributor multi-organisational record. I believe the lack of an identifiable guardian responsible for the SCR will result in a decay of its value.

Multi-contributor Records

Different practitioners have and need different sorts of records. A psychiatrist's records will be almost purely narrative text whereas an intensive care physician's will be represented by serial tests, measurements and results. One will be of almost no value whatsoever to the other. What each needs to know is the eventual outcome of the others involvement. The two doctors have no need to share the entirety of each others records, only the outcomes. The SCR is predicated on the former and not on the latter concept of interoperability. If the JGPITC's offer to assist Mr Granger with his implementation of the NPfIT had been taken up we would have advised against a "one system fits all approach" and for a strategy of interoperability. This advice has recently been re-iterated in the British Computer Society's review of the programme.

A Uniform Coding System

Most GP systems use a coding system known as Read codes. There are other coding systems used by secondary care. Exchanging or sharing data between systems that have disparate coding arrangements creates unnecessary complexity and introduces dangers. It is accepted that all systems in the NHS should use a common coding system and one has been identified; SNOMED. I understand that data in the SCR is to be held as SNOMED coded data but it will have been extracted from Read coded systems. Associated narrative text, which may be of great importance, may also have been removed. If this is the case there may be considerable safety issues.

The aspirations of the NPfIT cannot be delivered until the NHS commits itself unequivocally to a common coding system for all NHS IT systems.

Evaluation

There needs to be a rigorous evaluation of and genuine learning from the effectiveness of the pilots. After the pilots have taken place, the amount of data and the number of areas should be increased slowly and incrementally so that lessons can be learnt as appropriate. We are concerned that plans for rollout of the SCR are being made even before the evaluations have been commissioned.

Workload

General Practice is exceptionally workload sensitive as it bears the brunt of the interface with illness and does so on an ever more rapid turnaround time. Potential workload for practices must be recognised. The detail of the potential conflict between practice workload and fully-informed ongoing consent needs to be carefully teased out in conjunction with patients and the profession. Informed consent and clinician workload are the two most frequently stated concerns of GPs; getting the right balance between the two is of fundamental importance. Any model must also be appropriate for secondary care settings as well as minority groupings.

Maintaining the SCR

Distinct from this practice level workload but as identified earlier the SCR will need to have its "guardian" if it is to have enduring value. Such guardianship will need to be resourced whether this occurs within or external to the practice.

Failure?

Another concern of the JGPITC is that should CfH be seen to "fail" a great opportunity will have been lost. The JGPITC is keen to be involved in any re-organisation that may or may not occur so as not to loose the fundamentals that underpin the NPfIT, which are increased funding for IT systems, modernisation and improved patient care. We have been concerned that the focus on small numbers of large scale suppliers will stifle innovation and may result in architectures being created that might limit the scope for any future salvage of the programme.

Dr Paul Cundy
Joint Chairman, Joint GP IT Committee

24 April 2007

Supplementary evidence submitted by Dr Paul Cundy (EPR 73A)

Please find below my comments in response to the transcript of the hearing of the 26th April 2007. These comments are made on those points, or questions, not put to me but to the other witnesses.

Vested Interest

In several answers it was implied that GPs were being protectionist in order to protect vested interests. The new contract for GPs of 2003 relinquished the GP monopoly on the provision of primary medical services; now anyone can hold a contract to provide primary care services. If a GP contract holder fails to deliver his contractual obligations he will loose his contract and the contract (and professional) obligations require him to handover his records upon termination. It therefore follows that a GP cannot protect his contract by erecting false barriers around his patients' records.

Furthermore, the 2003 contract introduced the Quality and Outcomes Framework (QoF), a process by which up to one third of a GP's income is linked to contract delivery. The performance assessment is made by automated monthly reports taken from his patients' records system. This is the converse to protectionism. GPs ensure their self interest by opening up their record systems to automated external data extraction and reporting.

Conflicts

It is true that many GPs shoulder competing interests. My own personal circumstances are well know and widely publicised. This was an issue long before the National Programme for IT (NPfIT) arrived. In General Practice we dealt with this by amalgamating and mandating one committee as the "voice" of general practice during 1999 to 2001 (please see my separate earlier evidence on formation of the Joint GPC/RCGP IT committee), this committee reported back to its parent bodies (the GPC and the Royal College of General Practitioners) thus no individual is in a position to influence at either macro or micro level. All members of this committee are subject to election each year and the GPC co-chairman is subject to annual election. The RCGP co-chair is elected for 3 years. Conversely, it might be argued that everyone working for NPfIT has a tangible self interest.

All "For" or "Against"

It is wrong to suggest that GPs are either for or against the NPfIT. NPfIT is a major project with many facets. Some elements are supported without reservation by GPs. For example, broadband access for GP surgeries (N3), GP2GP transfer, the Electronic Prescription Service (EPS), some elements are supported but with reservations. Choose and Book, and others are a source of great concern. To suggest that any medical grouping can be so polarised is to underestimate the complexity of IT within the health community.

Not Engaging with GPs

GPs refute the suggestion that we have failed to engage and thus caused delays. In early 2003 the medical IT community met with Mr Granger and Professor Sir John Pattison. At that meeting Mr Granger was informed that in order to tap into GP opinion all he needed to do was to consult with one committee. We have previously submitted evidence that demonstrates our attempts to engage with NPfIT from 2003 onwards. Meaningful engagement with representative and accountable GPs bodies did not begin until 2006.

Sharing

It is nonsense to suggest that GPs do not share patient information. GPs routinely share the entirety of a patients record when the patient moves to another practice. This equates to 10-15 million "shares" a year. GPs also routinely share information with secondary care specialists via the referrals process. This sharing is based upon the sharing with the specialist sufficient necessary information for the specialist to advise upon the patients problem. In this case the GP is not sharing the whole record; they share an extract that is deemed to be appropriate. The extract is then handed over to the other treating organisation. This limits the exposure of the extract to the minimum necessary to treat. This sharing occurs on behalf of about 10% of the population each year and for some patients many times each year.

GPs also routinely, and probably more frequently, share information on a less formal basis with other members of the primary care team; practice nurses, district nurses, therapists, carers, OOH services etc. It is quite wrong to suggest that GPs are reluctant to share information when it benefits the patient.

This GP view of sharing is distinct from the Connecting for Health (CfH) model, which is to put all of the patient's data in one place and then "share" it by means of access control. Moreover, it should be remembered that the models in place in Scotland, Wales and also the Isle of Wight project are set up so that patient information is not accessed without explicit patient consent.

GPs believe that the risks of the latter model should not be underestimated. There is an increased risk created by the data being in a place accessible to manifestly greater numbers of individuals. This risk needs to be balanced against any benefit that derives from the greater exposure but until the scale of the benefit has been quantified such proposals should not be implemented in anything other than pilots.

Costs of Delay

The costs of the delays to NPfIT are probably quantifiable. Costs can be hard financial ones as well as soft; there has been a considerable cost in terms of GP engagement with NPfIT but also government policy. Choose and Book may have been tolerated for longer had it been seen as CfH and GPs trying to develop a mutually beneficial tool.

The failure to deliver the IT agenda of the New GMS contract has lead to widespread disenfranchisement of GPs, particularly around system choice. The failure to engage with representative and accountable GPs who had expertise in GP IT has lead to systems being delivered that were not fit for purpose. The failure to engage and tap into the enthusiasm, experience and expertise of IT literate GPs is difficult to quantify but probably real.

Delay has also caused "planning blight" for GPs, PCTs and Trusts and these can be quantified in terms of contract extension costs of existing systems.

Finally it is possible to directly cost the failure to incorporate GP Choice into the LSP contracts; that being the cost the Treasury is now having to bear to put it into place—reputedly £80 million, which equates to almost ten per cent of the spend to date.

Dr Paul Cundy
Joint GP IT Committee, Joint Chairman

10 May 2007

Evidence submitted by Dr Chris Pounder (EPR 74)

The Working Party of European Data Protection Commissioners has published a document on the privacy of medical data within an Electronic Health Records (EHR) system.[9] The document states that unless there is a substantial public interest to the contrary, the patients' wishes concerning the processing of their own medical data via an EHR system should prevail. There are several important elements which, at this late stage, I draw to the attention of the Committee.

The Working Party has also concluded that centralized EHR system (ie on the UK model) "assumes there will be single controller for the whole system separate from the healthcare professionals/institutions"—in the UK's case, this data controller could be the Secretary of State for Health.[10] The Working Party notes that in such a system "liability for the confidentiality of the system is taken out of the hands of medical professionals", and that this "might influence the amount of trust invested by patients into such a system".

The Working Party notes that risks associated with a lack of trust do not arise in a decentralized EHR system "where the health care professional/institution" is responsible for the medical file, or in patient-centric EHR systems (for example, the French EHR system) where patients exercise a significant degree of control over their own medical personal data.

I should add that when the Government offers an "opt-out" with respect to the EHR system, it is assuming that it is the data controller and not the medical professional,[11] as only the data controller has the obligation to offer the right to object to the processing found in section 10 of the Data Protection Act 1998.

The Working Party states that "all data contained in medical documentation in electronic health records" should be considered to be "sensitive personal data", even the "administrative data" associated with a medical record. The Party notes that if these administrative data "were not relevant in the context of treatment of a patient, they would and should not have been included in a medical file".

This does not appear to represent the position adopted in the UK, as it treats administrative personal data differently from those data which have a medical content. For example, the Statistics and Registration Service Bill[12] before Parliament has excluded health personal data from the substantial degree of data sharing of administrative personal data (eg as contained in the Summary Care Record) on the grounds that these administrative data are devoid of medical content.

The Working Party states that if patient consent is used as a basis of legitimising the processing of health personal data for other purposes, then such consent has to be freely given and fully informed. The document notes that it is "misleading" if the patient does not have "a genuine free choice and is subsequently able to withdraw the consent without detriment". When giving consent, the patient must be made aware that he is "renouncing the special protection" granted to medical records (ie the prohibition on the processing of health data in the absence of such consent).

The Working Party states that the processing of medical records within an EHR system can be legitimised by statute but only if that statute supports a "substantial public interest". In assessing this public interest, the Working Party stresses the need to respect "self determination" of patients whereby the patients' wishes with respect to the processing of their medical data plays a "significant role as a major safeguard".

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[9] Working Party on the processing of personal data relating to health in electronic health records.
[10] see section 251 of the NHS Act 2006.
[11] BMA may seek NHS records system boycott, http://www.out-law.com/default.aspx?page=7603.
[12] Clause 40 permits the Secretary of State or other public authority to disclose patient registration information to the Board.

This appears to contrast with the practice in the UK. For example, the Secondary Uses Service in the UK will consider wider uses of health personal data in the absence of consent. The position adopted by the Service is that if there is a substantial public interest for that secondary use, then there is no need to consider any aspect of "self determination".

The Working Party adds that the processing of health personal data can be legitimised on the grounds that the processing is undertaken by a health professional for a necessary "medical purpose". The Working Party then state that "medical research" is not included within the meaning of "medical purpose", and this implies that medical research by a health professional needs patient consent or has to be legitimised in terms of a "substantial public interest" where self determination is an important factor.

Finally, the Working Party states that only those professionals who are "presently involved" with a patient should have access to the health record (eg this limitation should apply to access to the Summary Care Record), and that "a patient should have the chance to prevent access to EHR data if he so chooses".

In summary, it appears that there are several requirements, which the NHS's own EHR system have yet to fully adopt. If I can be of assistance to the Committee, please do not hesitate to ask.

Dr C N M Pounder
Editor of Data Protection & Privacy Practice

4 May 2007

Evidence submitted by Professor Naomi Fulop, King's College London (EPR 75)

In relation to the term of reference as follows: "Current progress on the development of the NHS Care Records Service and the National Data Spine and why delivery of the new systems is up to two years behind schedule".

Introduction

We have been studying in detail the processes and outcomes of implementing the NHS IT programme in four acute hospital trusts in England since October 2003. The study assesses the local context and progress made in each trust through in-depth interviews of staff over a two year period, alongside efficiency indicators derived from routine data.[5] In August 2005 we reported findings from each trust's baseline assessment and information gathered from the first round of interviews which took place between September and December 2004.[6] In this second phase, we re-interviewed the same senior trust staff, or new personnel in the same posts, to revisit the issues previously raised, to describe how they may have changed and to identify new issues that may have emerged.

Methods

Baseline information was collected by meeting with key IT, finance and clinical directorate staff, document review, and from routinely published data. Data were also collected from two stages of interviewing. Stage 1 interviews took place over two phases, first, between September and December 2004 (see earlier paper)[6] and then again between January and April 2006 (the focus of this paper). Stage 1 interviews concerned the implementation of the NHS IT programme. Stage 2 interviews investigated how specific IT applications were experienced by staff and impacted on working practices (not reported here).

The data reported here are from the second phase of stage 1 interviews, with 25 senior NHS managers and clinicians in four acute trusts.. To enhance generalisability, we purposively selected four trusts which reflected a range of different organisational characteristics (Table 1). We chose trusts that served both urban and more rural populations. The trusts also differed in size, number of sites, in performance indicators and in their financial situation. They also differed in their level of e-function implementation. One site had a developed electronic patients record system, another site had not implemented any e-functions, whilst the remaining two sites had small pockets of implemented e-function.6 Participants were also selected purposively to include all local senior management staff involved in implementing the programme. At each trust these included the Chief Executive, Director of Information Management and Technology, Medical Director and Director of Nursing; these staff have responsibility for both fiscal and clinical probity.

Table 1

TRUST CHARACTERISTICS IN 2003

Characteristic	*Trust* *1*	*2*	*3*	*4*
Size	*Large*	*Large*	*Large*	*Small*
Number of main sites	2 [earlier merger]	2 [earlier merger]	1	1
Financial situation[a]	Moderate deficit <5m	Small surplus	Large deficit <10m	Small deficit <1m
Performance indicators[b]	1 star	2 stars	0 star	2 stars
e-functions present	Site 1—none Site 2—e-orders	Site 1—e-orders Site 2—e-orders PACs	None	PACS
Expected date for PAS replacement—in 2003*	Unknown	2007	2006	2004–05 earlier adopter e-booking

PAS—Patient Administration System.

PACS—Picture Archive and Communication System.

[a] Annual accounts for 2002–03.

[b] CHI Clinical Governance Review 2002–03.

* No patient administration systems were replaced during the study (2003–06).

Results

Six main themes emerged from our earlier study:[6]

1. The impact of multiple sites resulting from recent mergers.
2. Poor communication between CfH and local managers.
3. The impact of financial deficits.
4. The need to prioritise performance targets.
5. Supporting existing "legacy" IT systems.
6. The delayed timetable for replacement patient administration systems.

Eighteen months later, three of the previous concerns are still apparent (themes 2, 4, 5 below) and five new issues were raised:

1. Increased support for the overall goals of the programme.
2. Continuing impact of financial deficits.
3. Managers distracted from implementing the programme by other priorities.
4. Continuing poor communication between CfH and local managers.
5. Continuing delay in replacing patient administration systems.
6. Growing risk to patient safety associated with delays.
7. Loss of integration of components of the programme.
8. Discontent with Choose & Book.

The eight themes are representative of all 25 staff interviewed. The issues raised were similar among staff interviewed in both phases of the research and those staff interviewed only in the second phase.

Increased support for the goals of the programme

Since the first round of interviews, we found that support for the concept underlying the programme had grown. The overriding view was that the NHS urgently needs the benefits that can be gained from IT modernisation implemented in a standardised way. (Box 1) We found very little resistance to IT modernisation, with interviewees reporting that their staff are ready, and sometimes "desperate", for progress. However, alongside this growing support, we also found concern about the ability of programme

managers to deliver the programme. To maintain momentum, interviewees said that CfH needed to deliver products that work very soon. They also emphasised the need for independent evaluation to measure the benefits and costs. (Box 2)

Continuing impact of financial deficits

In our earlier interviews, senior staff in trusts facing financial difficulties were concerned about how to pay for the implementation costs associated with IT modernisation. Currently, financial difficulties within the NHS are even more widespread14 and this issue has become more important. Respondents reported that making savings is now more critical and that applications which are part of the programme are not the bargain they were expected to be. Implementation of picture archive and communication systems (PACS) is also causing disquiet. Some respondents reported that PACS applications supplied through the programme appear to be more expensive than market alternatives (Box 3), but a central CfH mandate has left them with no choice but to implement the more expensive programme option. (Box 3)

Managers distracted from implementing the programme by other priorities

Financial deficits not only cause concern about how to pay for implementation of the programme, but also act as significant distractions for managers. In the earlier interviews, some trust staff reported that recent mergers and the need to prioritise attainment of performance ratings made it difficult to prepare for the programme. Eighteen months later, the priority of trust finances dominated. Two of our four trusts have had "turnaround teams" in place (external consultants brought in to help trusts resolve financial crises). One trust also has the Department of Health's performance support team working with it. The dominant and immediate need to eliminate any overspend, whilst maintaining performance, appears to leave managers little time to commit to implementing the programme or any other new services or products. (Box 4) The programme was only reported to be a pressing priority in trusts where managers perceived a significant risk to patient safety from having to maintain existing legacy systems while waiting for new systems to arrive. (Box 8)

Poor communication between Connecting for Health and local managers

Previously, interviewees in all four trusts were concerned with a lack of clarity from CfH about the timetable for implementation. Eighteen months later, although respondents were enthusiastic about the goals of the programme, the perception of poor communication was unchanged. There is still uncertainty about the timetable for delivery of key components of the programme (eg core hospital administration systems compliant with the hardware and software applications that will make up the programme) and about the extent of financial assistance for "required" components. Respondents reported that much of the decision making has been between CfH and the local IT service provider. This lack of local involvement appears to have increased feelings of disempowerment and frustration. (Box 5) The uncertainty has also resulted in some trusts adopting policies that actively discourage staff from engaging with the programme (Box 6).

Continuing delay in replacing patient administration systems (PAS)

In the first interviews, respondents were concerned about when their PAS would be replaced. Originally, the national programme planned for PAS to be installed before any clinical applications. Due to delays in developing a PAS that can achieve connectivity with the "spine" (a nationally accessible summary patient record)[15] this plan has had to be revised and interim off-the-shelf applications are now being offered. The revised plan has slowed progress and trusts are still unsure when their replacement PAS will be implemented. Interim applications will allow trusts to move forward to some extent, but will not achieve the promised wider connectivity with other NHS hospital trusts and primary care teams. (Box 7)

Growing risk to patient safety associated with delays

Before the programme was conceived, NHS hospitals bought their own IT systems. When first interviewed, senior clinicians were worried that the replacement of these systems (often carefully customised to meet local needs) might result in a loss of functionality. This concern, though still evident in our recent interviews, has been largely superseded by the urgent need to replace legacy systems. When details of the programme were announced in late 2002, many trusts stopped investing in upgrading their existing IT systems, choosing instead to spend money on other priorities while waiting for applications compliant with the programme systems to be supplied. Delays mean that trusts in our study are still waiting for new systems. Where replacement systems were needed in 2002, the delay is now perceived to represent an unacceptable risk to patient safety, with trusts considering buying interim systems outside the programme. (Box 8)

Loss of integration of components of the programme

The original goal of access to information across the NHS, that underpinned the NHS IT programme appears to have been lost.16 The lack of integration offered by interim applications has left senior trust staff questioning whether NHS-wide connectivity will ever be achieved and, if not, why trusts have had to wait several years for the new systems. The purchase of interim applications does not seem very far removed from how the NHS acquired IT before the programme, with the problems of this approach seemingly perpetuated, such as databases that cannot be accessed from outside the trust. (Box 9) Managers also questioned how the Government vision of decentralising clinical services, by increasing private sector provision, aligns with a centralised approach to information sharing. (Box 9)

Discontent with Choose & Book

Since the first round of interviews, acute trusts and local primary care teams have proceeded with implementation of Choose & Book, a system which allows GPs to make patient appointments and referrals into acute trusts electronically. We found little support for the patient choice element of Choose & Book (patients being able to choose to be referred to one of a range of hospitals) among the staff we interviewed. (Box 10) The technical problems affecting electronic booking have also undermined confidence in other planned applications. None of the managers or clinicians we interviewed were optimistic about the ability of CfH to deliver the systems. The doubts expressed were twofold; whether it was technically possible, and whether the products would be delivered in a reasonable time frame. Feelings of frustration were expressed at the slow progress. (Box 10)

Discussion

Key findings

Over three years from inception, and despite a number of setbacks and some hostile media coverage,[17] the programme remains an objective that many NHS staff support. In line with the National Audit Office report 4 all of our interviewees were enthusiastic about the goals of the programme.

Set against support, were concerns about a lack of clarity and progress. Senior managers need to make financial savings and achieve efficiencies. Although IT modernisation should facilitate these goals, continuing uncertainty makes key managerial decisions more, rather than less, difficult. Trusts still do not know (a) what the local costs of implementation will be, (b) when a replacement patient administration system compliant with the programme will be available, (c) the timetable for delivery of interim applications, (d) the features of these applications and (e) the likely benefits and efficiencies from new systems (whether interim or planned).

Ministers and senior civil servants have acknowledged that the total cost of the programme will far exceed the current budget of £6.2 billion but have not clarified how the additional costs will be met.18 It is not clear how much more implementation and additional "required components" will cost trusts, nor what cost savings might be expected after implementation. Trusts have also not received guidance on how to maximise possible savings by, for example, redesigning local work practices.[4]

It has been difficult for trusts to prioritise the programme and engage staff when implementation timetables keep shifting. In the meantime trusts have employed a "patch and mend" approach to maintain existing systems. Major concerns over the risk to patient safety by continuing this approach have been expressed and reported elsewhere.[19] Trusts are attempting to mitigate the risk by opting for interim systems, although delivery of these interim systems is also delayed.[20] Purchasing interim systems outside the programme is also likely to be inefficient, if trusts subsequently have to buy new systems compliant with the programme during the lifetime of the interim system.

The programme in wider context

Although, the diversity of health care provision in other countries means projects on the huge scale of NPfIT are unlikely, the widespread implementation of electronic health care records is progressing in other countries.[21] France has a national electronic medical patient record system planned for introduction in 2007, combining all consultations, procedures, treatments, drugs and medical devices prescribed. Similarly Australia is trialling a new national management system for electronic patient medical records, called HealthConnect.[21] Creation of the Office of the National Coordinator for Health Information Technology in the United States also indicates a strong commitment from the current US administration to this task.[22]

For these countries, an important lesson to emerge from the study is the difficulty in achieving an appropriate balance of responsibility between government and local health care organisations. Devolving control of IT to local managers can result in a lack of standards, and disparate functionality. Central control is equally problematic. The National Programme covers the entire NHS in England. The sheer size of the task has made progress slow. Effective communication and a shared commitment to the task, across all health sectors has been difficult.

Implementation of Choose & Book illustrates these difficulties. There was no integration of trust and GP IT systems and acute trust staff were unable to reconcile implementation timetables and goals for Choose & Book with their primary care colleagues. Although GPs derive substantial benefits from using IT systems, for the day-to-day running of their practices, these systems have been specifically designed to meet their business needs. The systems underpin relatively simple clinical functions,[23] but very effectively allow GPs to run their practices. GPs may perceive that they have little to gain from the programme and, importantly, can choose not to have applications of the programme imposed on them.[24]

By contrast, acute hospital trusts have to deal with more urgent and complex demands, requiring fast communication between hundreds of staff across many specialties and professional disciplines, yet the IT systems to support this activity are poor. Acute hospitals stand to benefit hugely from modernisation, not least in achieving the efficiencies currently demanded of them. For managers and clinicians in acute trusts, the programme is desperately needed and has to work. Independent procurement of IT systems, in the absence of national standards, has already been tried with little success.[25]

These difficulties have led to a third, middle way being tried; setting central standards but with local implementation. As recommended by the British Computer Society,[26] CfH's role is now shifting away from implementation towards providing a national infrastructure and standards-setting body. Implementation will now be devolved more locally, as set out in the NHS national business plan for 2007–08.[27] Even with these changes the issues raised in our study, particularly in regard to risks to patient safety, still need to be urgently addressed.

Strengths and limitations of the study

The small number of participating trusts makes us cautious about generalising our findings. The trusts studied are located in only two of the five geographic implementation clusters. However, uncertainty over timetables and a lack of progress have been widely reported everywhere.[28] Moreover, mergers of IT companies also mean that the trusts studied are being supplied by two of [now] four local service providers.[28]

Concerns raised by respondents, about performance and finance, are prevalent issues in the NHS but may be more salient in our participating trusts than nationally. We found no substantive differences in views among staff interviewed in the earlier phase of the study and those interviewed later. Staff interviewed were all senior NHS personnel. The 14 recent employees would, most likely, have been recruited from similar NHS posts elsewhere, suggesting wider generalisability. Another limitation of our study is the lack of a primary care perspective, which we have discussed above.

Set against these limitations, ours is the only in-depth, longitudinal study of NHS IT modernisation. We interviewed a cross section of senior trust staff responsible for implementing the programme in NHS hospitals over a period of two years. These interviews have provided us with a detailed account of their views about progress, the challenges they perceive in implementing the programme in NHS hospitals and their information needs, in addressing these challenges.

Conclusions

The staff we interviewed were unreservedly in favour of IT modernisation but this support will quickly diminish unless more progress is achieved. In order to progress, and still maintain a vision consistent with the original goals of the programme, CfH needs to address the uncertainty experienced by trusts and take responsibility for advising about interim decisions. Trust managers urgently need concrete information, about implementation timetables, long term goals of the programme, and value-for-money. Finally, trusts need assistance to prioritise IT modernisation against other competing financial pressures, for example by including it in performance management frameworks.

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Text Boxes

Box 1: Increased support for the overall goals of the NHS IT programme

I still maintain it's the right thing to do. I think the principle, the principles, the philosophy and the vision I think are absolutely sound. The challenge has been deliverability . . . [Chief executive, Trust 4].

Two years on I still believe in the concept, um, because I think the biggest single problem we have is sharing information between organisations and actually even within organisations, so the idea of having a single system or common systems as an IT concept only makes sense. [Director of IM & T, Trust 4].

The consequences are, um, a complete re-think about the way that, um, IT is introduced and it's needed it desperately . . . NHS IT programme is visionary, brilliant . . . [Director of IM & T, Trust 2].

Box 2: More product placement and benefits realisation

We have to get some confidence back into the programme and that has to be about delivery because they can talk until the cows come home, but unless we see something happening on our own patch with a real clinical win to keep people onboard . . . [Director of IM & T, Trust 4].

I think one of the things that they haven't done very well is clarify some of the benefits they think that you're going to get out of it. . . . I haven't seen, you know, a good list of benefits . . . I mean, you know, about between GPs and consultants, I mean actually things like managing a waiting list. [Director of performance and improvement of information, Trust 1].

I think the . . . two big difficulties, the two big issues will be affordability, is it really going to deliver the benefits, um, for the cost and is it, is it a cost pressure rather than an enabler of better efficiency across the organisation as a whole? . . . we are dependent on getting benefits out of it. . . . and I'm not confident at this stage this stage that the system in operation will be so beneficial that it will really drive loads of things forward. [Chief executive, Trust 3].

Box 3: Expensive solutions especially PACS implementation

A lot of the things are being sold to us at a much higher price than we would have been able to get if we'd been in a real market situation, so the total costs to the NHS have been very high indeed. [Medical director, Trust 4].

You know, we went out to procure a PACS system that was not part of the national programme, and, you know, got told we couldn't do it. That's resulted in more, a lot more expenditure for the trust than the local solution, so I think that then heaps another layer of problems on . . . where we have a deficit, um, to be forced down a route that's more expensive without . . . financial support that really we should be getting about that, you know, it's just another disincentive really. [Chief executive, Trust 2].

. . . it's certainly extensive costs, um, and it's compulsory acquisition, we have to have it in by March, that's it. So, it's, it's just a cost pressure, it's another, another one of many cost pressures at the trust. [Head of system delivery, Trust 1].

Box 4: Managers distracted from implementing the NHS IT programme by other priorities

Actually motivating people in this particular trust at this particular time to have the vision to get involved in a nation-wide project, which isn't delivery, is virtually impossible. The majority of my colleagues are surviving day to day with no beds, cuts . . . There are real immediate issues, there isn't the, um, the luxury, I suppose, of people having the time and the intellectual capacity to pursue a ten year vision. We try to, we're trying to survive. [Medical director, Trust 2].

I would like to see good IT systems within the NHS . . . where I'm coming from in a trust that's got the Performance Support Team in and we've got the Turnaround Team in, um, we are trying to pull out a great deal of expenditure about ten percent of our budget . . . it does feel a little unreal trying to implement a large IT system on top of that . . . there's no real plans yet because we haven't got that far. And, to be honest, the whole other agenda [making savings] is just taking my time up. [Director of nursing, Trust 1].

Box 5: Continued uncertainty and feeling of disempowerment

The frustration is we're not the customers, as far as the suppliers are concerned . . .. CfH pull the strings, it's their contract, we're just the entity that takes the solution. [Director of IM & T, Trust 2].

The communication has been bloody awful really . . . we've kind of been the recipients of those relationships as opposed to being directly as influential as we would like to be in those relationships. I'm saying is every two months we say "Where's my pathology system?" "Oh, well, we've got to finish this . . ." so you kind of tune out, that's how it has felt, you've felt a little bit I guess disempowered really, um, because, you don't have the internal levers to actually, most problems I've got I can sort out a lot, but I feel it's not within my power to sort them out. [Chief executive Trust 4].

. . . so ourselves kind of at the bottom of the food chain we just, we don't get involved in any of this and it has been two-and-a-half years, it seems to be solid negotiation and re-negotiation between NHS IT programme and BT. [Director of IM & T, Trust 4].

Box 6: Lack of clinician engagement

I'm not driving the national programme forward at all . . .. We're not doing any enabling at all as far as that process is concerned. I'm definitely not going to do what some of my colleagues have and that's work on the basis that they were getting their slots and have ended up with staff employed, ready to go and nothing to go with. [Director of IM & T, Trust 2].

. . . we've actively discouraged it here [engagement], which is a strange thing to do, in a way, but because we didn't want to raise expectations . . . there is no software backing that up at the moment, or not that we've seen . . . I don't encourage our clinicians to get involved on the demonstration days. [Director of IM & T, Trust 4].

I wouldn't go out and sell it to people because I don't know when it's going to arrive. . . . getting people too enthusiastic on specific timescales would have been very dangerous. [Chief executive, Trust 4].

I think the biggest problem we've had, as an organisation, is, um, you have to have a product to sell to the clinical staff to get them enthused, to get them to use it, and the biggest problem we've had is that the product has not revealed itself to us yet. [Medical director, Trust 3].

Box 7 Continued delays and re-planning

. . . the dates keep getting re-planned because we're not allowed to say delayed anymore we joke in this trust that NHS IT programme is never closer than two years away and just when you think it's actually going to be closer it suddenly goes . . .. again and it's two years away again. [Systems training manager, Trust 3].

I see all the sort of stuff, the propaganda that comes out from CfH and they're always saying how a lot of these things are actually on time, despite what the press says, um, hundreds of people are using the new systems and all that sort of, and I must say, you know, there's not an awful lot of evidence of that across the country, I don't think. [Clinician lead for CfH, Trust 2].

They obviously, they know that the CRS isn't going to deliver in a sort timely manner, so they're kind of looking at this other product to work with existing PASs. [Assist. director of IM & T, Trust 4].

So we've got these tactical solutions coming in and that helps because we're seen to be moving forward. My only problem with tactical solutions is that in a few year's time one expects that tactical solutions to be replaced with whatever IDX is going to demand and I don't know that I really want to put my trust through implementing a tactical PAS and then doing it again. [Director of IM & T, Trust 2].

Box 8: Concern over growing risk to patient safety, some trust may go it alone

. . . our path system is extremely out of date, it's not just obsolescent, it's obsolete. When we had to buy some new bits for it recently we had to buy them through Ebay from someone in America because there's just no bits in this country, so it's a huge risk to the trust that we're still carrying this path system . . . [Medical director, Trust 4].

It's been urgent that it's replaced all the time I've been here, which is about three-and-a-half years, so I mean the first thing I heard about when I arrived was the fact that the PAS system needed to be replaced. It is a clinical risk. [Director of nursing, Trust 1].

And there are a number of risks that are associated with our old system, some very serious risks and risks in development and progress within the organisation and between the organisations due to this lack of putting a good idea into practice. [Divisional manager for diagnostic therapies and outpatients, Trust 4].

. . . that's a risk we, that is a risk. I mean it could, you know, die tomorrow, it's such an old system and then we are really stuffed, basically. [Director of nursing, Trust 2].

People are saying "Thank God we're going to get a new system that will replace this load of old, you know, cobblers." . . . Americans use the expression "You need a burning platform to get change". Well, I think from an IT perspective we've probably got one. [Director of IM & T, Trust 2]

One of the options I have is to say "To hell with it, I'll just go and buy one". Well, that's a kind of tricky decision and that's the decision some of my peers are making elsewhere, they're saying "Well, sod that, I'll go elsewhere". [Divisional manager for diagnostic therapies and outpatients, Trust 4].

Box 9: Loss of integration of components of the NHS IT programme [0]

I think it is back-peddling big time because I don't think the, right now they're in a position to deliver that original vision and so even things like the PACS was going to be an NHS-wide archive and then it was going to be a cluster archive and now they're just talking about having a trust archive. [Director of IM & T, Trust 4].

I'm just worried that the ideas are actually drifting away from the way that initial strategy, from the way the trust is working, whereas at one time you kind of offered a nice way forward I'm worried it's kind of diverging . . . [Divisional manager for diagnostic therapies and outpatients, Trust 4].

One of the things that's become apparent is that the original vision of a shared record between primary and secondary care is not at the moment on the, on the design, aim and design . . ..what they're looking to do is to use messaging systems between primary and secondary care, so effectively you'll have electronic letters and discharge summaries and those sorts of reports . . . and the spine won't, the spine is currently going to be quite thin, so it's not going to be data rich. [Clinician lead for CfH, Trust 2].

. . . we've got foundation trusts, we've got perhaps more importantly the mixed economy so, um, are we saying that a condition of a private provider receiving NHS work is that they have to be signed up to the national programme? . . . we're not going to have a national solution that actually is fit for purpose in a mixed economy and providers. [Chief executive, Trust 2].

I genuinely am not sure whether the solutions are solutions to yesterday's analysis rather than today's analysis . . . . I think what's happened over the last few years is we have moved from NHS PLC to healthcare, as an industry, which has lots of different players in it. [Chief executive, Trust 3].

Box 10: Discontent with Choose & Book & loss of confidence in the programme

I've not really talked to the clinicians about, about whether they think it's a good idea or not [Care Records Service]. They certainly think choose, choose and book is a crap idea, they hate it . . . [Director of performance and improvement of information, Trust 1].

. . . we'll call it choose and book because it helps with politics. The software is not fit for purpose . . . . We have an unstable middle-ware server because the spine keeps vanishing . . . what happens is the synchronisation messages from them to the other doesn't happen, things get lost, so you end up with patients booked, but we don't know about them. We're getting a 53, sorry 57% error rate at the moment. [Director of IM & T, Trust 2].

Technically I'm not sure that they can deliver it at the moment. I don't think they're, I don't think they have the architecture in place to actually deliver it on a national scale, let alone, actually even a cluster scale, to be honest, so I think they are struggling with it. [Director of IM & T, Trust 4].

. . . somebody, not here, but at the PCT level is trying to increase that all the time [usage by GPs] . . . I know that some GPs absolutely hate it and I get the impression that they're using it under duress and that the slightest fault is a case of "Well, what a rubbish system, would never work anyway." [Chief executive Trust 4].

. . . if it doesn't start delivering soon people will begin to say it can't deliver . . . they, um, they just feel resentment or that it's irrelevant or, worse still, it looks like money poured down the drain while they're having to make staff redundant . . . then there will gradually be a sort of almost a "We're going to make sure it doesn't work"" mentality coming. [Chief executive, Trust 4].

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30 May 2007

Further supplementary evidence submitted by the Department of Health (EPR 01D)

Questions were raised during the 14 June 2007 hearing about whether evidence existed for the levels of service availability provided by suppliers under the National Programme, and about the level of resilience provided to withstand significant system failure, and to maintain service to the end user.

I undertook to provide a note, specifically on details of the latter. I have had the attached note prepared, which I believe fully covers both these issues.

NOTE ON NPfIT SERVICE AVAILABILITY AND RESILIENCE

1. *System Availability*

Q629 Mr Campbell: . . . "we have been told that when clinical records are remotely hosted, the loss of the hosting centre or the network for more than a few minutes could lead to loss of life. So both the hosting and the network need to be available virtually all of the time. Is there any evidence of this?"

The systems provided by CFH are monitored and maintained by the relevant suppliers 24 hours a day 7 days a week to ensure that any incident is detected and the appropriate measures are taken to ensure all services are available to the end users.

Service availability statistics can be viewed on the Connecting for Health public facing web site www.connectingforhealth.nhs.uk. The Statistics section within the Newsroom tab provides information on service availability and service level achievements for National Application Services (Choose&Book, N3, NHS Care Records Service (NCRS), Connecting For Health (CFH) Service Desk, NHSmail) and Local Service Provider (LSP) application services (eg. Picture Archiving & Communications Systems (PACS Digital Imaging) Radiology Information Systems (RIS), Patient Administration Systems (PAS) etc).

This briefing summarises the levels of system availability and the performance against agreed system availability targets (Service Level Agreements—SLAs) with each supplier.

In line with normal industrial practice, where incidents do occur these are classified according to their impact on the business and the users and are classified as follows:

Severity 1:

A Severity 1 service failure is a failure which, in the reasonable opinion of NHS Connecting for Health, the contractor, or a National Health Service system/service user has the potential to:

- have a significant adverse impact on the provision of the service to a large number of users; or
- have a significant adverse impact on the delivery of patient care to a large number of patients; or
- cause significant financial loss and/or disruption to NHS Connecting for Health, or the NHS; or
- result in any material loss or corruption of health data, or in the provision of incorrect data to an end user.

Severity 2:

A Severity 2 service failure is a failure which, in the reasonable opinion of NHS Connecting for Health, the contractor, or a National Health Service system/service user has the potential to have a significant adverse impact on the provision of the service to a small or moderate number of service users; or

- have a moderate adverse impact on the delivery of patient care to a significant number of service users; or
- have a significant adverse impact on the delivery of patient care to a small or moderate number of patients; or
- have a moderate adverse impact on the delivery of patient care to a high number of patients; or
- cause a financial loss and/or disruption to NHS Connecting for Health, or the NHS which is more than trivial but less severe than the significant financial loss described in the definition of a Severity 1 service failure.

The following tables show concurrent, registered users and service availability statistics for all National and Local Programmes for IT.

CONCURRENT USERS AND SERVICE AVAILABILITY STATISTICS—24x7

National systems	*N3*	*QMAS*	*NHSmall*	*Choose and Book*	*Electronic Prescription Service*	*SPINE (excluding EPS)*
Potential uptime in user mins	470,807.2	2.220.0	57,799.0	2.168.0	2,840.0	64.339.0
Actual uptime in user mins	470,799.8	2.220.0	57,798.2	2.166.3	3.839.7	64,336.5
Lost user mins	7.4	0.0	0.8	1.7	0.3	2.5
No of users	975,000	4.119	118,223	6.337	7.866	149,453
Availability achieved for 1 year	99,998%	100,000%	99.999%	99.924%	99.990%	99.997%
Availability Target	99.99%	99.99%	99.99%	99.50%	99.90%	99.90%
Lost user minutes per user per year	7.6	0	8	263	106	8.2
Lost user minutes per user per month	0.6	0.0	0.6	21.9	8.8	6.9

Service Type	*PACS*	*PAS*	*PAS (excluding Maidstone)*	*Theatres*	*Theatres (excluding Maidstone)*	*Ambulance*	*GP (Primary Care/ Decision support)*
Potential uptime in user mins	2,623.6	5.031.8	5.031.8	188.5	188.5	221.3	4.011.1
Actual uptime in user mins	2,622.7	5.026.5	5.030.2	186.7	188.2	221.3	4.011.0
Lost user mins	0.9	5.3	1.6	1.8	0.3	0.00	0.04
No of users	6,846	13,361	13.361	424	332	496	9.064
Availability achieved for 1 year	99.964%	99.844%	99,962%	98.919%	99.832%	100.000%	99.999%
Availability Target	99.87%	99.90%	99,90%	95.00%	95.00	99.30%	99.20%
Lost user minutes per user per year	137	394	120	4.361	739	0	4
Lost user minutes per user per month	11.4	32.9	10.0	363.4	62.0	0.0	0.4

CONCURRENT USER AND SERVICE AVAILABILITY STATISTICS-—SERVICE HOURS

National systems	*N3*	*QMAS*	*NHSmall*	*Choose and Book*	*Electronic Prescription Service*	*SPINE (excluding EPS)*
Potential uptime in user mins	196.170.0	925.0	24.083.0	903.0	1,600.0	26.808.0
Actual uptime in user mins	196.167.0	925.0	24.082.4	901.8	1.599.9	26,806/1
Lost user mins	3.0	0	0.6	1.2	0.1	1.9
No of users	520.000	4.119	118.223	6.337	6,866	149.453
Availability achieved for 1 year	99.997%	100.000%	99.997%	99.864%	99.982%	99.994%
Availability Target	99.99%	99.99%	99.99%	99.50%	99.90%	99.90%
Lost user minutes per user per year	5.2	0	5	197	227	13
Lost user minutes per user per month	0.4	0.0	0.4	16.4	18.9	1.1

Service Type	*PACS*	*PAS*	*PAS (excluding Maidstone)*	*Theatres*	*Theatres (excluding Maidstone)*	*Ambulance*	*GP (Primary Care/ Decision support)*
Potential uptime in user mins	2,623.6	5,031.8	5,031.8	188.5	188.5	221.3	4,011.1
Actual uptime in user mins	2,622.7	5,026.5	5,030.2	186.7	188.2	221.3	4,011.0
Lost user mins	0.9	5.3	1.6	1.8	0.3	0.00	0.04
No of users	6.846	13,361	13,361	424	332	496	9.064
Availability achieved for 1 year	99.964%	99.884%	99.962%	98,919%	99.832%	100.000%	99.999%
Availability Target	99.87%	99.90%	99.90%	95.00%	95.00%	99.30	99.20%

REGISTERED USERS AND SERVICE AVAILABILITY STATISTICS—24x7

National systems	*N3*	*QMAS*	*NHSmall*	*Choose and Book*	*Electronic Prescription Service*	*SPINE (excluding EPS)*
Potential uptime in user mins						
Actual uptime in user mins	627,743.0	18,469.4	123,335.5	40.587.3	25,548.1	144,772.5
Lost user mins	627,733.1	18,469.4	123.333.7	40.585.6	25,547.1	144.760.1
No of users	9.9	0	1.8	1.7	1.0	12.4
Availability achieved for 1 year	1,300,000	34,323	253.994	87,400	52,440	297.158
Lost user minutes per user per year	99.998%	100.000%	99.9985%	99.9957%	99.9959%	99.9920%
Availability Target	99.99%	99.99%	99.99%	99.50%	99.90%	99.90%
Lost user minutes per user per year	14.0	0	7	20	32	6
Lost user minutes per user per month	0.9	0.0	0.6	1.7	2.6	0.5

Service Type	*PACS*	*PAS*	*PAS (excluding Maidstone)*	*Theatres*	*Theatres (excluding Maidstone)*	*Ambulance*	*GP (Primary Care/ Decision support)*
Potential uptime in user mins	3,272.2	29,798.5	29,798.5	1,916.7	1,917.0	1,641.4	3,877,409.2
Actual uptime in user mins	3,271.2	29,788.8	29,788.8	1,907.2	1,916.6	1,641.4	3,877,381.4
Lost user mins	1.0	9.7	9.7	9.5	0.4	0.0	27.8
No of users	6,163	69,552	69,552	4.198	3,081	3,742	8,982,307
Availability achieved for 1 year	99.968%	99.965%	99.965%	99.455%	99.975%	100,000%	99.999%
Availability Target	99.87%	99.90%	99.90%	95.00%	95.00%	99.30%	99.20%
Lost user minutes per user per year	166	139	139	2,260	105	0	3
Lost user minutes per user per month	13.9	11.6	12.0	188.4	9.0	0.0	0.3

REGISTERED USERS AND SERVICE AVAILABILITY STATISTICS—SERVICE HOURS

National systems	*N3*	*QMAS*	*NHSmall*	*Choose and Book*	*Electronic Prescription Service*	*SPINE (excluding EPS)*
Potential uptime in user mins	261,559.6	51,389.8	51,389.8	16,911.0	10,645.0	60,322.0
Actual uptime in user mins	261,552.2	51,389.8	51,388.5	16,909.7	10,644.3	60,312.7
Lost user mins	7.4	0.0	1.3	1.3	0.7	9.3
No of users	1,300,000	34,323	253,994	87,400	52,440	297,158
Availability achieved for 1 year	99.997%	100,0000%	99,9974%	99.9923%	99,9821%	99,9856%
Availability Target	99.99%	99.99%	99.99%	99.50%	99.90%	99.90%
Lost user minutes per user per year	8.0	0	2	15	24	31
Lost user minutes per user per month	0.7	0.0	0.1	1.2	1.6	2.6

Service Type	*PACS*	*PAS*	*PAS (excluding Maidstone)*	*Theatres*	*Theatres (excluding Maidstone)*	*Ambulance*	*GP (Primary Care/ Decision support)*
Potential uptime in user mins	1,363.4	12,416.1	12,416.1	698.6	799.0	683.9	1,615,587.2
Actual uptime in user mins	1,362.6	12,408.8	12,408.8	791.5	798.7	683.9	1,615,566.4
Lost user mins	0.8	7.3	7.3	7.1	0.3	0.0	20.8
No of users	6,163	69,552	69.552	4.198	3,081	3,742	8,982,307
Availability achieved for 1 year	99,943%	99.937%	99.936%	99,019%	99.955%	100.000%	99.999%
Availability Target	99.87%	99.90%	99.90%	95.00%	95.00%	99.30%	99.20%
Lost user minutes per user per year	166	139	105	2,260	79	0	3
Lost user minutes per user per month	13.9	11.6	9.0	188.4	7.0	0.0	0.3

2. *System Resilience*

Q636 Chairman: Do you have a comparator in terms of databases in the UK? I know there are different levels of resilience that evolve but what is the comparator with the one you are implementing for the national patient record?

Mr Granger: We asked CIOs and frontline clinicians in the NHS during the specification process what levels of resilience did they want and they had some degree of tolerance for planning downtime, and I can let you have a note on the details of this, and a low degree of tolerance for unplanned downtime.

Suppliers provide services from data centres, where IT systems are built to withstand significant levels of failure, and maintain service to the end user.

Suppliers have built primary and secondary facilities at different sites to provide a back up in the event of a highly unlikely failure affecting a whole site. Within these data centres there are multiple levels of resilience, to withstand more localised failures. In other words, the data centre suppliers ensure they do not have any "single points of Failure", where one piece of IT equipment will exist without a back up, or a resilient partner. Often the additional resilience is also provided to improve performance by increasing the capability of each piece of IT equipment, and hence the overall system or service. The data centres are monitored 24x7 to ensure failures are identified and fixed prior to them having an impact on end user service. Data is stored securely over multiple sites, to ensure in the event of failure that no data is lost.

Additional information is also provided on:

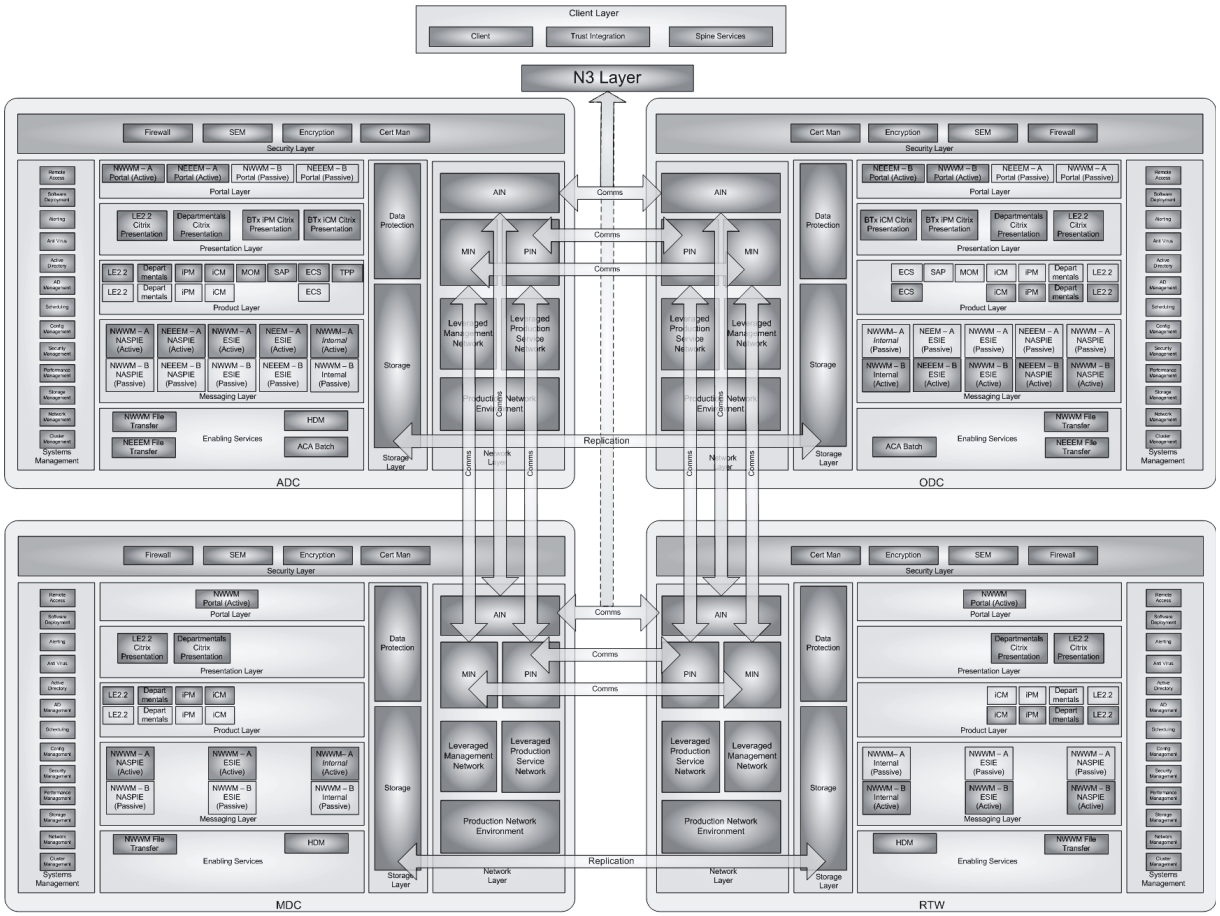
- The CSC quad data centre strategy in response to the service outage in 2006.
- National Application Service Provider (NASP) and Local Service Provider (LSP) data centre architecture and testing.
- Details of network switch and circuit resilience.

CSC Quad Data Centre Strategy

NHS Connecting for Health commissioned an independent review of the service outages in 2006 which helped to identify areas where the service provision could be further improved. Key to business continuity in these areas is the ability to failover one system to another data centre independently of any other service that is being hosted and with which it may interact.

With CSC taking over services that were being provided by Accenture in the North and East, CSC are building two new data centres to replace those that were being used. These new data centres will be operational this year and will embody the principles of independent failover that were highlighted in the review. CSC is undertaking a reworking of the architecture of the transitioned services to ensure that they will meet the high standards.

The new data centres have been constructed within 50 kilometres of the existing CSC/NHS sites, but at a sufficient distance to ensure that no large scale incident could impact more than once. This proximity allows the four data centres to be used eventually to support four way failover, with three sites available for Disaster Recovery. The locations also allow for a "metropolitan" high speed network to be implemented that will allow the failover of N3 connectivity and data storage services, providing further levels of resilience. The high level architecture diagram, Figure 1, shows the logical relationship between all four data centres. The infrastructure element relationships supporting continuity of service are illustrated by the bi-directional arrows.



NASP and LSP Data Centre Architecture and Testing

The BT Spine architecture typifies the approach across NASP and LSP suppliers. The Spine service is provided from two data centres known as Live A, and Live B. They are secure and resilient, being located and built in such a manner to minimise any potential disruption to service. They are classed as List X sites. A List X site is a commercial (non-government) site on UK soil, that is approved to hold UK Government protectively marked information (Confidential and above). The approval is in the form of formal accreditation by the Communications Electronic Security Group (CESG), the Information Assurance arm of Government Communications Headquarters (GCHQ). Because companies with this status are those normally involved with Defence research and manufacturing that is vital to national security, the details of how resilient List X data centres are is restricted information. However, the sites are formally and regularly audited both at Government and Customer level and offer service levels far in advance of non-List X sites.

The target to resolve a severity one incident is less than 2 hours. The severity one fix time target is linked to the target time to recover the service. Whereby if BT Spine were to experience a serious failure at one of the sites, which could mean service was going to be disrupted for an extended period if no action was taken, BT Spine would complete a failover to the unaffected site. This capability is regularly tested. In reality, service is resumed much more quickly than the target of 2 hours.

BT Spine meets the requirements laid out to them by NHS CFH and has completed regular successful tests. This major disaster recovery failover testing is completed by suppliers at a minimum of every 12 months, with some tests scheduled every 6 months. Between these times, suppliers also complete other tests, such as process walkthrough, configuration audits and resilience tests to ensure they are prepared and ready in the event of a live operational requirement to complete a failover.

In terms of the resilience within a data centre site, there is a significant level of testing prior to deployment to ensure the IT equipment performs as it was designed. Once implemented, the IT equipment is monitored 24x7 to identify any potential failures or issues, which, if not resolved, would cause failure.

In addition, the resilience is monitored to identify when it is invoked automatically, ie if a database fails and a resilient partner maintains live service, this will be tracked and the outcomes recorded as a means of testing the resilience on an on-going basis.

Details of Network Switch and Circuit Resilience

Resilience is provided in the network by the deployment of primary and secondary circuits and switches to maintain continuity of service. The level of resilience within the N3 network is based upon a combination of N3 specific elements and components of Disaster Recovery Service provided by the suppliers to N3 Service Provider including BT. The Network, which has been deployed, is based on Points of Presence (PoPs) and these PoPs are designed to facilitate the contractual requirement to be able to connect resiliently all access catalogue services into the N3 Core. The PoPs are designed to support connections from primary and secondary circuits from N3 Customer sites. In addition to N3 access circuits being resiliently connected into the N3 core, the core itself and all key infrastructure components that operate upon the network core (eg Internet Gateway, Domain Name Sever (DNS) and infrastructure for other N3 Foundation Services) have been built to a specification that are resilient in design. Taking this into consideration, business recovery strategies are in place for all standard elements of the network and strict SLAs are in place to ensure that N3SP restores service and original configuration of those services within the shortest possible time, should services be interrupted. Business Recovery Plans are also in place for other supporting service elements delivered by N3.

Richard Granger
Department of Health

5 July 2007

Further Supplementary evidence submitted by the Department of Health (EPR 01E)

Note from Department of Health to the House of Commons Health Select Committee commenting on the evidence provided by various witnesses.

1. The Health Select Committee is conducting an enquiry into the NHS electronic patient record, which is the cornerstone of the NHS National Programme for IT (the Programme). The Department of Health submitted written evidence in March 2007 and again on 12 June 2007. Departmental officials also gave oral evidence on 26 April 2007 and, with the then Minister of State Lord Hunt, on Thursday 14 June 2007.

2. The Committee has also taken or received evidence from a wide range of other witnesses. It is noted that this evidence contains a number of inaccuracies and a number of flawed conclusions. It is also clear that there has been some collaboration between witnesses who have made the same point without any supporting evidence whatsoever. To assist the Committee in reaching conclusions, this note comments on that evidence.

3. Where appropriate, specific witness statements are cited or reference is made to the relevant paragraph numbers from the transcripts of the oral hearings.

4. The comments are divided into the following sections:

1. Data standards, IT system security, system performance and general IT issues.
2. Timing and delays.
3. Local NHS costs and affordability.
4. The summary care record and patient confidentiality.
5. Consultation and professional engagement on the system specification.
6. Evaluation and benefits.
7. Public information and patient safety.
8. Other issues.

Section 1: Data standards and interoperability, IT system security, IT services and general Programme related IT issues

Section 1.1: *Issues Relating to Data Standards and Interoperability*

Data standards

5. A number of witnesses raised issues relating to the adoption of common standards:

5.1 In EPR 29 the UK Computing Research Committee says (at paragraph 25) that:

> " . . . many of the technologies are new and have not been tested. In particular, at the heart of the EPR are two standards—HL7 v3 and SNOMED-CT. We understand that neither has ever been implemented anywhere on a large scale on their own, let alone together. Both have been criticised as seriously flawed. It is imprudent to base the Electronic Patient Record, which will be part of the UK's national critical infrastructure, on a technology experiment."

5.2 This statement needs to be read in context. Currently the formally approved European (CEN TC251) and International (ISO 215) Standards' Bodies in health informatics do not require standards to be tested formally before approval. As many of the UK computing research community contribute to them, it is hoped they can improve the current situation, which is not peculiar to the National Programme but is a global issue. It is surprising that the UK Computer Research Committee has not acknowledged the substance and extent of the standards being used within the National Programme for IT, and particularly the prevalence and authenticity of SNOMED-CT and HL7v3.

5.3 At the heart of the National Programme is a range of standards that are both international and national. Many of these standards are pan-government like the e-government interoperability framework (e-GIF) and many have a long history (for example the Data Dictionary data standards, which arose from the Körner Report in 1981[13]). There are a range of special standards in the Electronic Patient Record which involve information governance and "health record and communication practice standards" which by definition are relatively new and rapidly emerging technologies.

5.4 SNOMED-CT is the most widely used, most comprehensive, and most extensively tested clinical terminology in the world. It builds upon the successful use of its component Read Codes (1983) in the UK and the successful use of its component SNOMED codes (since 1965) in a variety of settings worldwide. For example Kaiser Permanente is a fully integrated health-care delivery system in the United States that cares for 8.5 million people. Kaiser Permanente HealthConnect is their electronic health record and information system. Deployment began in 2003 and is now almost complete, with over 13,000 physicians and 150,000 staff using it for nearly all daily duties and more than two million of their members logging-on to use their health data (with more every day). SNOMED-CT is also a foundational element of secondary data use for research and health services' planning in Kaiser Permanente. It is one of the critical factors in helping them produce value from the system by measuring and improving health.

5.5 The most important characteristic of a coding system for clinical care is comprehensiveness, that is, the ability to provide a coding solution for the vast breadth of health care. In independent evaluations of content coverage, SNOMED-CT is uniformly found to be the most comprehensive of all extant clinical coding systems, usually by a fairly large margin. SNOMED-CT is now owned by nine countries globally through an open International Health Terminology Standards Development Organisation based in Denmark. They have made quality improvement at the heart of its operation so SNOMED CT will become even better to meet the needs of clinicians and citizens worldwide.

5.6 Within health informatics HL7 is the international standard for messaging. HL7 V2 is a widely adopted standard within the NHS and V3 updates that standard using XML formats for interchange (XML is the underpinning formatting standard for modern internet communications).

5.7 HL7 V3 allows for rich interchange of clinical information, embedding modern clinical terminologies such as SNOMED-CT. HL7 is supported by a wide international community, with working group meetings three times a year. In particular, the Programme is using Clinical Document Architecture (CDA) for key parts of the Summary Care Record, which allows for blending of rich semantic information using SNOMED-CT with textual clinical information. CDA is a key HL7 V3 standard that is being widely adopted internationally.

5.8 The National Programme is leading the way in the implementation of interoperable healthcare solutions. Hence, we are implementing requirements which stretch the international standards. Where standards are found lacking for our use we endeavour to incorporate our work back into the international standard, taking a leadership role where possible.

5.9 We have engaged with HL7 in a number of ways, through the co-chairs appointed to key committees. We have initiated a number of projects in this arena for the benefit of the National Programme and the wider supplier community. Current ones include message format improvements (known as an Implementation Technology Specification or ITS) and clinical content modelling (known as HL7 Templates).

5.10 The standards arena is developing for clinical communications. HL7 V3 is a leading standard, and is working towards harmonisation with other standards such as CEN13606. We are monitoring these standards, and working with the standards' organisations, to ensure that our messaging strategy is reflected in the development of those standards.

5.11 HL7 has a working group known as TermInfo that provides standard guidelines on the embedding of terminologies in HL7 messages. In addition, NHS Connecting for Health's message development team provides a variety of additional and detailed constraints on the use of SNOMED-CT inside messages, distributed to suppliers in the Message Implementation Manual (MIM). This ensures a consistent and interoperable exchange of coded clinical information.

5.12 In case Dr Thomas' comments (Q108) should be interpreted as casting doubt on the matter, NHS Connecting for Health has ensured that the many systems and services that have been delivered, and continue to be delivered, through the Programme are compliant with HL7 version 3 and the Dicom digital imaging international standards. NHS Connecting for Health is, in fact, the global leader in the implementation of HL7 V3 messaging and is also the host organisation of the International Health

[13] First Report of the Steering Group on Health Services Information (The Korner Report), HMSO, London.

Terminology Standards Development Organisation National Release Centre in the UK, which will provide a central point for managing, distributing, supporting and controlling the use of SNOMED-CT terminology and related assets throughout the UK. Adoption of these standards will ensure interoperability, so that confidential patient information will be more readily and securely transferable across the NHS.

5.13 It is noted that a number of members of the UK Computer Research Committee have contributed to evidence from other sources. In particular, Professor Randell and Dr Thomas, along with Ross Anderson, are among the 23 academics who called for an independent review of the National Programme.

System interoperability

5.14 It would be helpful to expand on some of the evidence on system interoperability. There have been a number of assurance / accreditation / compliance schemes for existing systems' providers in the NHS. including the Requirements for Accreditation (RFA) scheme commonly referred to as RFA99.

5.15 RFA99 was a technical aid for suppliers to develop systems for testing and accreditation. It was also used by Health Authorities and purchasers of GP systems in providing guaranteed levels of functionality. It included an accreditation process that focussed on a set of test scripts.

5.16 The Common Assurance Process (CAP) is the replacement for all of the existing schemes. RFA99 requirements have been superseded by the CAP-GP Core Requirements, which have been updated to include the Programme's standards and policies, including the use of the international standard HL7V3 and the N3 network.

5.17 CAP-GP supports the GP Systems of Choice (GPSoC) programme. GPSoC provides six levels of system compliance, each of which provides increased functionality in line with the strategic objectives of the National Programme. Each level comprises a detailed set of requirements and standards that a supplier must meet. These include the interoperability requirements defined in the Message Implementation Manual using HL7V3, including the use of the Personal Demographics Service, Choose and Book, Electronic Prescriptions and GP2GP messages. This approach is driving interoperability across the GP-provider environment.

NHS number as the unique identifier

5.18 The evidence relating to the use of the NHS number (Q617) would also benefit from expansion.

5.19 The work on the NHS number in the 1990s provided a set of basic enabling tools, such as the NHS Tracing Service. However, there were initially few incentives for the NHS to use the number, mainly because the concentration was on systems within individual organisations. After the *NHS Plan* was published in 2000, it became increasingly clear that this work was not sufficient, and three major steps were taken:

— the commissioning of the NHS Numbers for Babies Programme;

— the investigation of groups of individuals without NHS numbers (eg service personnel);

— reviewing the mechanisms to encourage NHS organisations to use the NHS number.

5.20 The *Building the Information Core* statement in 2001 outlined targets for trusts to use the NHS number in communications such as requests for tests and results.

5.21 The National Programme then considered recommendations from the Information Standards Board (ISB) that the NHS number should be adopted as a key identifier for use by the Programme's systems and by associated existing IT systems that do or will interface with those of the Programme. Whilst the benefits of using the NHS number were recognised, the issues for organisations migrating from local numbers and the consequential need for the transition to be managed carefully, were also recognised. The Programme accepted the recommendations and asked that the ISB adopt the NHS number as a fundamental national standard as soon as possible. However, given the recognition that the work involved in adopting the NHS number was not a trivial task, it was agreed that a project-based, incremental, approach should be adopted to undertake the co-ordination, communication, steering and issue resolution that would be required.

5.22 The establishing of the National Programme provided the opportunity to rationalise the demographics systems in use across the NHS to provide an operational, up-to-date record (the Personal Demographics Service (PDS)) which could be accessed by authorised users across the country. This was critical to ensuring the delivery of care records which were intended for individual patients, rather than for separate institutions. The Personal Demographics Service (PDS) is an essential element of the NHS Care Records Service, underpinning the creation of an electronic care record for every registered NHS patient in England. It serves as a gateway to the clinical record, enabling authorised healthcare professionals to locate quickly the clinical record that is uniquely associated with each demographic record.
Unlike the previous services, this single authoritative source of demographics is accessible throughout the NHS and is integrated fully with the other applications and services delivered as part of the National Programme for IT. These include Choose and Book, Electronic Prescription Service (EPS), GP to GP and

HealthSpace. It provides more convenience for patients as they need only notify one authorised healthcare organisation of a change of address and this change will be available to all healthcare organisations as and when the patient records are accessed.

5.23 Progress made with the PDS since the NHS numbers programme includes:

— Integration with LSP Systems—Local Service Provider systems integrate with the PDS to allow nationally held patient demographics to be used at the point of care. This means that it is possible to use the NHS number reliably as soon as the patients presents themselves.

— Immediate Birth Notifications to PDS—the NHS Numbers for Babies System (NN4B) issues NHS numbers on new births. From 1 June 2006, a link between NN4B and the PDS made information on new births available immediately in the NHS Care Record Service. As a result, 93% of babies are now allocated an NHS number within 12 hours of being born. Prior to this, it could take up to eight weeks for a baby's demographic information to be available to the NHS outside the unit in which the baby was born.

— All Primary Care Back Offices in England can immediately identify a patient's NHS number from the PDS. Where the patient is not present on the PDS, 53% of Primary Care Back Offices can allocate a NHS Number immediately. This will be extended to all sites by the end of September 2007. Subsequently, it will be made available through the Local Service Provider solutions across the NHS as a whole.

5.24 Finally on this topic, at Q523 Dr Markham suggested that:

> "we have no unique identifier in England, and . . . ..this is one of the reasons why at the moment we cannot share images across the borders" and that "the technicalities of issuing them (NHS numbers) are too challenging at the moment."

5.25 On the contrary, a standard format NHS number has been introduced across the NHS in England and is used as the primary record key for the NHS Care Record Service. The NHS number is issued at birth to all babies born in England and Wales, and to adults and children not born in the UK when they register with a GP practice. From later this year the NHS Care Record Service will be able to assign NHS numbers for adults presenting for care in emergency scenarios. Although Scotland (which has a separate healthcare administration) uses a different numbering system, there is close coordination and cooperation between the two health services, and the numbering schemes are designed to be compatible with each other. It is not the use of different numbering schemes which prevents the sharing of digital images or other information between the two countries, but rather the legacy of locally-commissioned systems that are not interoperable and hence do not support the transfer of information across the NHS. In a typical week 6.5 million HL7v3 messages are processed by the demographics service and 5.3 million messages by the central database, which is accessed on a typical NHS day by 50,000 authenticated unique users.

5.26 Work underway currently with the authority of the National Programme Board is aiming to ensure that the NHS number is mandated by the Information Standards Board and subsequently adopted incrementally for use within IT systems across the NHS within a reasonable period.

Section 1.2: *Issues Relating to IT System Security*

6. Many of the witnesses raised issues relating to the security of the systems that the National Programme will provide:

Access controls

6.1 The Department's evidence to the Committee in paragraphs 30–39 of EPR1 and in paragraphs 31–32 of the further written evidence provided on 12 June 2007 demonstrate that the new systems will be protected by state of the art security measures of the highest standards, well in advance of what has been the case previously. As such, the fears expressed by some witnesses are unfounded.

6.2 In paragraph 7 of EPR 37, Symantec implies that presently there are no access controls on NHS electronic records. This is not true. Existing systems have a range of access controls and the Programme's systems use a proven information governance framework including role-based access control, auditing actions by individual user account and checks for established legitimate relationships between a clinician's work group and the patient. These mechanisms, which are already in place, ensure that only appropriately authorised NHS personnel with an appropriate role and an established legitimate relationship with the patient can access patient confidential information in the NHS. Access rights given to NHS personnel are already monitored and audited and alerts are generated automatically when attempts to transgress these controls are made.

6.3 The Programme has therefore already introduced all the controls Symantec assert are needed. A national NHS data store is not necessary to enforce these controls, merely that a national identity is used within a common information security framework with consistent information security functions applied across applications. This exists for all the Programme's applications. Paragraph 6 of the Symantec evidence relates to the same issue but actually illustrates something that the National Programme for IT in the NHS

is already providing, ie a data management solution that enables patient information to be held securely and only made available to appropriately authorised NHS professionals. However, existing NHS procedures mean that, from time to time, patient information (eg demographic information) will need to be accessed by non-medical staff, so it is not true to assert that only medical staff will need access to patient information and also not true to assert therefore that only medical staff are able to keep patient information confidential. It is surprising that Symantec are so ill informed.

Security of email and instant messaging

6.4 Paragraph 8 of Symantec's evidence concerns the security of email and Instant Messaging within the NHS. NHSmail, the email service operated by Cable and Wireless on behalf of NHS Connecting for Health, is designed and operates as a secure email service for the transmission of patient confidential data. NHSmail is open to all NHS employees, regardless of whether their employing trust has taken the opportunity to eliminate the cost of their local email service. Again, information was provided as part of the Department of Health's written evidence submission EPR01. Guidelines exist for local NHS trusts to understand the risks associated with Instant Messaging (in the Information Governance Toolkit and in the Information Governance Good Practice Guides). Use of Instant Messaging and the guidance given to users locally on appropriate use are matters for the local trust, which must ensure they also comply with related data protection legislation. NHS Connecting for Health secured an Enterprise Agreement with Microsoft in 2004 that made secure Instant Messaging technologies available to the NHS. Implementation of these technologies according to existing "good practice" guidelines is the responsibility of each NHS organisation. The policies that Symantec assert should be given "serious consideration" already exist, either at local or national level. They do not need to be uniform across the NHS in order to comply with the legislation.

Security of mobile devices

6.5 Symantec then continues (in paragraphs 11 and 12 of EPR 37) to question the security of mobile devices used by the NHS. In practice, the Enterprise Agreement with Microsoft that began in 2004 gives access to technologies that allow NHS organisations to protect information held on mobile devices that are adequate for the display or use of Programme applications. All clinical applications within the Programme use either Transmission Layer Security (TLS) or Socket Layer Security (SSL) or Internet Protocol Security (IPSec) to protect patient confidential data in transit across data communications' networks, regardless of whether these are across private (within N3) or public (the Internet) networks. Additionally, on Microsoft Windows XP, the use of Microsoft's Encrypting File System, according to guidelines published through the NHS Common User Interface Programme, enables trusts to secure any information stored on mobile computer hard disks.

6.6 Whilst NHS Connecting for Health has been providing guidance to NHS organisations on the use and security of mobile devices used in the NHS, these devices remain the responsibility of local NHS organisations. NHS Connecting for Health has been providing guidance to trusts on appropriate techniques to manage and secure all devices connected to their networks and used to access patient confidential information. Guidance exists that, if followed ensures trusts can secure communications over wireless networks. NHS Connecting for Health entered into a Corporate License Agreement with Novell in 2005 that made Identity Management and Electronic Software Distribution software available to all NHS organisations. It remains a local trust responsibility to implement these technologies. The assertion (in paragraph 13 of EPR 37) of the need for common policies is rendered redundant by the existence of a central single sign-on capability in the Spine and the use of this Public Key Infrastructure (PKI) across all Programme clinical applications, regardless of local supplier. In other words, what Symantec suggest is needed already exists.

6.7 The above paragraphs also respond to the points made by Dr Sarah Dilks in her evidence (EPR 10) relating to the security of data in mobile devices. Other issues that she raises are dealt with elsewhere in this note.

Testing system security

6.8 Andrew Hawker told the Committee, in response to Q160:

> "I did suggest that there should be . . . some testing that showed that you were actually operating in line with internationally approved information security standards, and, in the end, the simplest way is to have people have a go at getting into it and use other objective measures of whether it is easy or not to get across the security barriers that you have laid down."

6.9 It is easy to make such statements that imply a lack of attention to security testing but nothing could be further from the truth. The Committee will wish to be aware that NHS Connecting for Health places security testing as a fundamental requirement on all suppliers. NHS Connecting for Health incorporates security penetration testing requirements into its compliance process, including the requirement for compliance with ISO-27001. Guy Hains' evidence to the Committee (Q280) outlined just how all-embracing this was.

6.10 It is a NHS Connecting for Health standard that security testing of National Application products or services is performed by "CHECK" approved security teams. This provides assurance that all primary and secondary suppliers to the National Programme will conduct testing to an agreed standard. The CHECK standard is managed by the Communications Electronic Security Group (CESG), which is the information assurance arm of the Government Communications Headquarters (GCHQ). The CHECK Teams are commissioned by the supplier of the product or service to be placed under test, both at the "Ready for Operations (RFO)" phase, and annually thereafter.

6.11 The CHECK Teams work with suppliers and NHS Connecting for Health to provide the following service:

(a) Devise the scope of the security testing. This may be any (or a combination) of:
   — external network penetration test;
   — internal infrastructure test (weak passwords, systems unpatched etc);
   — an "Ethical Hacker" test of the actual application or database.

(b) With the scope set, the CHECK team then produces a test plan which is agreed by both the supplier and NHS Connecting for Health as valid and fit for purpose.

(c) The security test is performed by the CHECK Team.

(d) The output of the test comprises a list of vulnerabilities. These are rated as "High", "Medium" or "Low" by the CHECK Team, which identifies any vulnerabilities in the product or service which may compromise the confidentiality, integrity or availability of information processed. The test output is considered extremely sensitive and is made available only to NHS Connecting for Health's Infrastructure Security Team, via encrypted media.

(e) A Corrective Action Plan (CAP) is produced by the supplier detailing how, and within what timescale, each vulnerability will be fixed. This must be agreed by NHS Connecting for Health.

6.12 Mr Hains also confirmed (Q315) that:

> "there is not a statement which says 10 breaches over a period are acceptable; it is a zero tolerance environment."

The Programme's contracts in fact contain obligations on suppliers to comply with comprehensive and detailed security requirements. Suppliers are obligated to report any breach of the security requirements and to make recommendations for the remedy of any such breaches. NHS Connecting for Health may call in a third party to monitor its suppliers and make reasonable recommendations in the event of any such breach and/or escalate the matter for dispute resolution if the remedy proposed by the supplier is not acceptable. In the event of a breach of security incapable of remedy or which is not remedied, NHS Connecting for Health ultimately has a right to terminate the relevant contract immediately without paying any compensation to the supplier.

Public access to the data

6.13 Many industries now use the Internet to allow the public to access their data. The National Programme is developing HealthSpace to deliver this facility for the Summary Care Record. Healthspace is being developed with security integral to its design and undergoes security penetration testing from external experts prior to being deployed.

6.14 Patients have the choice of having a Summary Care Record or not and of having a HealthSpace account or not. Where a HealthSpace account is required, strict criteria are applied for the registration of the patient. Once registered the patient is provided with a card containing a unique set of numbers. These are required to allow access to their record and avoid the weaknesses of simple username/password access approaches. This provides a more secure approach than adopted by most financial organisations. This approach will be evaluated during the early adopter programme. Other "token" technologies to manage access are also being considered.

6.15 Evidence from Joyce Robins (Q190) stated that no website was secure and cited the MTAS site as demonstrating the fact. MTAS was not delivered by NHS Connecting for Health and did not meet the standards that NHS Connecting for Health operates for the National Programme. There are no grounds for linking MTAS with NHS Connecting for Health.

Security of the NHS Smartcard

6.16 The NHS Smartcard is a "chip and pin" type of card. The "chip" contains an electronic certificate. The NHS Smartcard uses a passcode which can be alphanumeric and longer than the four digit bank pin. Chip and pin cards are in use for UK retail banking and issues have been raised about the cloning of these cards. The cloning of chip and pin bank cards relies on the fact that most bank chip and pin cards also have a magnetic strip. The magnetic strip is maintained to allow for backwards compatibility with older payment systems and ATM access abroad. It is the magnetic strip that is copied and manipulated in the cloning activity.

6.17 NHS Smartcards are not susceptible to cloning. They do not have a magnetic strip used for authentication and so are not vulnerable to this attack (some do have a magnetic strip if local Trusts wish to use the strip for access to buildings/car parks etc but not for logon to computer systems). The "chip" part cannot be cloned and it is the chip that NHS Smartcards use for authentication.

Security of centralised/distributed databases

6.18 In paragraph 12 of EPR 03, Dr Smith said that:

> "a distributed database, with file servers in each practice, is less vulnerable to massive data loss through equipment failure or power outages and malicious interceptions than area-wide or National databases."

This is simply untrue, as recent events evidence. In the recent flooding at Sheffield, 12 GP practices were without power on the Tuesday morning. Nine of these were on shared servers. The PCT was able to facilitate authorised access to information to the affected practices that operated with hosted servers to enable safe effective care until their power was restored. This, of course was not possible for the practices without hosted servers.

6.19 At the same time two practices had to be abandoned due to flooding of the premises. In the first, a practice of four GPs in Louth, with a list of over 10,000 patients, relocated to the local hospital emergency department. The practice was operational within 30 minutes of arrival due to their clinical system being hosted in a data centre. All that was required was their own NHS Connecting for Health security smart cards to allow the staff to access the system. Equipment at the practice was replaced and they returned within 48 hours. A similar success was achieved in North Lincolnshire, where a 1500-patient practice had to vacate its premises.

6.20 The security measures in place on the national system are far in advance of any implemented on file servers at individual practices. There is also a considerable degree of maintenance and monitoring of malicious activity, which we know from experience is simply not undertaken on practice-based systems.

Security of facsimile machines

6.21 Dr Peter Smith also claims (paragraph 11 of EPR 03) that a facsimile machine cannot be hacked. This is a bold statement and not borne out by the evidence.

6.22 Due to the unauthenticated nature of facsimile transmissions, devices are susceptible to Denial of Service (DoS) attacks such as the sending of large documents or documents with large areas of black colouring. It may be possible within certain devices to limit the size of incoming documents although this may not prevent smaller documents being sent many times. Published facsimile device vulnerabilities include:

- Polling—a feature that permits a facsimile machine to call another machine and request it to transmit documents
- Redirection.
- Forwarding.
- Remote Control.

6.23 Many modern facsimile devices include remote diagnostic facilities which allow hackers to monitor and amend the following:

- Configuration.
- Details of incoming calls.
- Copies of faxes stored in the device buffer.

6.24 Many modern multi-function devices include facsimile capability and may operate using a compact operating system such as Windows CE. These devices are therefore susceptible to all attacks against the operating system and the proprietary software which runs on them. The use and physical security of machines also raises security issues and, if procedures are not in place to ensure that devices which receive sensitive information are secured, and paper copies of faxes are not exposed to unauthorised users, then significant security breaches can occur. Good practice includes the use of:

- Logging and audit of fax use.
- Storage of fax machines in manned offices.
- Access control to devices handling sensitive information.
- Authorisation of faxes to prevent forgery and masquerade.

6.25 Fundamentally, the modern facsimile is a computer with a hard drive. It stores information and sits on a network. It presents vulnerability because it is considered low-tech when that is not the case, and therefore is not appropriately patched and managed.

6.26 As with all technology the risks identified above can be mitigated, but to pretend they do not exist is quite wrong. The technology also, of course, carries with it the inherent security risks of a paper environment and of sensitive material being accessible on an indiscriminate basis where, for example, machines are left unattended.

Illegitimate use of databases

6.27 At paragraph 15 of EPR 08, Dr Gooderham refers to the illegitimate use of a database by those with legitimate access being an important potential threat to confidentiality. Whilst this is undoubtedly the case, the only alternative to safeguards and controls is to fail to take advantage of the significant benefits for patients that result from ensuring that those who need access to data have that access. Our position on the misuse of data was made clear in a statement published, jointly with the General Medical Council and the Information Commissioner, on 25 April 2007.

6.28 Dr Gooderham also refers to the sharing of usernames and passwords in a busy A&E setting in Warwickshire as a cause for concern. Whilst this concern is right, in this often-quoted example the sharing was limited to a small number of A&E clinicians and there was no breach of patient confidentiality. The A&E Department has recognised that they were acting in breach of NHS Connecting for Health's smartcard policy and the poor practice has now ceased. The time taken for authentication and to start the application was the key reason cited for the need to share cards. These have been reduced significantly through improvements in the technology and process over the past 12 months. NHS Connecting for Health is working with SHAs and PCTs on reviewing smartcard usage across the NPfIT with the aim of ensuring smartcards are not shared and that organisations enforce the no smartcard sharing policy.

Security of locally-owned desktop computers

6.29 NHS Connecting for Health does not own or manage the desktop computers through which users access the Programme's applications. This is the responsibility of the local organisation and as such comes under the organisation's security policy. The local organisation is responsible for ensuring that local applications are suitably protected against unauthorised access through the implementation of solutions such as desktop screensavers.

6.30 NHS Connecting for Health ensures that National Programme applications provide functionality to protect against unauthorised access to patient information from unattended sessions. This functionality ensures that the application is terminated after a set period of inactivity. The applications are protected by NHS Connecting for Health's Spine Idle Timeout solution. NHS Connecting for Health is working with the health professional bodies to provide national guidance on the appropriate values of inactivity timeouts across different care settings.

6.31 Access to NPfIT applications can be protected further through the ability to disable access for users reporting lost or stolen smartcards.

Reliability and security documentation

6.32 Finally on system security, Professor Randell was not told (Q316) that NHS Connecting for Health did not have reliability and security documentation. He was told that this existed but that, for reasons of confidential and commercially sensitive content, they could not be disclosed to third parties without reference to the suppliers.

Section 1.3: *Issues Relating to System Performance*

7 A number of issues were raised relating to the capacity, reliability and performance of the Programme's systems:

System resilience

7.1 The Department supplied a note on system performance and resilience to the Committee. In respect of Symantec's evidence (paragraph 9 of EPR 37), relating to ensuring critical information, applications and systems are available continuously, all Programme systems have the levels of protection Symantec assert to be vital; and all the assertions made in Symantec's evidence are therefore without foundation. Professor Randell also commented on NPfIT systems' resilience and the likelihood of failure (Q325). It should be noted that Professor Randell is one of the 23 academics who called for an independent review of the National Programme in April/May 2006. At that time, this group foretold of catastrophic failures with the systems being implemented. Whilst no new problems have emerged, many more systems have been implemented and system reliability and resilience continue to be high, as evidenced by the system availability figures published on NHS Connecting for Health's website. The group of academics has not produced any evidence to warrant

a review but merely produced newspaper articles and a series of Parliamentary Questions—hardly the "evidence" one would expect from computer scientists. However, in view of the comments from these two sources, a further note of evidence is enclosed as Annex 1 of this note.

Professionally run data centres

7.2 It is also worth adding some information in support of the points made about the merits of professionally run data centres (Q594). The TPP primary care application is a data centre hosted application provided by CSC to NHS providers in the North, Midlands and East of England. Whilst the service is well regarded in its own right, recent flooding in the UK has demonstrated very clearly the additional benefits of the National Programme's approach at GP surgeries in flood affected areas:

- data is held securely in a remote data centre, not locally, and therefore no loss of data occurred and no re-creation of records was required;
- no data loss was experienced, where a locally hosted system could have endured a hard service shut down due to sudden electricity power failure;
- local Business Continuity Plans are enhanced because GPs can connect to the service from any N3 connected site (eg in an alternative GP surgery or local hospital) with minimal configuration;
- there is minimal disruption to re-establish service once the local GP premises and infrastructure are restored—no locally hosted servers to be rebuilt to enable access to system.

As explained above, these benefits have been demonstrated at GP surgeries in Grimsby and Louth in the last two weeks.

Response times of IT applications

7.3 In respect of Q598, which related to the speed of IT Applications and/or networks in GP surgeries, a lot of support has in fact been provided by NHS Connecting for Health to PCTs and GP practices to ensure that local configuration of legacy systems provides a good end user experience. Local PCT IT teams have a key role to play in this. For example a study of over 900 PCs at one PCT showed that poor user experience relating to 71% of the PCs was because the PCs themselves required remedial action, or were under the minimum specification.

7.4 The N3 broadband network service provider (BT) and the principal legacy system supplier (EMIS) have also worked together to investigate reported performance issues of the EMIS LV application, when operating over the N3 "Main to Branch" Network, and to provide a fix to the issue. The results from the trials have been very encouraging with the joint team witnessing significant improvements to how the application is now running over N3.

Dependency on the systems of Choose and Book

7.5 Returning to the evidence of Dr Peter Smith, he says, in paragraph 18 of EPR 03, that access to services such as Choose and Book should not be dependent upon the medical record upload. It is important to note that with respect to the data around individual patients, it is not. It does, however, depend on the infrastructure, namely, the N3 network, the security framework, the demographics service and the messaging infrastructure.

Capacity of the bandwidth

7.6 In EPR 37, paragraph 3, Symantec said that:

> " . . . due to the lack of bandwidth allocated to the database, the Spine will not be able to hold all the medical information relevant to each patient. The lack of bandwidth means the amount of data able to be stored on the database will be limited and the ability to download the data in any meaningful timeframe restricted."

7.7 This statement is not only untrue, but also makes little sense. The term "bandwidth", as commonly used in the context of Information Technology, is a measure of the capacity of a data communications network to transmit a volume of data over a period of time (usually expressed in millions of bits (binary digits) per second). The NHS New National Network (N3) has sufficient capacity to provide adequate bandwidth between any two locations in the NHS that need to exchange data. As evidence of this, NHS organisations routinely transfer diagnostic images in digital format of several tens of megabytes (there are eight bits per byte and a megabyte is over one million bytes) across this network, throughout the day, using the Picture Archiving and Communications Service (PACS). The N3 network transmits seven terabytes (millions of megabytes) of data each day. Further information has already been provided as part of the Department of Health's written evidence EPR01.

7.8 Clinical records, in comparison to diagnostic images (X-ray or MRI scan images), are relatively small amounts of data; perhaps a few megabytes at maximum, once coded using appropriate clinical terminology. To suggest that there is insufficient bandwidth for the Spine and that this limits its ability to hold all medical information is clearly wrong. Even if the assertion related only to the database capacity necessary to store all detailed patient records, this is still wrong, since the database products that store Spine data are already used for other databases many times the size of that needed to store 50 million detailed patient records.

7.9 To exemplify the point with more specific detail, the data centres hosting the Spine are provisioned with resilient (dual) network links. These links have recorded 99.99% availability over the last 12 months (against a 99.9% Service Level Agreement (SLA)). The availability of the Spine Data Centre and its services has been 99.97% over the last 12 months (against a 99.7% SLA). All Data Centres in this infrastructure are architected to have fault tolerant network connections featuring assured end-to-end separation of the two physical cables entering the Data Centre. This means that at no point in their journey between the Data Centre and the rest of the network are they close enough to fail or be damaged in a single action. Within the Data Centre, this separation continues, with separate local area network links, separate power supplies, separate network adapters in the separated pairs (or clusters) of servers providing this service.

7.10 Presently, the average size of a detailed medical record sent over the National Programme's GP2GP service between GP EHR systems is approximately 547 kilobytes (indeed, less than 1% of detailed medical records so far transferred are larger than 5 Megabytes). Even if these detailed records were to be transferred to the Spine it would not cause problems for the links in the N3 network or to the Spine Data Centres. The N3 network has a range of capacities available for site connection, each installed appropriate to the site's individual needs. The "core" of the N3 network has a capacity of 4.5Gbps. Such a network is able to transmit an average detailed medical record in less than one millisecond. The links into the Spine Data Centres can transmit the average detailed record in just over 56 milliseconds (a twentieth of a second). This means that even if all detailed records did need to be transmitted to the Spine in one go (a highly unlikely situation, but useful as a "worst case scenario") with the network links upgraded to their maximum capacity, it would take less than 5 days to transfer 50 million records. This highly unrealistic "worst case scenario" illustrates that the capacity available in the network to deal with detailed medical records, even if they were to be sent to the Spine, is easily adequate for the job.

Section 1.4: *General Programme Related IT Issues*

8. A number of more general issues were raised in respect of the Programme's IT products and services:

Cerner Millennium Release 0

8.1 To clarify Q389/90, Cerner Millennium Release 0 (R0) is the clinical application implemented at both the Newham and the Homerton Hospitals. 15 NHS hospital trusts to date across London and the South have elected to implement Release 0 as a precursor to the full clinical suite of Cerner Millennium Release 1. This incorporates a fully anglicised Patient Administrative System, together with the clinical applications that support Ordering and Results Reporting of diagnostic tests and care pathways.

Maintenance of the vision of integrated records

8.2 In response to Q398, where it is suggested that the focus has been on hospitals rather than primary care and that the vision of an integrated system has been lost, it should be noted that In London 42% of all PCTs and half of all mental health trusts have implemented the Local Service Provider (LSP) Rio application. This solution will be integrated fully with the Cerner Millennium solution to provide a patient centric integrated solution, working across organisational and professional boundaries. In the North, Midlands and East, the LSPs have implemented nine GP systems and over 1,200 applications to Primary Care Trusts to support the delivery of Community Services.

Would the same progress have been made without the Programme?

8.3 Dr Cundy observed (Q81) that:

> "we have now recently developed technology, through a project which was begun before the national programme, to exchange GP records wholesale from one practice to another. Six hundred practices in the country have that, and it is almost getting on for 10%, and that exchange can occur in a matter of minutes."

It is a matter of speculation as to how far forward this process would have moved without the involvement of NHS Connecting for Health, bearing in mind that enabling it depends on the existence of a reliable network with suitable bandwidth and the definition of adequate standardisation and messaging structures.

None of these would have been in place without the Programme. When NHS Connecting for Health announced on 19 March 2007 the first interoperable transfers of Electronic Health Records in Croydon PCT, Dr Cundy was widely quoted as saying:

> "These first transfers of GP electronic patient records between different practices using different computer systems is a watershed for patients, practices, the Programme and the NHS. It represents a significant and tangible leap forwards in the modernisation of the NHS and is a tribute to close collaborative and clinician led working. I would like to personally congratulate the entire team and look forward to the next stages of widened supplier involvement and national rollout."

8.4 To make it happen on the ground NHS Connecting for Health has driven GP2GP forward within a structured project management framework and ensured that the solutions developed, and being developed, by the clinical system suppliers are subject to a rigorous compliance process. This ensures that clinical and patient safety is at the fore and that Spine interactions are carried out safely. Clinical systems which do not comply in these areas cannot be accredited as GP2GP-compliant.

8.5 Dr Cundy also stated (Q96) that many of the PACS systems being installed now are the PACS systems that were on order books in 2001–2004 but were put on hold:

- Of the 122 Trusts that no had form of PACS in 2003, only 31 had live PACS projects.
- Ten of these 31 Trusts went on to implement these projects outside of the Programme. They were therefore not "put on hold".
- The other 21 have implemented, or are implementing, NHS Connecting for Health's PACS solution. In many cases delays were experienced because of trusts' failure to write business cases. They could hardly be described as ready to procure their systems.

8.6 In a similar vein, Dr Markham told the Committee (Q508) that:

> "the Southern Cluster, as is now, was almost ready to roll out (PACS)."

This is not so. The Southern cluster was in fact purely a consequence of co-operation between the newly-created National Programme and the Broadband Britain initiative, to segment the NHS into regional groupings suitable for the maintenance of a contestable framework.

8.7 Finally, Dr Cundy stated (Q99) that it was "not a good thing" that general practitioners will be offered a choice of suppliers for their electronic record system. This is in direct conflict with a quote by him in the 13 February edition of "e-health Insider" magazine that:

> "this (The GP Systems of Choice initiative) is great news for GPs and great news for the programme. I am reassured that this is finally going to happen."

Sealed envelope functionality

8.8 Guy Hains commented (Q305) that he would need to see a more detailed specification than that contained in the spine functionality plan to implement sealed envelopes within his Local Service Provider (LSP) environment. Sealed Envelope functionality will be delivered in the Spine in 2008. LSP solutions will deliver Sealed Envelope functionality in two phases:

- in the detailed care record;
- in the messages that the LSPs exchange with the Spine.

The Sealed Envelope integration with the Spine can occur only post 2008 after the Spine functionality is delivered. The major sub-contractors (iSoft and Cerner) have committed to delivering Sealed Envelope functionality in 2009.

Direction of information flow

8.9 Professor Korff was wrong to suggest (Q198/99) that there will be only one direction to the flow of information from local to central records. Right now local NHS records are deriving their demographic information from the centrally held Personal Demographics Service. We envisage that local records will pull through elements of the national record to ensure patients enjoy continuity of information. Medications and allergies are an obvious example. At the very least local records should compare themselves to the national Summary Care Record and highlight to the responsible clinician when they are different.

Purpose of the secondary uses service

8.10 Dr Walport was not well informed when he said (Q336) that the initial aim of the Secondary Uses Service (SUS) was about management. Misgivings about the name should not be taken as implying that the need to support research was not designed into the care record specification at the outset. The published specification in July 2002, the contract specification in May 2003 and the first SUS consultation document in February 2004 were all explicit in identifying the requirement to support research.

Structure of the electronic health record

8.11 Dr Sarah Dilks (in paragraph 3 of EPR 10) seems to assume that the electronic health record is a single unstructured document. That is not the case. The electronic health record is structured in a number of ways, and access to information is "partitioned" in a number of ways. Additional evidence was provided to the Committee on this subject on 12 June 2007. To be clear:

For the Summary Care Record held on the Spine:

- Each entry is held separately with a set of data to identify it including author and organisation.
- Within each entry Care Record Elements categorize the data, eg, Medications, Allergies, etc.
- Entries to the Summary Care Record are submitted using structured HL7v3 messages so the structure can be maintained.
- If an entry contains sensitive information the patient may place it in a Sealed Envelope.
- Role based access ensures that people can access only the information about a patient which is relevant for them in their role, so a doctor can access clinical information, but a receptionist may access only booking data.
- Legitimate relationships ensure that in all instances access to patient information held in the NHS Care Records Service creates an audit trail of who accessed what information and when. Inappropriate access generates an alert to a Caldicott Guardian who may investigate the matter further.

For the Detailed Care Record held on local systems:

- Data is stored in a structured data store (typically a relation database) with each element identified within that structure.
- The principles of Legitimate Relationships and Role Based Access Controls referenced above are also applicable to accessing detailed records.

Section 2: Timing and delays

9. Delays to the Programme were cited by a number of witnesses. The Department's evidence accepted that delays have occurred though some of the evidence of individuals is worth commenting on:

Priority of electronic prescribing

9.1 Frank Burns said (Q544) that electronic prescribing:

> "is not a priority of NPfIT, and it should be one of the first things that are rolled out across the hospital service".

In fact, ePrescribing is a priority but the specification was not available at the commencement of the National Programme and NHS Connecting for Health has worked hard to get it in place. This has involved wide consultation.

9.2 The functionality to be provided by ePrescribing systems is now extensively detailed in the ePrescribing Functional System. It will include:

- computerised entry and management of prescriptions;
- knowledge support, with immediate access to medicines information;
- decision support, aiding the choice of medicines and other therapies with alerts such as drug interactions;
- computerised links between hospital wards/departments and pharmacies;
- ultimately, links to other elements of patients' individual care records.

9.3 The programme will also focus on supporting the new working processes and cultural changes needed to make the introduction of ePrescribing systems a success.

9.4 LSPs are currently developing the basic and advanced ePrescribing components of their strategic solutions and are currently contracted to deliver ePrescribing between 2008 and 2010. Separately, £11.5 million capital funding has been made available to acute trusts via SHAs to purchase interim oncology ePrescribing systems, to treat oncology ePrescribing as a priority, in support of the National Cancer Plan. It was a condition of the funding that procurements should commence by 31 March 31 2007.

Problems with legacy data

9.5 In general, the extent to which the time required for the implementation of Patient Administration Systems (PASs) is affected by data quality is determined by the priority given, and the resources made available, in individual organisations to cleanse data prior to migration. In total this can easily amount to several man years of specialist input. Indeed the scale of the task, exemplified by Mr Hains (Q276), to

eliminate duplicate and corrupt data when replacing existing computerised records cannot be overstated. NHS organisations have an accumulation of current and historic data held within their patient indices on their PASs and other electronic systems, or on paper records. Duplicate records exist in all PAS systems, mostly created when patients use different names or addresses to records already held, or when NHS numbers are not used. Duplicates also exist when hospitals merge and continue to operate two or more PASs simultaneously. It is estimated that most existing/legacy systems operate with a duplicate rate in excess of 9%.

9.6 The introduction of the NHS Care Record Service will result in closer integration of national and local records (both demographic and clinical) and the opportunity to build an individual's summary of key clinical events, diagnostic results and current medication. It is important therefore that the quality of the information recorded is high and that the number of duplicate records on the system is minimised, as any level of duplication will increase clinical risk.

Progress on interoperability

9.7 The reference by Dr Paul Cundy (Q102) to "moving towards" interoperability does not adequately reflect the level of progress achieved. Some 115 systems have now been through the compliance programmes for the new IT systems. This has created a level of systems' interoperability that was unimaginable three years ago, as a result of which, in a typical week 6.5 million HL7v3 messages are processed by the demographics service and 5.3 million messages by the central database, which is accessed on a typical NHS day by 50,000 authenticated unique users."

Delays to PACS in the North West

9.8 Dr Markham told the Committee (Q551) that:

> "the North West and the West Midlands [PACS] is delayed, because there were some contractual problems initially."

In fact, the subcontracted PACS' provider to the main supplier missed a number of key milestones. Their contract was terminated and another vendor was selected by CSC. A proven alternative solution was subsequently delivered to the NHS within three months. This is an example of the procurement arrangements working as designed.

Section 3: Local NHS costs and affordability

10. There has been much misinformation about the costs and affordability of the Programme, most of which can be dismissed following the publication of the NAO's study of the Programme last year.

10.1 Frank Burns told the Committee (Q556) that:

> "the resources are all locked up in NPfIT, and . . . . nobody can do anything because NPfIT has the money."

The figures simply do not bear out this assertion. Whilst there has been significant investment centrally in the National Programme through NHS Connecting for Health it is also the case that local IT spending in the NHS is significantly greater than that on the central programme and NHS IT spendind is also continuing to increase. This is demonstrated in the table below:

Table: Local NHS spending on Information Management and Technology—increases on previous year:

	2004–05	*2005–06*	*2006–07 (planned)*
Total IM&T spend (£'000s)	1,251,814	1,398,335	1,576,716
£'000s increase over previous year	103,286	146,521	178,381
% increase over previous year	8.99%	11.7%	12.76%

10.2 There is further evidence that local costs are reduced significantly as the systems are supplied through the Programme. Annex 2 contains illustrative examples of affordability comparisons between NPfIT solutions and local procurements.

10.3 The central PACS' procurement also demonstrated significant advantages over local procurements; with many commodity items costing 70% less than previous procurements. The significant delays in rolling out the PACS applications were due to NHS trusts' inability to get business cases approved by their Boards and the subsequent raising of Purchase Orders. There would have been considerable additional delay had Trusts attempted to justify business cases where the cost of ownership was considerably more expensive than was achieved by the Programme.

10.4 Dr. Markham implied (Q512) that the lack of availability of resources—subsequently provided through the National Programme—was the key obstacle to the rapid deployment of PACS. When the National Programme took on board acceleration of the procurement and deployment of PACS, one difficulty was that many radiologists wished to specify a local system, which would have driven up costs and delayed implementation. However, deployment of PACS under the Programme is not necessarily the same product as the earlier deployments. The National Programme systems offer a Trust:

- Trust-wide PACS
- Radiology Information System integrated fully with the PAS and PACS
- PACS in A&E, theatres and on wards
- Cross site access to images
- Access from outpatient clinics and outreach clinics
- The support of specialisms such as orthopaedics.

The installations prior to the National Programme did not all have this scope and it is this broadening of scope and widening of availability that has led to the delivery of benefits.

10.5 Frank Burns stated (Q516/7) that he had had a very sophisticated, fully functioning clinical system for 17 years. The Wirral Hospital NHS Trust elected to undertake independent procurement in 2004 for the replacement of the system that had a very high cost of ownership. The procurement was based on the NPfIT specification for clinical applications for an NHS acute hospital. The Trust, at considerable cost to the NHS and to the supplier community, got to "preferred bidder" stage in 2006. However, the cost of the solution was over twice that already achieved by NHS Connecting for Health for the Cerner Millennium Solution. Minded of the advanced functionality already enjoyed by Wirral Hospitals NHS Trust, and that their solution would "expire" at the end of 2007–08, putting patients and staff at risk, NHS Connecting for Health agreed with Fujitsu Services (the LSP for the South) to make available the Trust's preferred supplier's application at the NPfIT contracted rates. Subject to satisfactory conclusion of commercial discussions, the Wirral Hospital NHS Trust is planning to take the Cerner Millennium PAS in the first quarter 2008. Of course the substantial cost of procurement incurred by the NHS could not be recovered.

10.6 Contrary to Dr Taylor's evidence (Q546) the Shires Consortium did not include early delivery of the PACS applications. The consortium was a loosely federated purchasing consortium that demanded different applications and approaches to implementation, but that agreed to procure services locally. The cost of the Shires' procurement as determined in the business case was at least double that obtained during the NPfIT procurement. The NPfIT procurement further enjoyed more beneficial terms and conditions, greater levels of integration and significantly improved service availability for the NHS.

Section 4: The Summary Care Record and Patient Confidentiality

11. Many witnesses commented on the summary care record and the confidentiality issues. Most of the witnesses support the concept. The Department of Health gave extensive oral evidence on this issue, as well as making the case for the record in its initial written evidence (EPR 01) and in its further note dated 12 June 2007, which aimed to clarify some of the issues that had arisen at the oral hearings.

The summary care record

11.1 The Summary Care Record will be populated initially from the patient's computerised GP notes (unless a patient dissents from storing or sharing their record with the Summary Care Record system). It will be made available to authorised clinicians within the Out-of-Hours setting. As the Department indicated in its original written evidence to the Committee, the initial summary upload will include:

(1) Patient demographic details:
   - Current and other address details (eg contact address when different).
   - Date of birth.
   - Contact details (telephone numbers, email address etc).
   - NHS number.
   - Contact preferences including preferred language.
   - Consent status.

(2) Medications (Repeat prescriptions in last six months, acute prescriptions in previous six months, discontinued in last six months)

(3) Allergies and adverse reactions.

11.2 Subsequent uploads can include other information that the GP and the patient think would be useful in the Summary Care Record, including:

- Diagnosis.
- Treatments.

— Problems and issues.
— Care events.
— Clinical observations and findings.
— Investigation results.
— Risks to patient.
— Family history.
— Lifestyle.
— Social and personal circumstances.
— Personal preferences.
— Provision of advice and information to patients and carers.
— Administrative procedures.

11.3 In areas where hosted GP systems are being rolled out by Local Service Providers, out-of-hours services will be able to access shared GP systems directly from the LSP data centre. Specific Out-of-Hours functionality is being developed to ensure that appropriate controls and functions are available to the out-of-hours' community. This will provide data and facilities to ensure far greater continuity of care than that currently generally available.

Consultation on the summary care record

11.4 The answers given by witnesses to questions 177–186 do not reflect the extensive consideration and consultation that has taken place on the consent issue. The issue has been considered by seven separate groups, all of which concluded that opt-out was the most appropriate policy.

11.5 The policy that patients should opt out of having a Summary Care Record was proposed in 2003 by the NPfIT National Programme Board based on recommendations from the NPfIT Patient Advisory Group and the National Clinical Advisory Group, the membership of which included the Medical Royal Colleges and other clinical bodies. The recommendation from the National Programme Board was approved by a Ministerial Taskforce on NHS Information Technology in November 2003 and was subsequently endorsed by Ministers. The Ministerial Taskforce included members from the patient community, the NHS, the Department of Health, the Academy of Medical Royal Colleges, the BMA, the Royal College of Psychiatrists and the Government e-Envoy. Information has already been provided as part of the Committee's evidence session on 26 April 2007.

11.6 The Care Record Development Board (CRDB), established in 2004 and chaired by Harry Cayton, asked its Ethics Advisory Group, chaired by Professor Dame Joan Higgins, who also chairs the statutory Patient Information Advisory Group, to revisit the opt-out policy. The Ethics Advisory Group recommended that the previous decision that patients should opt out was appropriate. The CRDB considered the evidence and accepted the advice of the Ethics Advisory Group.

11.7 In September 2006 a Ministerial Taskforce on the Summary Care Record was established, chaired by Harry Cayton. The membership of the Taskforce included the NHS, patient representation, the BMA, the Royal College of General Practitioners, the Royal College of Nursing, the Professor of Bio-ethics from Oxford University and the College of Emergency Medicine. The Taskforce considered the opt-out policy and, having recommended an appropriate period to allow patients to opt out, supported it unanimously. The Taskforce set out clearly the arguments for and against both the opt-out and opt-in positions in paragraphs 4.3–4.5 of its report. They concluded that it was more ethical to allow patients to opt out.

11.8 All the information published makes it clear that patients have a choice and that the NHS will continue to provide the best care that it can irrespective of whether patients have a Summary Care Record.

Explicit consent

11.9 In paragraph 6 of its written evidence to the Committee (EPR 11) Patient Concern expressed the view that the explicit consent of patients should be gained prior to uploading data into the Summary Care Record. The Ministerial Taskforce did not support this approach. Concerns over an explicit consent approach have been that it would:

— take considerable time to implement and therefore delay the delivery of the benefits associated with having a Summary Care Record;
— disadvantage the most vulnerable members of society who may benefit most from the new record but may not be provided with one for a considerable period, or who may be difficult to contact to gain consent. Patient Concern's suggestion that vulnerable people could be contacted in writing to obtain consent is misleading as the very nature of their vulnerability would exclude many such individuals;

— require everyone to take action when, based on the experience of other countries who have implemented similar electronic records, only a very small minority will request not to have a Summary Care Record at all. In Canada a legal requirement for explicit consent was swiftly amended when health professionals complained about the time taken away from patient care when more than 99% of patients were not concerned about appropriately managed electronic health records.

11.10 Patient Concern also suggested that developments in France and Greece had demonstrated that explicit consent can be gained for the upload of records. No specific evidence was provided about the relative scale of developments in those countries, though it is accepted that in some circumstances it would be practicable to gain explicit consent. However, there are no true comparisons between the creation of the Summary Care Record and developments in these other countries. The cost of an explicit consent process for 50 million people, in terms of NHS staff time and the associated opportunity cost of patients not seen, particularly in the light of the position adopted by the Ministerial Taskforce, is not sustainable.

Sealed envelopes

11.11 Professor Korff told the Committee (Q195) that:

> "provisions about sealed envelopes that cannot be opened without the consent of the data subject; and the right of every patient regularly to receive a log of every person in the NHS who has had access to his data, including, I daresay, any researcher who has access to his data and who can be identified. Those are safeguards that can be built in; they are not envisaged here now."

11.12 Professor Korff also stated (Q218) that he understands that:

> "all the data in the sealed envelope will be available for research with minimal anonymisation and pseudonymisation."

He said that the

> "envelopes are not sealed very well" and that "It is fairly easy for practitioners to break them open."

11.13 Professor Korff's understanding is flawed and the statements he made are incorrect. Patients will have the choice of two types of sealed envelope:

— The first, which we refer to as sealed and locked, prevents data from being available outside of the clinical team that recorded the information, whether for research or any other purpose. The data will remain available to those who recorded it whilst they are caring for the patients.

— The second, the ordinary sealed envelope, does permit data to be extracted, in a fully anonymised form for research purposes, and it will also be available for clinical staff in emergencies when the patient is unconscious or with the patient's consent. The mechanism for breaking the seal in these circumstances is simple, though there are strong managerial controls to prevent misuse, as it is expected the seal will need only to be broken without consent at times when the patient concerned is in desperate need for urgent care. Whenever the seal is broken the circumstances will be investigated and the patient will be informed.

11.14 The NHS Alliance presented written evidence to the Committee on this topic (EPR 19). In their paragraph 3.1.4 they said:

> "Again, the NHS Alliance would recommend that . . . patients should also be informed when their sealed envelopes have been opened. This is not planned at present and is a SERIOUS omission; . . . "

11.15 In due course patients will be notified, through HealthSpace, whenever there is activity on the record involving a change in the sealed record status. This includes creating a seal, breaking a seal, and any action to override dissent. In addition, a NHS Caldicott Guardian/Privacy Officer will receive an alert when a seal is broken (with or without consent from the patient). Virtually any action, including changes to sealed record status and clinicians self-claiming legitimate relationships so they can break the seal, creates an audit trail. Patients cannot access their audit trail directly (through HealthSpace or any other route); though Data Protection Act Subject Access Request provisions will provide this information on application.

Safeguarding confidentiality for patients with mental and sexual health issues

11.16 Joyce Robins expressed her concerns on confidentiality for patients with mental and sexual health issues to the Committee on 10 May 2007 (Q204). On 15 March 2007, over a hundred clinicians, information governance staff and representatives of patient groups in Reproductive and Sexual Health Medicine came together to debate whether the safeguards being offered by the National Programme were enough for the specific confidentiality needs of this community. Throughout the day, delegates were asked to discuss a range of issues and provide answers using tablet PCs on their tables; some were repeated at the end to see whether opinions had changed.

11.17 One question that showed a shift in views was: How do you feel the National Programme for IT will affect the confidentiality of information (including test results) in your clinical environment?

	Before	*After*
Will improve	6%	15%
May improve	23%	51%
Unlikely to impact	15%	7%
May worsen	37%	16%
Will worsen	19%	11%

11.18 A very clear steer on what delegates wanted was provided by questions such as: Who should decide how far information is shared?

— Patient: 23%

— Clinicians (Genito-Urinary Medicine clinic, reproductive health service or GP): 0%

— Patient and clinician together: 77%

— NHS Connecting for Health: 0%.

Section 10 of the Data Protection Act

11.19 In paragraphs 5–11 of his written evidence (EPR 08), Dr Peter Gooderham refers to and quotes Section 10 of the Data Protection Act 1998, which provides patients with the right to require a Data Controller, in this case, the Department of Health, to cease processing personal data where this is causing, or may cause, substantial damage or substantial distress where that damage or distress are unwarranted. He suggests that breach of confidentiality may be regarded as "substantial damage", but recognises that there are exceptions to Section 10 and quotes one such exception where the processing is in the vital interests of the data subject.

11.20 The Department of Health accepts that this may be the case, but any consideration of the application of Section 10 must be conducted on a case by case basis. This would need to consider:

— the content of the record and the damage or distress that might be caused by unauthorised disclosure;

— the circumstances of the data subject—keeping records of an individual who puts others at significant risk may be warranted even where this causes the individual concerned substantial damage or distress;

— the importance of the record to the data controller or others—the need to maintain evidence against future complaint or litigation may require the record to be kept even where a patient objects;

— the safeguards and controls that are in place, as, if there is no risk of breach of confidence, then the Section 10 notice may be rejected.

11.21 In paragraph 10 of his submission, Dr Gooderham suggests that if prominent individuals such as MPs are allowed to object, but others are not, then such a distinction may be discriminatory. Whilst, at the direction of Ministers, all adult patients may choose not to have a Summary Care Record, there is no other automatic right to prevent processing. Any request, regardless of the celebrity of an individual, will need to be considered on a case by case basis.

How many will opt-out of the summary care record?

11.22 Experience from the early adopter primary care trust areas in England where the summary care record is being trialled shows that the number of people who wish to opt out of the Summary Care Record has been very significantly exaggerated on the strength of the views of a small minority. Only just over a thousand people out of a total of over 350,000—less than one third of one percent—have to date requested not to have a summary care record. The following statistics provide the latest information from the Early Adopter Programme:

— 9,952 clinical records have been uploaded to the NHS CRS;

— 350,759 letters detailing the NHS CRS options available have been sent to patients, resulting in a total of628 calls to the NHS CRS Helpline;

— 939 consultations have taken place at public events and at the practices that have so far contacted their patients;

— the number of patients choosing not to have a summary care record is 1,068 (0.29%).

Incremental approach to developing the summary care record

11.23 Joyce Robbins, apparently on the strength of attending a single presentation, misrepresents (Q203) as ill-considered and ad hoc what is in fact a planned incremental design and consultation process for developing the Summary Care Record. Our Care Records Service National Clinical Reference Panel (Chaired by Dr Simon Eccles, NHS Connecting for Health) is actively considering further content and enhancements of the Summary Care Record. The Reference Panel includes representative clinicians from a wide range of nursing, medical and allied health backgrounds and many different care settings. It also includes patient and patient advocate representatives. Information was provided as part of the oral evidence session on 14 June 2007.

11.24 The Panel is taking a very broad look at the future of the Summary Care Record, taking care to balance any possible future addition against the need to keep the summary record as a clinically useful and accessible record which does not swamp the user with information. It will be looking at suggested future content with specific regard to enhancing patient safety; increasing clinical and patient utility; and the benefits of the additions compared to the technical difficulty of achieving them. As ever, the intention is to consult with the widest possible range of clinical and patient stakeholders.

Early adopter sites

11.25 As explained in the Department's written evidence EPR01, the deployment of the Summary Care Record (SCR) has started in the Early Adopter PCTs. The Early Adopter Programme will run to April 2008 and is subject to an independent evaluation by University College London. The Early Adopter Programme will refine the implementation approach and facilitate preparation for the subsequent National roll-out that is expected to commence in financial year 2008–2009. To date:

- SCR implementation has started in two PCTs (Bolton and Bury).
- So far, the two PCTs have sent letters to over 350,000 patients (100% Bolton patients and 59% Bury patients) initiating the process.
- Both PCTs have launched significant public information programmes to inform their patients.
- The SCR upload process has begun in Bolton and the local out-of-hours provider is preparing to begin access (to commence in August).
- Bury PCT will follow shortly (there is a 16 week period between the patients being informed through letters and the commencement of access to their records).
- Shortly following access for out-of-hours in Bolton and Bury, access will be made available in other unscheduled care settings (eg Accident and Emergency, NHS Walk-in Centres, Minor Injuries Units and Ambulance Services).

11.26 The other Early Adopter PCTs have plans in place and are currently in the advance stages of preparation for launching the SCR.

Electronic records for children

11.27 On 10 May 2007 the Committee considered some issues relating to electronic health records for children (Q206 onwards). The Care Record Development Board has established a working group to examine the issues around electronic records for children. The group is chaired by the DH National Clinical Director for Children, Young People and Maternity Services and its members represent the National Children's Bureau, the Royal College of Nursing, the General Medical Council, Safeguarding Children, Sure Start and Information Sharing and Assessment Units of the Department for Education and Skills, the Royal College of General Practitioners, the Royal College of Midwives, the Royal College of Paediatrics and Child Health, the Royal College of Obstetricians and Gynaecologists, the Office of the Children's Commissioner, the Royal College of Psychiatrists, the Community Practitioners' and Health Visitors' Association, the Department of Health and the NHS.

11.28 The group has considered the issues surrounding electronic records for children, including discussing them with a group of children, and has produced a new section for parents and older children in the 2007 revision of the Care Record Guarantee (already submitted to the Committee by Harry Cayton). This describes the rights of parents and children around access to children's records. The group is also producing an appropriately targeted version of the Care Record Guarantee for younger children. The children and young people's section of the Guarantee stresses the importance of developing autonomy for young people.

11.29 It seems that in responding to these questions Ms Robins and Prof. Korff have confused detailed care records and the Summary Care Record. The question asked whether it should be mandatory for children's detailed care records to be stored electronically. The position is that detailed records of treatment have to be kept and it is the responsibility of the clinician providing the treatment not only to keep the record but also to decide the medium on which the record will be kept. Patients, or in this case possibly their parents,

can request that records are not kept electronically but they cannot demand it. The merits of electronic records in terms of security, legibility and transferability via the GP to GP transfer functionality are well documented.

11.30 Professor Korff raised the issue of parents consenting to a detailed record for a child. His example was one of a child with leukaemia where the child requested not to have a record at an age when they were considered competent. As far as detailed records are concerned, paper records have a minimum retention period and it is right that electronic ones do too. We are currently consulting with the regulatory bodies and the medical insurers what the retention period for electronic records should be. The Committee might wish to note the reduced storage requirements of electronic records.

11.31 It has always been made clear that, having initially said that they wanted a Summary Care Record, patients can change their minds and this applies equally if a parent has decided that a child should have a Summary Care Record and when they become competent the child disagrees. As the Summary Care Record may have been used as part of treatment it cannot be deleted and so is archived and can only be accessed if needed for medico-legal purposes.

11.32 The National Programme's Child Health Programme is also exploring the potential for information sharing to the benefit of the child. This includes consideration of issues relating to children's records in terms of accessibility and sharing. They will be taken fully into account when drawing conclusions, with specific attention to:

- the current and emerging policy position and initiatives, including the obligations currently placed on NHS bodies to provide certain information about children to other public agencies;
- guidance from the joint work of the Care Record Development Board, under the chairmanship of Harry Cayton, and the Director for Children, Young People and Maternity (Sheila Shribman);
- the outcome of legal advice that has been sought.

11.33 The Child Health Programme is also looking to build on the existing (paper-based) Personal Child Health Record (the "Red Book"), issued for all children, as an exemplar of the potential content of a shared record and also of the issues involved in access and sharing of this record for health professionals with the consent of the parent.

11.34 The Child Health Programme sees its remit as to identify solutions to implement current policy for children as it relates to information sharing, taking account of professional and legal perspectives as well as policy drivers.

11.35 Professor Korff's assertion that the NHS will attempt in a divisive way to incorrectly infer the competence of children is wrong. Neither the NHS, nor the Programme, is developing or seeking to assert its own policies regarding information sharing.

11.36 In addition, NHS Connecting for Health has been working very closely with the previous Department for Education and Skills to implement the policy "Every Child Matters." This work aims to ensure that healthcare practitioners and other care professionals working with children can be identified to share information when vulnerable children are at risk.

Availability of HealthSpace

11.37 Joyce Robins also said (Q191):

> "I do not know when [Healthspace] will be available."

Basic HealthSpace functionality to act as a personal health organiser is already available to all patients aged 16 or over in England. Patients are currently able to record and manipulate information such as their weight, smoking habit or alcohol consumption to help them manage their health. Calendar and diary functions are also available and Healthspace also gives patients access to the Choose and Book on-line booking service. It is therefore wrong to assert that HealthSpace does not exist.

11.38 Recently, HealthSpace has added the capability for patients to view their Summary Care Record (SCR) once they have been uploaded to the Spine. This capability is being rolled out to a number of Early Adopter PCTs during the remainder of the year in line with the roll-out of the SCR itself. A national roll-out of this functionality is intended from 2008 onwards. Detailed planning to achieve this will be undertaken once the lessons learned and feedback from the Early Adopters is available.

11.39 It is expected that from some point in 2008, HealthSpace will allow patients to add information to their SCR. The items that can potentially be added to the SCR are:

- Religion—the religion of the patient
- Spiritual support—whether the patient would like to see a representative of their faith during a stay in hospital
- Religious customs—details of any religious customs that the patient would like to observe during a stay in hospital that may require special facilities or considerations (eg prayer facilities, Ramadan etc)
- Dietary requirements—patient's dietary preferences eg Vegetarian, vegan, etc

— Access requirements—what special access needs does the patient have?

— Transportation—does the patient require hospital transport to get to their appointment?

— Wheelchair user—Is the patient a wheelchair user?

— Hearing aid user—does the patient have a hearing aid?

— Patient comment—multi-purpose free text comment entered by the patient.

11.40 The Care Record Service Design Steering Group is considering these options and HealthSpace will implement those items which are considered to be suitable by the appropriate HealthSpace governance boards.

11.41 Separately from the SCR, future options for HealthSpace to become a utility provider of personalised health information are being considered. This is likely to include more facilities to help patients manage long term conditions and chronic diseases.

NHS use of identifiable and non-identifiable patient data for care and for secondary uses

11.42 The oral evidence provided by certain witnesses to the Committee on the distinction between identifiable data and non-identifiable data, how these may be used and shared, and how they are protected in the National Programme's systems, was poorly informed and at times misleading. To provide clarification, a note has been included as Annex 3.

Section 5: Consultation and professional engagement on the system specification

12. One recurrent criticism is that there has been insufficient consultation, especially with clinicians, around the overall design and operational aspects of the National Programme. This was examined extensively by the Committee on 14 June 2007, when the Department gave evidence of just how much had been done, whilst agreeing that there is always a case for doing more.

12.1 Attached for information (at Annex 4) is a copy of a response to a Parliamentary Question given on 21 June 2007 to Stephen O'Brien MP by the Department's then Minister of State, Caroline Flint, on this matter. This demonstrates the depth of consultation on the specification of the NHS Care Records Service.

12.2 Dr Hale told the Committee (Q273 and Q312) that:

> "speaking from the point of view of my own trust and the Royal College of Psychiatrists, we have not been able to make a great deal of input."

In fact clinicians from across the spectrum of clinical specialties were given the opportunity to contribute to the specification of the requirements. The extent to which this opportunity was taken up in each case is not something the Department could necessarily influence. The specification itself was built on years of experience across the NHS, and many clinicians were involved in the drafting—in particular the Academy of Colleges Information Group contributed the first module of the specification for the NHS Care Record Service. During 2003, a group of clinical advisors worked with the National Programme; this included Martin Elphick, a consultant psychiatrist from Oxford. The nature of the contracts (using the OGC-approved method of producing an Output-Based Specification) means that the specific design is the responsibility of suppliers, but with users involved in the review of supplier proposals. The later consultation activities, covering areas such as consent and sealed envelopes, have been led by the National Clinical Leads within NHS Connecting for Health, in conjunction with representative professional bodies. The principle is to ensure full user engagement in the definition of requirements rather than the technical design of the solution.

12.3 Engagement with the Royal Colleges has been an ongoing process throughout the life of the Programme. In 2002, the representative body was the Academy of Colleges Information Group (ACIG), which brought together input from all the Royal Colleges. This group commented on the July 2002 specification and contributed an entire module to the 2003 specification. From the earliest days of the Programme meetings were held with leaders of the colleges. Peter Hutton then set up the National Clinical Advisory Board is 2003, and this took over the responsibility for bringing input from the Royal Colleges. Professor Michael Thick, as the Chief Clinical Officer of the Programme, with his team, has now taken on this liaison role.

Section 6: Evaluation and benefits

13. The Programme will be subject to evaluation. In 2006 NHS Connecting for Health commissioned Birmingham University to run an overall programme of evaluation on its behalf—the "NHS Connecting for Health Evaluation Programme." This programme of work is headed by Professor Richard Lilford.

Evaluation of the NHS Summary Care Record Early Adopter Programme

13.1 Subsequently, University College London (UCL) was awarded the contract to conduct a year-long independent evaluation of the NHS Summary Care Record Early Adopter Programme, to fall within the wider programme. UCL were selected following a competitive tendering exercise run by Birmingham University which saw seven applicants submit bids to conduct the evaluation. The year-long evaluation commenced formally on 1 May 2007 and a final report is due to be published in the summer of 2008.

13.2 The primary aims of the evaluation can be summarised as: to assess usability, usage, functionality and impact of the Summary Care Record in Early Adopter sites, and place this in context; to set the stage for the step-wise inclusion of further sites and further data sources; to provide timely feedback to stakeholders; and to contribute to the generation of an evaluation culture within NHS Connecting for Health and the National Programme for IT.

13.3 The evaluation will inform the national rollout of the SCR from 2008 onwards although any emerging findings will of course feed into the ongoing implementation of the Summary Care Record within Early Adopter communities.

Benefits of PACS

13.4 In her evidence (Q217), Joyce Robins cast doubt on the benefits of having digital X-rays automatically uploaded to detailed care records. At the end of June 2007 benefits analysis for the first year of PACS implementation had been completed for 65 Trusts. The total financial benefit in the first year of service was approximately £18.5m, with £9.9m of this total saving being projected by 48 trusts from data recorded 3 months after the implementation of PACS. Additionally some Trusts have reported reductions in the incidence of repeat X-Rays by over 75%. Reporting times and the percentage of reports completed in 48 hours have also improved significantly, and this has been shown to be influenced by the deployment of digital dictation and voice recognition.

Loss of benefits if patients have the right to remove their NHS electronic record

13.5 Returning to the evidence from Symantec in EPR 37, paragraphs 4 and 5 effectively support the objectives and case for the National Programme, although the assertion that full benefits will not be realised if patients have the right to remove their NHS electronic record is a gross oversimplification. Benefits of storing medical data electronically accrue largely to the patients themselves; hence lack of an electronic medical record mostly impairs the patient's ability to receive safe and efficient medical care. The reduction of NHS benefits is largely a consequence of lowering the efficiency of processes to deal with patients when they have no electronic record and these inefficiencies scale with the number of patients electing this option. These inefficiencies are largely operational (it will take more time to treat a patient without an electronic record) and are only indirectly related to the inability to benefit from the change in technology.

Benefits of mobile clinical records

13.6 The recently reported evidence emerging from the early implementations of mobile clinical records is precisely the opposite of what Dr Dilks suggests at paragraph 8 of EPR 10. In the community staff-based trial in Nottingham[14] where laptop computers were connected through encrypted wireless links to the NHS network (N3), the results of the trial showed that on average staff had 38 minutes additional productive time per person per day with the potential to save 60 minutes a day. The trust saw a reduction in travel times of 32% and realistic additional potential to reduce commuting by 50%, with the potential for a 25% increase in productivity.

Nationally, in broad terms the number of front line staff who have access under the National Programme for IT to shared electronic health records is as follows—

13.7 On average 96% of patient notes were completed on the day, rather than a typical delay of up to 48 hours previously. Users perceived an average of 70% improvement in facilities to do their job. The success was not limited to one particular group of clinicians. The trial included community matrons, paediatric physiotherapists, paediatric occupational therapists, and paediatric speech and language therapists. A video of the clinicians talking about their experiences is available[15]. Security and staff training were included within the trial.

13.8 Emerging evidence of savings and efficiencies on this scale are extremely compelling. When the new hardware (discussed below) becomes available at the end of the year we expect to see rapid take-up and deployment of clinical systems in the community-based services.

[14] http://www.ehiprimarycare.com/news/item.cfm?ID=2855
[15] http://www.healthexectv.tv/home.asp

13.9 Trials of mobile computing platforms are currently in progress in several acute trusts, including Salford Royal NHS Foundation Trust and University Hospitals Coventry and Warwickshire NHS Trust. Evidence from the Salford trial with the phlebotomy service showed very rapid changes and improvements in clinical workflow. This has led to Phlebotomists being able to:

- start new orders whilst mobile. This enabled laboratory processing to begin sooner—potentially speeding result-reporting, as well as treatment plan adjustments;
- resolve questions quickly. The portability made it easy for phlebotomists to locate requesting clinicians, address questions, and capture corresponding order-updates;
- chart each blood draw at, or close to, the time of the event. This gave phlebotomists a sense of completion, minimising the chance of forgetting important information, and making information available more quickly to other clinicians;
- ensure positive patient identification. The built-in radio frequency identification (RFID) reader enabled phlebotomists to positively identify those patients wearing RFID wristbands;
- reduce paperwork;
- eliminate the need to wait for access to a hospital ward's personal computers to enter patient data;
- avoid unnecessary blood draws resulting from previously unrecognized discontinued orders. Needle sticks are painful and stressful for patients. Avoiding these unnecessary draws has benefited patients and enhanced overall service efficiency.

13.10 A larger business benefits analysis is currently underway in Salford but early results show patient discharge being accelerated by a half day.

13.11 As part of the wider picture NHS Connecting for Health's Technology office has been working closely with Intel to catalyse and define a new category of mobile computer ("mobile clinical assistant") designed specifically with the clinician in mind. Four suppliers (with more to follow) have announced that they are working on the delivery of units to this specification. Without the input from NHS Connecting for Health it is unlikely that these units would have been built. The work was done by Intel and the suppliers at their own risk. No NHS monies were spent on the development or prototyping of the devices.

Section 7: Public information and patient safety

Section 7.1 *Issues Relating to Public Information*

Use of the postal service

14.1 Also in her evidence (Q187), Joyce Robins said that what:

> "we suggest is that when this bit of rubbish goes out to patients with it should go a copy of the record that is going to go in. Connecting for Health very quickly jumped on me and said that the postal system was not nearly secure enough for that."

This point needs further explanation.

14.2 The letter had, in fact, been trialled with patients during its development and discussed with the Information Commissioner. Sending letters and leaflets to patients in the post is one of several strands of the Public Information Programme that supports the introduction of the Summary Care Record. Alongside the letters and leaflets are road-shows in prominent local locations, support centres (Information Booths) within PCT premises, posters and leaflets in GP surgeries and advertising campaigns in local media. The independent evaluation of the Early Adopter Programme will examine the effectiveness of each strand of public information activity.

14.3 Whilst sending letters and leaflets is an effective part of a wider information programme, it is not a suitable mechanism for sending print-outs of patient records to large numbers of patients. Information from the University Hospital Birmingham suggests that 3% of mail was misdirected prior to the introduction of the Personal Demographics Service and 0.44% after its introduction. For a PCT with 300,000 patients, a 0.44% misdirection rate would lead to over 1000 misdirected patient records. In addition, there are further concerns and risks posed by shared addresses and potential risks in the postal service itself (for example, Postcomm's £9.62 million fine applied to Royal Mail in August 2006 for failing to secure mail).

14.4 Instead, through the Public Information Campaign, the patients will be told where they can go to view their record (the location is arranged by the PCT). This way, a patient's identity can be checked prior to revealing sensitive patient data.

The public information campaign

14.5 In her response to Q196, Joyce Robins either seems to believe the Hampshire project was a part of the National Programme, or seeks to make direct comparison between the two. Both are a misconception. The public information programme supporting Summary Care Record Early Adopters is not the same as the information campaign implemented in Hampshire and the Isle of Wight. NHS Connecting for Health held a workshop with the team from Hampshire and the Isle of Wight specifically to learn the lessons from the information campaign that had been implemented there. These were:

- that patients need to be told a specific date by which they need to make their decision on whether to opt-out or not. As a result, the letter sent to patients in Early Adopter PCTs tells them by which date they need to tell their GP surgery if they wish to opt-out;
- that not enough information was available to patients who wished to opt-out. Additional information is available to patients who wish to opt-out of having a Summary Care Record. This includes information on the implications of choosing to not have a Summary Care Record;
- that more information was needed about where the information came from and who would have access to it. The information available at Early Adopter PCTs tells patients where the information comes from and who can access it;
- that there weren't enough sources of information for patients other than by phone or email. NHS Connecting for Health has made additional materials available to patients including a detailed leaflet about confidentiality and patient records and the Care Record Guarantee Drop-in sessions are also available for face-to-face conversations for those people who would prefer to discuss their options;
- more could have been done to reach foreign language speakers and ethnic minority groups. The leaflet about the Summary Care Record is available in twelve languages, the leaflet about confidentiality in six and the Care Record Guarantee in thirteen. Leaflets are also available in Braille and large print. Audio support is also available. Leaflets can be ordered by phone, post or email. As a result, NHS Connecting for Health supports the Early Adopter PCTs to engage and reach hard-to-reach groups within their local areas;
- Hampshire and Isle of Wight used Royal Mail's household drop service which means one un-personalised letter or information pack per household. This was thought ineffective. The NHS Connecting for Health Public Information Programme includes sending a personalised information pack to all registered patients aged 16 and over.

Section 7.2: *Issues Relating to Patient Safety*

15.1 In response to Q246, Joyce Robins presents a partial interpretation of patient safety statistics. The figures she quotes imply a level of significant (if non-fatal) incidents resulting from lost records of roughly equivalent numbers to those of MRSA-related deaths annually. But this is only a small piece of the greater issue. A study of adverse drug reactions as a cause of hospital admission published in the British Medical Journal in 2004[16] concluded that:

- one in 16 hospital admissions are the result of an adverse drug reaction (ADR)—72% of which are avoidable;
- this equates to 4% of hospital bed capacity;
- at any one time the equivalent of 7 x 800 bed hospitals are occupied by patients admitted with ADRs;
- ADRs causing hospital admissions are responsible for the death of 5,700 patients every year;
- the annual cost to the NHS is £466 million.

15.2 This and other powerful evidence of the very significant patient safety benefits to be achieved from electronic patient records is provided in the paper attached as Annex 5.

15.3 To suggest that:

> "medical records . . . ..can be provided by GPs within 48 hours, or shorter"

is a disingenuous comfort to patients who present for treatment, ever increasingly, out-of-hours or for unscheduled care. To cite one tragic recently-reported case, that of Penny Campbell, who contacted the out-of-hours service eight times over four days, the doctors working for the out-of-hours service treated each contact as a "one off" because none of them had access to her clinical record; and none of the doctors after the first had been aware of the earlier contacts. One of the criticisms of the circumstances was that the patient had been required to describe her symptoms on eight separate occasions. The inquiry concluded that the paper-based system of record keeping used by the out-of-hours service was a direct factor in the patient's death.

[16] Pirmohamed, M. *et al*: Adverse drug reactions as a cause of admission to hospital: prospective analysis of 18,820 patients: BMJ 2004; 329: 15–19.

SECTION 8: OTHER ISSUES

Accountability for delivery of the Programme

16.1 In his oral evidence (Q519/20) Frank Burns suggested that accountability for delivering the Programme has been and remains too centralised. This issue has in fact been addressed. The NHS Chief Executive, David Nicholson, initiated the NPfIT Local Ownership Programme (NLOP) in October 2006, in line with the recommendations of the National Audit Office report, to re-position the Programme as part of mainstream NHS business, and to ensure that the products and services being delivered under NPfIT were meeting the current priorities of the NHS.

16.2 On 1 April 2007 formal accountability for implementation and the realisation of benefits moved to the Strategic Health Authorities. SHAs are now responsible for the local prioritisation of NPfIT systems, establishing and overseeing local implementation plans and local product and service requirements.

16.3 NHS Connecting for Health continues to be responsible, within the Department, for the NPfIT commercial strategy, contractual negotiations with suppliers, management of NPfIT funds, national services and products, the provision of the Programme Office and the development, maintenance and enforcement of the national NPfIT architecture. To ensure relationships with Local Service Providers continue effectively, three local Programmes for IT have been established, for London; the South; and the North, Midland and East. The Programmes for IT will work alongside the SHAs to facilitate a joined-up approach in implementing NPfIT across constituent SHAs.

16.4 In respect of the response given to question 501, whilst the National Programme has been in existence since 2002, NHS Connecting for Health was established on 1 April 2005.

16.5 Nicholas Beale (in EPR 14) suggests that the creation of NHS Connecting for Health was simply a re-branding exercise. This is not the case. The NHS National Programme for IT has retained the same name since its inception. The Programme is delivered by NHS Connecting for Health which, as an agency of the Department of Health, delivers all the national IT requirements of the NHS, including the legacy services. The Agency was set up in April 2005 following the closure of the NHS Information Authority. This was done for administrative and efficiency reasons, taking account of a separate decision to establish the NHS Information Centre. It had nothing to do with re-branding the Programme and no action was taken to suggest that it was.

16.6 Whilst dealing with Nicholas Beale's evidence, it is not right to suggest that the Programme's origins are at arms' length from the front line of the NHS. The Chief Executive of the NHS is the Senior Responsible Owner of the Programme.

Evidence submitted by Stalis Ltd (EPR 05)

16.7 The evidence from Stalis makes a number of inaccurate claims and appears to reflect the fact that the company failed in its bid to be a National Programme contractor and wishes to continue to market its existing systems.

16.8 Their remarks about the "haste" in getting the contracts in place contrasts with the NAO's conclusion of "commendable speed." The NAO also reported on the strength of the contracts. Although Stalis complain of haste, it should be noted that most successful suppliers complain that multi-year government procurement arrangements are unsatisfactory.

16.9 Annex 6 of this note shows that 115 existing systems' suppliers have obtained work under the Programme, which refutes Stalis' allegations in their paragraphs 6–11. Stalis inaccurately quotes remarks made by Richard Granger regarding the very poor level of interoperability of systems, including those provided by Stalis Ltd. These remarks were made some five years ago, expressly about systems which were unable to move data on the same software between sites. It is assumed that this is a failing in functionality which Stalis would not continue to support.

16.10 In respect of paragraph 8 of Stalis' evidence, the very considerable number of NHS existing systems' suppliers that have obtained work under the National Programme (Annex 6) provides substantial contradiction of the selective marshalling of information on this matter. Some 60% of the hospital-based systems were procured from a UK listed entity; the major central infrastructure components of the Programme (the Spine and N3) were also procured from a UK listed company; and a UK entity, ConMedica, was selected originally for 20% of PACS business.

16.11 Contrary to the assertion made in paragraph 9, relevant experience of comparable projects and subcontractor mix was evaluated alongside the resource arrangements that the suppliers had in place. For example, the selection of IDX from the USA, though not an LSP, as the main subcontractor for the London and the South Cluster areas was on the basis of their successful deployment at the Chelsea and Westminster NHS Trust, which remains far in advance of the product marketed by Stalis Ltd.

16.12 The assertion at paragraph 10 regarding experience of the NHS on the Programme in 2002 through to 2005 is also untrue. In 2002 the Programme was led by Professor Sir John Pattison, the former Dean of a medical school, the Director of Research, Analysis and Information at the Department of Health. Subsequently, the Programme was co-led by the Deputy Chief Medical Officer, a distinguished

gynaecologist and obstetrician, Professor Aidan Halligan and a substantial number of senior NHS personnel have been involved continuously in the Programme both as clinicians and senior managers. Similarly, the assertion that the suppliers had had no NHS involvement is also untrue. BT was, in 2002, the largest supplier of services to NHS trusts with an annual turnover in excess of £200 million.

16.13 Contrary to paragraph 11, it is not true that funding was unavailable for migration and cleansing of data. Funding for this is provided in two ways. Firstly, the trusts get to keep the savings from their existing contracts with organisations such as Stalis Ltd, following the implementation of national systems. In addition, £166 million has been provided over the period 2004–5 and 2005–6 for this express purpose. It should not go without comment that the cleansing of data within existing systems, such as those supplied by Stalis, is something which the company assumes it is right should funded by the National Programme.

16.14 Paragraph 12 alleges that:

> "the LSPs commenced the programme with little or no experience in UK healthcare and little experience anywhere of the systems required by the NHS. Although this has improved with some LSPs it is not consistent across the NHS and remains an issue today."

In fact, assessment of prime contractor capacity and capability at the pre-qualification stage of the NPfIT procurements required evaluation of relevant similar services. The prime contractors who subsequently became LSPs provided examples of their experience. These are contained in Annex 7 of this note.

16.15 Contrary to paragraph 14, the substantial cost of ownership of legacy systems was very well understood. This cost remains a driving force for reducing the number of configurable components within the Programme, since the cost of acquiring interoperability is above and beyond the NHS funding envelope.

16.16 Paragraphs 20 and 21 contain some broad-brush assertions that are not borne out by the facts. The involvement of, for example, System C, Hedra, Tribal and others are examples of pre-existing NHS expertise being used to the greatest extent possible, but, unlike previously, within contracts which now provide adequate protection to the taxpayer.

16.17 The National Programme is a transformation programme for the NHS that will underpin the Government's system reform programme. It is supporting delivery of key reforms such as patient choice, the 18 weeks referral to treatment patient pathway, the GP contract, and practice-based commissioning, but at the same time is designed and is being engineered to retain flexibility to adapt to, and adopt, future policy. The risks suggested in paragraph 23 are therefore being managed.

16.18 Far from being a "counterproductive" task as suggested in paragraph 26, replacement of some long-standing PASs is essential. Many are facing hardware obsolescence and software which is unsupported. Not to replace them will put the care of patients in those hospitals at unacceptable levels of risk and it would be irresponsible not to proceed with replacement, simply because some software suppliers would like to see continuity of revenue.

16.19 In paragraph 27 Stalis fails to acknowledge that the devolved approach had not made acceptable progress across the NHS as a whole. The NHS Care Records Service will provide an integrated national service for all NHS clinical applications. This is being delivered as part of an overarching information strategy that allows the portfolio of systems from the Local Service Providers and the existing systems' providers to be integrated into a coherent service. The clear evidence that this approach is proving effective is that 115 systems have been through the compliance programmes, creating a level of systems interoperability that was unimaginable three years ago.

16.20 The statement in paragraph 34 that the UK supplier industry was ruled out is fundamentally wrong. That they were uncompetitive in part, undercapitalised and unable to contract with well-capitalised global players, is not something which could be blamed on the Department of Health. Further, the corporate failures or frailties of Torex, iSoft, and ConMedica all validate arrangements which avoided direct contracting with small and mid-sized entities that were unable to bear payment on completion risk for a programme of this scale. Preferential treatment for domestic suppliers, on this criterion alone, would have been unlawful under the EU Procurement Directive and WTO arrangements.

16.21 The final specific comment on the Stalis evidence relates to their paragraph 43. The policy of self-determination advocated by Stalis is largely incompatible with the objective of safer patient care—recognised as important at their paragraph 39—which is supported and enhanced by the interoperability of systems and Spine compliance provided under the National Programme.

16.22 More generally, Stalis clearly believes that it is possible to integrate multiple different systems to common standards to allow joined up care. However, they fail to acknowledge that prior to the inception of the National Programme for IT there was little evidence of this being done. The NPfIT has created the environment which will allow this multi-system approach to become a reality through the central architecture (that has been successfully delivered) and by the Local Service Providers acting to coordinate multiple suppliers in the overall delivery. The LSPs have become more plural over time (eg BT using Rio and InPractice Systems as well as Cerner; CSC using The Phoenix Partnership and HSW as well as iSOFT). This trend is increasing and will become more apparent in the coming months.

16.23 The criticisms levelled by Stalis are of an already past world from which NHS Connecting for Health has moved on in order to serve the NHS better. The LSP actions to diversify their portfolio of systems, the Existing Systems Programme, GPSoC and more recently the procurement exercise to increase the number of suppliers to the Programme are all clear evidence of this.

16.24 Stalis' reference to statements made by Richard Granger to the UK supplier community at the outset of the Programme seem not to appreciate that this was in effect part of a negotiation which has led to a much better deal for the NHS both in the short term and for years to come. Many UK suppliers have benefited from this process. Contrary to what Stalis imply, many UK NHS expert IT suppliers are part of NPfIT. These include for example:

- The Phoenix Partnership, providing GP/Primary Care/Child Health/Community solutions across the North, Midlands and East;
- CSE Servelec, providing Mental Health/Community solutions in London;
- HSS providing Radiology Information Systems in all areas other than London;
- In Practice Systems providing GP Systems in London;
- Liquid Logic and CSW providing Single Assessment Process (SAP) solutions to link with Social Care;
- Health Solutions Wales (HSW) providing Child Health Systems in the North-West;
- Clinisys providing Pathology Systems in London;
- PICIS providing Theatre Systems in London;
- SystemC providing implementation support services nationally.

16.25 All of these organisations are peers to Stalis in terms of size and expertise in the NHS and all of them are UK companies. Stalis was not offered the opportunity to become Choose and Book/Spine Compliant because they had only one EPR installation within the NHS at the time (2005). All investment made by the NHS would have been just for that one site. In choosing Silverlink as the replacement PAS, Moorfields chose a system from a company that had successfully replicated and grown its business, working with iSOFT (Silverlink Patient Care System (PCS) was sold as iSOFT iCS). Silverlink was also amongst the first Acute suppliers to achieve Choose and Book compliance (it is installed at Harrogate and Mid Cheshire, both early Choose and Book adopters).

16.26 The current list of Choose and Book compliant Acute PAS systems (non-LSP ie equivalent to Stalis) is as follows:

Supplier	*System*
Anglia	ICE
Ascribe	eCAMIS
Ascribe	Barwick
Ascribe	EPEX
Atos	Helix
Cambio	Cosmic
Capula	OASIS
EDS	Swift
Filetek	Meditech
IMS Maxims	Hearts
IQ Systems	Utopia
iSOFT	Clinicom
iSOFT	iExpress
iSOFT	iPM
iSOFT	iCS (Silverlink PCS)
McKesson	Totalcare
McKesson	STAR
Misys	CPR
Streets Heaver	Compucare
SystemC	Medway

16.27 Stalis also fails to recognise that the required expertise in programme management necessary to implement the programme was non-existent within the NHS, which had never previously managed programmes of anywhere near the same size. The appointment of Richard Granger and that of other IT professionals brought large-scale programme management expertise and included NHS expertise in the team from the outset.

Evidence submitted by Symantec (EPR 37)

16.28 Comments on Symantec's evidence are included in relevant parts of this note. On a general point, their generally critical stance with regard to the National Programme needs to be understood in the context of its own commercial interests. In early 2005 Symantec approached the National Programme for IT with a proposition to procure licenses centrally, on behalf of the NHS, for Symantec's Ghost Solution Suite product. Symantec presented NPfIT with anecdotal information it had gathered about the use of Ghost within the NHS. Symantec had performed a survey of NHS trusts in the months leading up to contact with NPfIT, ostensibly to gauge demand for their anti-virus products, but had also asked how trusts had installed "images" of their standard desktop software onto new computers. Without validating their responses, several trusts had replied that they used Ghost. Symantec took this anecdotal information from the trusts they spoke to and extrapolated it across the whole of the NHS in England. When compared with their sales records from their resellers and direct channels, this information suggested a significant under-licensing of the Ghost product across the NHS. NPfIT were presented with an offer to agree an enterprise wide agreement on behalf of the NHS or Symantec would start legal action. The scale of the NHS and the relative immaturity of its local IT asset management capabilities in 2005 meant that to prove whether Symantec's claims were accurate or not would have cost the NHS several millions of pounds in largely manual surveys. It was known that other technologies had been used to create these desktop "images", but to prove the relative use of these versus Symantec's Ghost product would still have necessitated a full survey. As the least cost and least risk option for the NHS, NPfIT robustly negotiated an agreement with Symantec to cover the NHS with an Enterprise Wide Agreement for Ghost Solution Suite at a cost approaching £1.8 million for perpetual licenses and time-limited support, which was duly put in place in July 2005. Symantec did not then pursue any legal action.

Evidence submitted Tom Brookes (EPR 70)

16.29 The evidence submitted by Tom Brookes contains some significant inaccuracies which is surprising since he claims to have been involved in the early stages of the programme and continues to operate as a management consultant in the NHS. He declares other connections that link him with evidence submitted by other groups. The NHS Numbers project that he claims to have led in the mid-1990s installed a 1970s batch system that, whilst improving the allocation of NHS numbers from manual processes at the time, has significant drawbacks through the time taken for batch processes to operate in the effective allocation of NHS numbers when babies are born to ensure accurate identification. The on-line Personal Demographic Service that provides a much needed replacement for Mr Brookes' project under the Spine contract will enable immediate access from over 7,000 locations with over 70,000 users to 50 million records to immediately allocate a NHS number on-line and enable improved and accurate identification of babies in the first hours and days when attention is needed by multiple clinicians and midwives.

16.30 Mr Brookes maintains that Newham and Homerton hospitals procured IT systems outside of NPfIT. This is because the contracts were awarded in 2003 following a procurement that preceded NPfIT. The Trust has since assigned their contracts to BT within NPfIT and took disaster recovery and affordability issues into account in coming to that decision. The Chief Executive of Homerton has taken a leading role on the Programme Board of the London Programme for IT as part of the National Programme which demonstrates evidence of commitment that Mr Brookes overlooks. Similarly, Wirral hospital initially investigated a separate procurement route but chose to continue within NPfIT with a Cerner product. The same is true of Bradford, Shires and University College London who decided that NPfIT offered the greatest value.

16.31 The references to the detailed care record are simply inaccurate. It has never been the intention to make a detailed care record available nationally and evidence was submitted on 12 June 2007 to clarify the difference between the summary and the detailed record. All published documentation refers to a summary care record being made available at the point of need and this will bring real benefits for patients requiring unscheduled care. In contradiction with the allegation that this is too complicated and unachievable, the summary care record is already live in the early adopter sites in Bolton. The witness casts doubt on the delivery of the Spine functionality. However, the performance of BT in meeting Spine release delivery dates has delivered the last 14 of 14 releases on or ahead of time.

16.32 The allegations about the architecture and the Spine being unable to cope are unfounded. The Spine has been sized and tested to accommodate the needs of the NHS and the performance in supporting over 350,000 registered users who have accessed Spine records over 350 million times to date is regularly meeting or exceeding service levels. The publication of the Message Implementation Manual (MIM) to all suppliers working with NPfIT demonstrates a robust approach to standards and architecture that enables on-line interoperability between multiple systems that transfer patient information for the benefit of the patient. This was not possible with the NHS Number system that is lauded by this witness.

16.33 The references to a monopoly situation with suppliers are also untrue. The replacement of ComMedica as a PACS supplier for poor performance and the replacement of Accenture and IDX demonstrate that there is a competitive marketplace. The inclusion of existing system suppliers having achieved over 100 compliant releases of software also bears testimony against this incorrect allegation.

16.34 This witness is in collaboration with the other groups that have called for an independent review but have, as yet, produced no evidence that would warrant such a review.

Helen Wilkinson

16.35 Ms Robins stated incorrectly (Q247) that Helen Wilkinson has been denied registration with a doctor. The fact is that Ms Wilkinson refuses to be registered with a doctor because the consequence of registration is that a record is kept centrally of that registration as a matter of law. Ms Wilkinson continues to claim that she is being denied NHS care. Again, that is absolutely not the case. Ms Wilkinson refuses to present for NHS care because of the consequential record keeping that would result. The care is there and available to her, but not on her terms. The architecture of NHS IT and NHS business processes must respect the legal rights of individuals, but it must also be as efficient and cost effective as possible and cannot be tailored to provide individuals with costly bespoke arrangements. Ms Wilkinson continues to pursue her claim for financial compensation from the Department of Health and the NHS and to actively campaign against the NHS IT modernisation programme.

Department of Health

16 July 2007

Annex 1: System resilience and the likelihood of failure

Note: Detailed information about system performance and resilience has been provided previously by the Department in a note to the Committee. However, further information is provided here.

In evidence submitted by Prof Randell, he quotes a friend's guesstimate that the NPfIT system would be likely to fail every four days. This assertion is not supported by any evidence and does not concur with the live service availability consistently being demonstrated by the Programme's systems. Service availability statistics are published weekly on the NHS Connecting for Health web site.

It appears that Prof Randell is making the assumption that the NPfIT is delivering a single computer system. The NPfIT in fact consists of a large number of discrete computer systems or "Services" built and delivered by many different suppliers. Each Service interoperates with other NPfIT Services by utilising mandated clinical coding and messaging standards with the common objective of providing patient data at the point of need. Each Service is built to satisfy a particular set of functional and non-functional demands to support a particular clinical usage.

Each service is itself made up of a number of components, eg, application software, hardware, network and storage. It is inevitable that some of these components will fail, and, given the scale of the NHS, failures can be expected to occur frequently—a natural consequence of operating any large, complex, interconnected system. The idea is thus to implement a system that minimises the impact of failures—what is termed "resilience. This was recognised by the NPfIT from the beginning and the solution has therefore been architected and designed to be resilient to component failures. There are two fundamental architectural approaches that have been used to provide the required resilience:

(1) The component systems are loosely coupled, that is to say a system should be able to continue operation even if it cannot access the other services (for example, should the central demographic service be unavailable, the hospital PAS will continue to operate).

(2) The component systems are delivered without single points of failure, so, should a component fail, the system automatically fails over to "spare" (backup) components.

The failover requirement is taken extremely seriously. As an example, the BT data centre has three generators and sufficient fuel to provide weeks of independent power, so, should there be a power failure to the site, the dedicated generators can be deployed to provide power. There are three generators so that should the site be running off their power and maintenance is needed on a generator; there is still a backup generator in case of failure. And of course BT has two geographically separated data centres both of which are equipped in this way should a catastrophic event happen at one of them.

It is NHS Connecting for Health's preference to host centrally as many services as is practical, because:

— It is difficult to offer a resilient service on locally owned and deployed infrastructures.

— Hosted services offer increased resilience options and controlled environments for backup and maintenance operations.

— Hosted environments are easier to physically secure and keep up-to-date with the latest security countermeasures.

— It is much more cost effective to deliver centrally hosted hardware resilience than equivalent resilience at multiple locations.

NHS Connecting for Health does not own all of the services deployed as part of the National Programme—so, for example, external organisations transmitting electronic prescriptions do so from their own networks, using their own infrastructure and using NPfIT accredited software of their choice. As such, there are many failure conditions outside of the direct control of the Programme. However, every service that can be deployed within the NPfIT goes through extensive clinical safety reviews and compliance testing before it can be connected and utilised as part of the NPfIT.

Those services that are procured directly by the NPfIT are typically operated by external suppliers in highly resilient data centre environments which offer industry-leading levels of resiliency and disaster recovery. This typically includes:

- An Active/Active Primary Data Centre configuration and a secondary data centre that is either an active (Spine) or passive (London) replica of the Primary data centre:
  - There is Active/Active resilience built into the Primary Data Centres, and, should a disaster occur, the backup data centre is available to support the operations within the availability requirements for the System (currently 99.999% at the Spine, and 99.9% with improved performance objectives over time in London[17])
  - Interrupted connections will resume according to the agreed SLA.
- Multiple network connections, so should one connection be lost, another is available automatically.
- Hardware redundancy at all levels:
  - Protects against disk and hardware failure
  - Redundant processing power is available should a machine fail.
- Zero data loss architectures :
  - Data is written simultaneously to the two Spine data centres, thus ensuring that no patient data is lost (there are effectively ten copies of each database across the two Spine data centres).
  - The Primary Data Centre at the London LSP shares a Storage Area Network (SAN) across the Active/Active configuration, and the SAN at the backup site is synchronously updated with the Primary Site.
- End-to-end system monitoring against specific Service level agreements:
  - Automatic real-time alerting occurs in case services degrade or become unavailable for any reason.
- Rigorous data security standards:
  - The System is designed, developed, tested and operated according to BS7799-2 Security Standards.
  - The Data Centres are secured physically at a level similar to Ministry of Defence systems (secure premises, guarded and badge access control, etc.)
  - Patient data confidentiality is protected via Role Based Access Control.
  - All authorised users are required to have Smart Cards issued by a central Registration Authority for Single Sign-on to the system via access rights granted through Spine Security Services.

Availability, failover and recovery of each Service have been designed to match clinical need. Dependencies between Services have been clearly identified and consideration given to various failure scenarios. Guidance has thus been given to all suppliers regarding how to construct their applications to limit the impact should a failure occur.

This decoupling approach is pervasive through all of the NPfIT and supplier-proposed solutions are evaluated against this as part of the NHS Connecting for Health assurance process. Such decoupling allows Services to continue to offer a range of capabilities regardless of whether a dependant service (eg, the National Summary Record) is available. The NPfIT end-to-end architecture supports the local queuing of messages for onward transmission to the failed service when it becomes available.

NHS Connecting for Health services currently deployed have proven to be highly resilient in live service. But regardless of this, NHS Connecting for Health continues to work with suppliers and NHS Organisations to help maintain coordinated Business Continuity Plans in the event of a catastrophic failure. Each plan is tailored to which service could be affected and is highly specific to the clinical function it supports and the way it is integrated within a particular organisation's business and technical infrastructure.

All NHS Connecting for Health Services have been designed with high availability, and SLAs and performance statistics are made public. It is expected that the Trust Organisation will select and deploy any NPfIT services that are appropriate and update their Business Continuity Plan accordingly, based upon the Services they use and the clinical usage for which they are employed.

[17] 99.9% availability equates to approximately 45 minutes of outage per month for the System.

Annex 2: *Savings by Local NHS Organisations*

	Acute Trusts		*Mental Health Trusts*		*Primary Care*	
	University Hospital Birmingham Hospitals NHS Trust		*Barnsley PCT*		*North Sheffield PCT*	
	1. Cost of current level PAS: (over term)		1. Cost of System renewal with no additional functionality: (over term)	(£1.35m)	1. Cost of GP Implementations:	
	Operating cost	(£30m)	Operating cost		Cost of operating existing contracts	(£130k)
	Implementation costs for new system	0.7m	Implementation cost for new system	£0.34m	Implementation cost for new system	36k
	Net saving to Trust by transfer to CfH Solution	(£29.3m)	Net saving to Trust by transfer to CfH Solution	(1.05m)	Net saving to Trust of transfer to CfH Solution	(£94k)
Case Studies	2. Cost of Trust Procurement: (over term)		2.Cost of System renewal with additional functionality: (over term)		Bradford and Airedale PCT (Bradford City, North Bradford,	
	Cost of local purchase of more sophisticated PAS Operating Costs	(£25m) 1.7m	Operating cost	(£2.9m) £0.34m	Bradford West) 2. Estimated savings case study	(250k)
	Net saving to Trust of CfH solution	(£23.3)	Implementation cost for new system	(£2.6m)	Annual savings	
			Net saving to Trust of transfer to CfH Solution		Net Savings to Trusts over term	(£2.5m)
	Wirral Hospitals NHS Trust:					
	3. Cost of NHS CRS Level 6 PAS etc procured independently of Programme (over term)				SW Manchester Community PAS Project:	
	Implementation Costs (based on UHB Business Case)	(£27m)			3. Community PAS Projects:	
	Net saving to Trust by transfer to CfH solution	1.0m			Cost of operating existing contracts (Avg NHS stocktake)	(£3.25m)
		(£26m)			Implementation cost for new system	(£0.962m)
					Net saving to Trust of transfer to CfH Solution	(£2.288m)
					West Yorkshire Community	
					4. The Trust identified that it will cost £10k per practice to implement the NHS CRS solution. Savings to date have been in the region of £5k pa. The Trust will recover all implementation costs within two years of "Go Live".	
National Equivalent Value	Net savings to NHS of implementing nationally procured NHS CRS Acute solution with additional functionality (excludes local procurement costs)	(£4.008bn)	Net cost of savings for Mental Health Trusts of implementing CfH procured solution	between (£108m) and (£232m)	1. Net savings to GPs 2. Net savings for PCTs implementations 3. Net saving for Community PAS implementation	(£399m) (£189m) (£138m)

Annex 3: *NHS use of identifiable and non-identifiable patient data for care and for secondary uses*

1. The oral evidence provided by certain witnesses to the Committee on the distinction between identifiable data and non-identifiable data, how these may be used and shared, and how they are protected in NHS Connecting for Health systems, was poorly informed and at times misleading. This note aims to provide clarification.

2. Joint working between the Department of Health, the General Medical Council, the British Medical Association, the Information Commissioner and a range of patient groups, followed by extensive formal consultation, resulted in the publication of a confidentiality code of practice for the NHS in November 2003. This represented, for the first time, an agreed interpretation of how confidentiality law, and key aspects of Data Protection law, should apply in the NHS.

3. Clinical patient information is confidential and classed as sensitive in the Data Protection Act 1998 when it is held in a form that would enable the patient to be identified, as is the case with clinical records. The Data Protection Act regulates how this information is used, but does not prevent it being used for legitimate NHS purposes. Confidentiality law goes further and prevents information from being shared without consent except in exceptional circumstances (statutory provisions, court orders or significant public interest justification).

4. The confidentiality code of practice clarified the circumstances where consent could be implied (opt-out) and those where a stronger evidentiary basis (opt-in) was required. Essentially implied consent was deemed appropriate for care purposes and work to assure the quality of care provided, but not for secondary uses of data, eg research and management.

5. Patient contact, or demographic, details are subject to Data Protection Act provisions but are generally not confidential and so do not require consent for processing. Exceptions exist however and many people regard their address details as private, so it is Department of Health policy to safeguard contact

details to the extent that NHS business requirements permit. NHS Connecting for Health will also make available controls that prevent NHS staff from viewing these details when a patient requests that this be the case.

6. The Courts[18] have determined that when effective steps have been taken to prevent the individual from being identified, the information is no longer confidential and patient consent is no longer required. Where the process used to anonymise the information is reversible, the information, whilst exempt from consent requirements, may remain subject to the Data Protection Act provisions—this has not been tested in Court, but Department of Health policy is to accept that this is the case. Where it is irreversibly anonymised it is not subject to either consent requirements or the Data Protection Act.

7. The NHS Connecting for Health Secondary Uses Service is being introduced to make anonymised and pseudonymised data available to appropriate users so that essential research and other work can be conducted without breaching confidentiality or privacy. Although information disclosed for secondary uses in a pseudonymised or anonymised form cannot identify individuals and doesn't require consent management controls, it is still subject to a range of safeguards.

8. There is considerable evidence however, that some purposes cannot be satisfied through use of anonymised information and that it may not be practicable to gain consent for these purposes either. In these cases, a statutory basis is required. A key statutory provision in respect of research and other secondary uses of patient data is Section 251 of the NHS Consolidation Act 2006 (previously known as Section 60 of the Health and Social Care Act 2001) which allows obligations of confidentiality to be set aside in limited circumstances under the supervision of the statutory Patient Information Advisory Group (PIAG). Key conditions for use of information under these provisions are that it must be impracticable to gain consent or to anonymise the information concerned.

9. Professor Korff suggested in his evidence that PIAG is "quite easy about giving access" to data but it is evident that the research community would not support this view. In its January 2006 report on Personal data for public good: using health information in medical research the Academy of Medical Sciences stated that "Although admirable, this [PIAG's] approach creates difficulties for research because PIAG has set a policy direction that appears to ratchet up existing legal standards. Rather than assess whether applications involve proportionate interference in privacy, PIAG applies a stricter standard of absolute and proven necessity."

10. The application of law, requirements for consent and the safeguards that are being developed and deployed for data held within the NHS Care Records Service and the Secondary Uses Service are set out in table 1. This illustrates the strong safeguards that are in place for all types of data.

Table 1 (to Annex 3)

	Non-clinical personal data	*Personal clinical data for care*	*Personal clinical data for secondary uses*	*Pseudonymised data for secondary uses*	*Anonymised data for secondary uses*
Confidentiality law applies?	Not generally	Yes	Yes	No	No
Data Protection Act applies?	Yes	Yes	Yes	Yes—the legal position is unclear but accepted as a matter of policy	No
Patient consent required for creating a record?	No	No, but patients given choice around the Summary Care Record as a matter of policy	No	N/A	N/A
Patient consent required for sharing?	No	Yes	Yes, unless there is a statutory basis	No	No
Implied consent sufficient?	N/A	Yes	No	N/A	N/A
E-GIF level 3 registration of staff ?	Yes	Yes	Yes	Yes	Yes
E-GIF level 3 authentication of users via smartcard?	Yes	Yes	Yes	Yes	Yes
Audit Trail of user actions?	Yes	Yes	Yes	Yes	Yes
Audit Trail available to patients on request?	No	Yes	No	No	No
Role Based Access Controls?	Yes	Yes	Yes	Yes	Yes
Legitimate Relationship Access Controls?	No	Yes	No	No	No
Patient dissent to information sharing recorded and acted upon?	No	Yes	Yes	Yes	No
Sealed envelope prevents sharing of identifiable data?	No	Yes	Yes	Yes	No
Locked envelope prevents sharing of any data?	No	Yes	N/A	N/A	N/A
System alerts generated when users change their own access rights eg to break a seal?	No	Yes	N/A	N/A	N/A
Patient may request that contact details are hidden from NHS staff?	Yes	N/A	N/A	N/A	N/A

[18] R *v* Department of Health, *ex parte* Source Informatics (2000).

Annex 4: *Reply to Parliamentary Question given on 21 June to Stephen O'Brien MP by the Department's then Minister of State, Caroline Flint*

21 Jun 2006 : Column 1946W

Caroline Flint: A list of names of all the organisations and individuals that responded at one or other stage of the consultation process around the national specification for integrated care records service is not held centrally. Some of the responses were provided by organisations which are no longer active.

The original "National Specification for Integrated Care Records Service (Consultation Draft)" was issued in July 2002 by the NHS Information Authority. Some 190 responses to the document were received from suppliers, clinicians, chief information officers (CIOs) information technology (IT) departments of national health service bodies and others, commenting on such aspects as architecture, functional omissions and the realisation of benefits that such a system would produce. These comments were included and formed the base document for the early draft of the output based specification (OBS). This draft was then refined. The clinical input was provided by almost three hundred individuals and the IT community (IT managers and CIOs) numbered a further one hundred. A broad spectrum of NHS stakeholders was then engaged to review the draft OBS. The review group encompassed leading clinicians, practitioners, policy advisors, health informaticians and managers and included representatives from the Department, the NHS Information Authority, strategic health authorities, NHS trusts, primary care trusts, general practitioners, academic groups and other Government Departments.

It is known that many of these people also sought input from colleagues and we estimate that this cascade has resulted in many thousands of individuals having had a material input to the content and quality of the product.

A final list of 239 people was invited to review the OBS, from which a total of 105 formal review documents were received. From the 900 pages reviewed there were 1,175 comments of substance. These comments resulted in a further refined version of the OBS which was then distributed for any final comment. A response to every individual comment was returned to the reviewer in question.

Reflecting a level of transparency unprecedented for major projects within Government, the OBS was published to the public domain in July 2003 and is available on the Department's website at www.dh.gov .uk/PublicationsAndStatistics/.

In addition to many hundreds of internal meetings, there were 44 meetings held by the clinicians from the national programme with important stakeholders and stakeholder groups. These included several chairs of the Royal Colleges, and presentations to many hundreds of clinicians at various locations around the country.

Data on those consulted on ways of managing the confidentiality of patient health information have been placed in the Library [see list below].

23 meetings were carried out as part of the research phase in addition to eight focus groups and 56 face-to-face interviews, involving patients, researchers, suppliers, senior care service managers, and NHS information governance professionals.

Addenbrookes NHS Trust

Age Concern

Age Concern Harrow

Association for Improvements in the Maternity Services (AIMS)

Aintree Hospitals NHS Trust

Airedale NHS Trust

Airedale Primary Care Trust

Alderney Hospital

Alzheimer's Society

AMS Consulting

Anite Public Sector

Ashford & St Peters NHS Trust

Association of Community Health Councils for England & Wales (ACHCEW)

Association of Directors of Social Services (ADSS)

Avon Gloucestershire & Wiltshire Health Authority

Avon Information Management & Technology Consortium

Avon/Wilts Mental Health

Barnet Enfield & Haringey Mental Health Trust

Barnsley Community Health Council

Barnsley District General Hospital NHS Trust

Barts & the London NHS Trust
Basildon & Thurrock General Hospitals NHS Trust
Bebington and West Wirral Primary Care Trust
Bed & Herts Local Medical Committee
Birkenhead and Wallasey Primary Care Trust
Birmingham Children's Hospital
Birmingham Heartlands Hospital
Black Country Mental Health NHS Trust
Blackpool Primary Care Trust
Blackpool Victoria Hospital
Bolton Asian Elders drop-in Centre
Brain and Spine Foundation
Brain Injury Rehabilitation Trust
Braintree Care Trust
Bridgend Local Health Group
Brighton & Sussex University Hospitals
British Heart Foundation
British Medical Association (BMA)
British Paediatric Surveillance Unit
British Polio Fellowship
Bro Morgannwg NHS Trust
Bro Taf Health Authority
Bromsgrove & Redditch Community Health Council
Broomfield Hospital
Buckinghamshire Mental Health NHS Trust
Buckland Hospital
Bucknall Hospital
Budshead Health Centre
BUPA
BUPA Hospital Southampton
Burnley, Pendle & Rossendale Community Health Council
Burton Hospitals NHS Trust
Bury & Knowle Health Centre
Calderdale & Huddersfield NHS Trust
Cambridge Community Health Council
Cambridgeshire & Peterborough Mental Health Partnership NHS Trust
Cambridgeshire Constabulary
Cancer Bacup
Canterbury & Thanet Community Health Council
Carers UK
Central Cornwall Primary Care Trust
Central Derby Primary Care Trust
Central Lancashire & Fylde Coast Hospital Information Systems
Central Manchester and Manchester
Children's University Hospitals
Central North West London Mental Health Trust
Central Suffolk Primary Care Trust
Centre for Health Services Studies (CHSS)
Charlotte Keel Health Centre
Charlton Lane Centre
Chelford Surgery

Cheltenham General Hospital
Cherwell Vale Primary Care Trust
Cheshire Central Community Health Council
Chichester Community Health Council
Child & Family Service (Wellington)
Child Health Centre
Child Health Informatics Consortium
Children's Heart Foundation
Chorley & South Ribble Primary Care Trust
Christie Hospital NHS Trust
Churches Together in England
Citizens Advice Bureaux (CAB)
City & Hackney Community Health Council
City General Hospital
Civica Services Ltd
Clatterbridge Hospital
Clinical Trials Service Unit
Colchester General Hospital
College for Health in London
College of Health
College of Occupational Therapists
College of Optometrists
Commission for Healthcare Audit and Inspection (CHAI)
Communicable Disease Surveillance Centre
Community Health Council Pensioners' Forum
Community Pharmacy
Consumer Association
Contact A Family
Convent of Mercy
Conwy Federation of Community Health Council's
Cornwall Information Services
Countess of Chester Hospital NHS Trust
County Durham Health Authority
Courtesy Call Ltd
Coventry & Warwickshire NHS Trust
Coventry Community Council
Coventry Primary Care Trust
Crown House Surgery
CSW
Darlington Memorial Hospital
Darlington Primary Care Trust
Dental Practice Board
Department of Health (DH)
Derby City General Hospital
Derbyshire Royal Infirmary
Derriford Hospital
Derwent Shared Services
Dewsbury District Community Health Council
Diabetes UK
District Hospital (Roehampton)
Diverse Minds

Doncaster Central Primary Care Trust
Doncaster Community Health Council
Doncaster Royal Infirmary
Dudley Beacon & Castle Primary Care Trust
Dudley Group of Hospitals
Dudley Social Services
Dudley South Primary Care Trust
Durham & Chester-le-street Primary Care Trust
Durham Dales Primary Care Trust
Dyfed & Powys Health Authority
East Dorset Community Health Council
East Hertfordshire Community Health Council
East Kent Hospitals NHS Trust
East Kent Primary Care Trust
East Staffs Primary Care Trust
East Surrey Community Health Council
East Sussex Hospitals NHS Trust
East Yorkshire Community Health Council
Eastern Cheshire Primary Care Trust
Eastern Leicester Primary Care Trust
Epilepsy Action
Enigma Health UK Ltd
Ethitec
Fairfield Hospital
Farnborough Hospital
Federation of Irish Societies
Fellowship of Depressives Anonymous
Ferndown Primary Care Trust
Fertilization and Embryo Authority
Fleet Hospital
Foundation of Information Policy Research(FIPR)
Frimley Children's Centre
Frimley Park Hospital NHS Trust
Front Street Surgery
Gateshead Health
General Medical Council
George Eliot Hospital NHS Trust
Glen Acre House CFS
Gloucester Local Implementation Strategy
Gloucester Partnership NHS Trust
Gloucestershire Royal Hospital
Goole Hospital
Gosport Health Centre
Grantham and District Hospital
Graphnet
Great Ormond Street Hospital for Children NHS Trust
Great Western Hospital
Green Lane Hospital
Greenwich Community Health Council
Gwent Community Health Council
Hackney Social Services

Harefield NHS Trust
Hampshire and Isle of Wight Strategic
Health Authority
Hampton Clinic
Harrow Pensioners' Forum
Harrow Primary Care Trust
Health Data Protection Ltd
Health Service Ombudsman
Healthy Islington
Hearing Voices Network
Heatherwood and Wexham Park Hospitals NHS Trust
Help the Aged
Hertford County Hospital
Hertfordshire County Council
Hicom Technology
Hillingdon Hospital NHS Trust
Hillingdon Primary Care Trust
HM Prison Service
Holy Family Presbytery
Hospice care
Hounslow Community Health Council
Hull Community Health Council
Humanity
Humberstone Grange Clinic
IBM
IMECE Turkish Speaking Women's Group
IMS Health
IMS MAXIMS
Independent Complaints Advocacy Service
Independent Healthcare Association
Information Commissioner
Institute for Quality Assurance
Institute of Health Sciences
Intellect (UK system supplier trade body)
Interface Devices Ltd
Ipswich Hospital NHS Trust
Iranian Community Centre
Island & Portsmouth Health ICT Service
Isle of Wight Healthcare NHS Trust
Islington Bangladeshi Association
Islington Community Health Council
Islington Health and Race Forum Group
Islington Primary Care Trust
Islington Zairean Refugee Group
JADE Direct UK
Jewish Care
Jubilee Day Hospital
Kennet and North Wiltshire Primary Care Trust
Kent and Medway Hospital Information Systems
Kent County Council
Kettering General Hospital NHS Trust

Kidderminster Community Health Council
King's College Hospital
Kingston Hospital NHS Trust
Kirkham Health Centre
Kokai Supplementary School
Leeds Community Health Council
Leeds General Infirmary
Leeds North West Primary Care Trust
Leeds Teaching Hospitals NHS Trust
Leicester City West PCT—Child Health Services
Leicester General Hospital
Lincoln County Hospital
Lincolnshire Shared Services
Liverpool Central & Southern Community Health Council
Liverpool Eastern Community Health Council
Lloyds Pharmacy
London School Hygiene and Tropical Medicine
Macclesfield District General Hospital
Macmillan Cancer Relief
Manchester Mental Health and Social Care Trust
Manchester NHS Agency
Manchester Royal Infirmary
Manor Gardens Advocacy Project
Medical Defence Union
Medical Protection Society
Medical Research Council
Medical Research Council Consumer Liaison Group
Medway Maritime Hospital
Mendip Primary Care Trust
Mentis Management Consultants Ltd
Mersey Care Trust
Mid Downs Community Health Council
Mid Surrey Community Health Council
Mid Surrey Wheelchair Service
Mid Yorkshire Hospitals
Milton Keynes Community Health Council
Moorfields Eye Hospital
Moss Pharmacy
Musgrove Hospital
National Audit Governance
National Care Standards Commission
National Confidential Enquiry into Perioperative Deaths
National Council of Women
National Patient Safety Agency
National Pharmaceutical Association
National Programme for Information Technology (work stream leads)
NDC health
New Roots
Newcastle General Hospital
Newchurch Ltd
Newhall Surgery

Nexor
NHS Confederation
NHS Information Authority
NHS Litigation Authority
Nightingale Macmillan Unit
Health & Social Care Community of North & East Devon (previously N&E Devon Health Authority)
North & Mid Hants Health Authority
North East Yorkshire & North Lincolnshire Strategic Health Authority
North Manchester General Hospital
North Staffordshire Community Health Council
North Staffordshire Hospital Information Systems
North Staffordshire Hospital NHS Trust
North Tees & Hartlepool NHS Trust
North Tyneside Community Health Council
North Warwickshire Primary Care Trust
North West Lincolnshire Community Health Council
North West London Hospitals NHS Trust
North West London Strategic Health Authority
Northallerton & District Community Health Council
Northampton General Hospital NHS Trust
Northern Cancer Network
Northern General Hospital
Northrop Grumman Missions Systems
Norwich Primary Care Trust
Nottingham Acute Hospitals Partnership
Nottingham City Hospital NHS Trust
Nottingham Health Informatics Service
Nuffield Orthopaedic Centre NHS Trust
Nurses of British Computer Society
Oldwell Surgery
Optx Ltd
Orion Health
Ottery St. Mary Hospital
Our Lady's Convent
Oxford City Primary Care Trust
Oxford Radcliffe Hospital
Parkinsons Disease Society
Partnership with Older People
Patient Concern
Patient Forum
Patient Reference Group
Patient Voice
Patients' Association
Peapod consulting
Peninsular Medical School
Pennine Acute Hospitals NHS Trust
Pennine Care NHS Trust
Perinatal and Epidemiology, Oxford
Per-Se Technologies
Peterborough District Hospital
Pilot Patient Project Lewisham

Plaistow Hospital
Plymouth Primary Care Trust
Pontypridd & Rhonda NHS Trust
Poole Hospital NHS Trust
Portman Clinic
Portsmouth City Council Social Services
Portsmouth City Primary Care Trust
Prescription Pricing Authority (PPA)
Prison Health Department (DH)
Psychological Support Service
Psynapse
Public Health Laboratory Service
Queen Elizabeth Hospital
Queen Mary's Hospital
Queen Victoria Memorial Hospital
Queens Hospital
Queen's Hospital (Burton upon Trent)
Queen's Park Hospital
Queens Park Medical Centre
Railway Medina Tavern
Redbridge Assertive Outreach Team
Rethink Mind
Richmond & Twickenham Primary Care Trust
Robert Jones/Agnes Hunt Orthopaedic and District Hospital NHS Trust
Romsey Dental Care
Rotherham District General Hospital
Royal Albert Edward Infirmary
Royal Alexandra Hospital
Royal Berkshire Hospital
Royal Bolton Hospital
Royal Bournemouth Hospital
Royal Brompton Hospital
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of Paediatrics and Child Health
Royal College of Physicians
Royal College of Speech and Language Therapists
Royal College of Surgeons of Edinburgh
Royal College of Surgeons of England
Royal Devon & Exeter Health Care NHS Trust
Royal Free Hampstead NHS Trust
Royal Gwent Hospital
Royal Hallamshire Hospital
Royal Leamington Spa Rehabilitation Hospital
Royal London Hospital
Royal Manchester Children's hospital
Royal National Institute for the Blind (RNID)
Royal National Orthopaedic Hospital NHS Trust
Royal Oldham Hospital
Royal Pharmaceutical Society
Royal Preston Hospital

Royal Surrey County Hospital NHS Trust
Royal United Hospital
Royal Victoria Infirmary
Royal West Sussex NHS Trust
Royston, Buntingford & Bishops Stortford Primary Care Trust
Rusholme Health Centre
Salford Royal Hospitals NHS Trust
Salisbury Healthcare NHS Trust
Salters Meadow Health Centre
Sandwell Hospital
Scarborough Hospital
Schlumberger Sema
Sedgefield Primary Care Trust
Selby & York Primary Care Trust
Selly Oak Hospital
Sexually Transmitted Disease Clinic
Sheffield South West Primary Care Trust
Sheffield Teaching Hospital NHS Trust
Sisters of St Joseph of Peave
Social and Community Services
Social Care Information Policy Unit
Society & College of Radiographers
Society of Chiropodists & Podiatrists
Somerset Coast Primary Care Trust
Somerset Local Medical Committee
Somerset Partnership NHS and Social Care Trust
Somerville Medical Centre
South Birmingham Mental Health Trust
South Brooks Community Health Council
South Bucks Community Health Council
South Devon Healthcare Trust
South Downs Health NHS Trust
South East Oxon Primary Care Trust
South Staffordshire Healthcare
South Tees Acute Hospitals
South Tees Community Health Council
South Tees Hospitals NHS Trust
South Tyneside Community Health Council
South Warwickshire Community Health Council
South West Dorset Primary Care Trust
South West Kent Primary Care Trust
South West Surrey Community Health Council
Southampton General Hospital
Southend Community Health Council
Southend Hospital NHS Trust
Southend Patients' Public Voice
Southern Derbyshire Acute Hospitals NHS Trust
Southern Derbyshire Community Health Council
Southport & Formby Community Health Council
Southport District General Hospital
Southward Primary Care Trust

St Andrew's Hospital
St Bartholomew's Hospital
St Catherine's Hospital,
St Dominic's Priory
St Francis Presbytery
St Georges Hospital
St Helens & Knowsley Community Health Council
St Helens & Knowsley Hospitals Trust
St Helier Hospital
St James' Hospital
St James' University Hospital
St Joseph's Church
St Luke's Hospice
St Nicholas' Hospice
St Teresa's Presbytery
Stafford General Hospital
Staffordshire Moorlands Primary Care Trust
Staffordshire University
Stockport NHS Trust
Stockport Primary Care Trust
Stoke Mandeville Hospital NHS Trust
Suffolk Social Services
Sunderland Community Health Council
Sunderland Royal Hospital
Sunderland Teaching Primary Care Trust
Surrey Ambulance NHS Trust
Surrey Oaklands NHS Trust
Sutton & Merton Primary Care Trust
SW Surrey Community Health Council
Swindon & Marlborough NHS Trust
Syntegra UK
Tameside & Glossop Acute Trust
Tameside & Glossop Primary Care Trust
Target Four
Taunton and Somerset Hospital
Taunton Deane Primary Care Trust
Teddington Memorial Hospital
Tees and North East Yorkshire NHS Trust
Telford & Wrekin Primary Care Trust
The Audit Commission
The British Polio Fellowship
The Haemophilia Society
The Health Centre
The Hospice of St Francis
The Medical Centre
The Surgery
The Walton Centre for Neurology & Neurosurgery
Tolworth Hospital
Torbay Hospital
Torex
Tower Hamlets Community Health Council

Trafford General Hospital
Trent Cancer Registry
Triple G
Tunbridge Wells Community Health Council
UK Carers Organisation
UK National Screening Committee
UK Newborn Screening programme Centre
UK Transplant
United Bristol Healthcare NHS Trust
University College Hospital London
University Hospital Aintree
University Hospital of Hartlepool
University Hospitals of Coventry & Warwickshire NHS Trust
University Hospitals of Leicester
University of Birmingham
University of Central England
University of Leeds—School of Healthcare
University of Leicester
University of Salford
University of Sheffield
University of Warwick
Vale of Aylesbury Primary Care Trust
Vega consulting
Victim Support
Voluntary Action Leeds
Wakefield West Primary Care Trust
Walsall Community Health Council
Walsall Primary Care Trust
Wandsworth Community Health Council
Wandsworth Contact a Family
Wandsworth Pilot Patients Forum
Warrington Community Health Council
Watch Tower (Jehovah's Witnesses)
Watercress Medical Centre
Watford & Three Rivers Primary Care Trust
Webstar Health
Welsh Assembly Government
Welsh Language Board
Wessex Local Medical Committee's
West Cheshire Hospital
West Hertfordshire Hospitals NHS Trust
West Kent NHS & Social Care Trust
West Lancashire Primary Care Trust
West Lincolnshire Primary Care Trust
West London Mental Health NHS Trust
West Middlesex University Hospital
West Midland Strategic Health Authority
West Midlands Ambulance NHS Trust
West Midlands Perinatal Institute
West Suffolk Community Health Council
West Suffolk Hospitals NHS Trust

West Surrey Health Community
West Sussex Health and Social Care
Weston Area Health Trust
Weston General Hospital
Wexham Park Hospital
Whiston Health Centre
Whiston Hospital
Whittingdon Hospital NHS Trust
William Brown Centre
Winchester and Central Hampshire Community Health Council
Winchester and Eastleigh NHS Trust
Wirral NHS Trust
Wolfson Institute of Preventive Medicine
Wolverhampton City Council
Worcestershire Mental Health Partnership NHS Trust
Worthing and Southlands NHS Trust
Wyre Forest Primary Care Trust
York Hospital

Annex 5: *Patient safety benefits to be achieved from electronic patient records*

Key to understanding how the systems being developed by NHS Connecting for Health can play a part in reducing adverse events, particularly medication errors, is an appreciation of:

— the scale of the problem,
— the root causes of any avoidable errors,
— the evidence supporting the role of IT in reducing some of the root causes, and
— an explanation of the new systems themselves.

Scale of the Problem:

There is evidence from international literature that medication errors occur in all health care settings, with some errors occurring repeatedly not just within one healthcare system, but across healthcare systems worldwide. Whilst the UK evidence base is not as strong as it is in other countries, particularly the United States, this does not mean that the NHS in England is immune from this problem. As such, the study by Charles Vincent *et al* is particularly helpful in demonstrating the reality of this global phenomenon within the context of the health service in England.

Whilst the authors do indeed state that "we can not extrapolate with any precision" it is nevertheless the authors themselves who do extrapolate the findings to the whole of the NHS with the conclusion:

> "Our findings strongly suggest that adverse events are a serious problem in the NHS, as they are in the United States and Australia. We estimate that around 5% of the 8.5 million patients admitted to hospitals in England and Wales each year experience preventable adverse events, leading to an additional three million bed days. The total cost to the NHS of these adverse events in extra beds days alone would be around £1billion a year".

Of course, this study only looks at adverse events occurring within hospitals. It is important not to overlook adverse events occurring outside the hospital setting. In this respect you may be interested in another UK based study which looked specifically into adverse drug reactions as a cause of hospital admission. This study, published in the British Medical Journal in 2004[19] concluded that:

— One in 16 hospital admissions are the result of an adverse drug reaction (ADR)—72% of which are avoidable.
— This equates to 4% of hospital bed capacity.
— At any one time the equivalent of 7 x 800 bed hospitals are occupied by patients admitted with ADRs.
— ADRs causing hospital admissions are responsible for the death of 5,700 patients every year.
— Cost to the NHS = £466 million.

[19] Pirmohamed, M *et al*: *Adverse drug reactions as a cause of admission to hospital: prospective analysis of 18,820 patients*: BMJ 2004; 329: 15–19.

Whilst neither of these studies is without its limitations, they nevertheless are extremely important in helping to quantifying the scale of the actual problem we face, and indeed are facing up to in England. Academic studies such as these do not become irrelevant just because they were conducted a number of years ago or because the situation may have improved since the study was conducted. Having acknowledged the scale of the problem, our focus now is on tackling the root causes of avoidable patient safety incidents rather than simply engaging in further studies to re-confirm that there is indeed a problem.

Root Causes:

Although patient safety incidents are diverse in nature, a study carried out by National Audit Office in 2003–04 and reported in "*A Safer Place for Patients*"[20] revealed that the most common patient safety incidents in hospitals after patient falls related to medication errors, record documentation error and communication failure.

This is supported by the Audit Commission in their report "*A Spoonful of Sugar*"[21] which made the following conclusions:

- Complications arising from medicines treatment are the most common cause of adverse events in hospital patients.
- Errors may occur from the initial decision to prescribe to the final administration of the medicine, and these include choice of the wrong medicine, dose, route, form, and frequency.
- Most errors are caused by the prescriber not having immediate access to accurate information about either the medicine (its indications, contraindications, interactions, therapeutic dose, or side effects); or the patient (allergies, other medical conditions, or the latest laboratory results).
- Hand-written prescriptions or patients' notes also contribute to errors as they may be illegible, incomplete, subject to transcription errors or make use of inappropriate shorthand.
- Prescription sheets themselves may also be temporarily unavailable or lost.

Safe, effective clinical care also depends on reliable, error-free communication between different providers of care. Communication breakdowns between healthcare providers are a common feature in episodes of avoidable patient harm. This was highlighted in the Department of Health publication "*Building a Safer NHS for Patients: Improving Medication Safety*":

> "Effective communications are critically important when patients move from one care setting to another; many medication errors occur at such 'handover points'. Serious errors have occurred because of poor communication between primary and secondary care. Accurate information about current treatment is essential when patients are admitted to hospital to enable an accurate clinical assessment and to plan future treatment. And on discharge, the patient's drug regimen and treatment plan need to be communicated in a timely and reliable way to ensure safe and seamless transfer of care back to the primary care team"[22].

Information Technology & Patient Safety—The Evidence

Research sources provide ample evidence that information technology can improve patient safety through eliminating many of the root causes described above. The enclosure to this Annex provides a summary of just some of the available evidence. NHS Connecting for Health has taken account of this research evidence in framing the scope of the Programme to ensure the delivery of better care and improved safety for patients.

National Programme for IT in the NHS- Supporting Patient Safety

The following is a brief explanation of how some of the elements of the overall NHS Care Record Service will contribute to reducing incidents of patient harm. In places this includes data obtained from the National Patient Safety Agency's, National Reporting & Learning System (NRLS) to help highlight the potential patient safety benefits. However, it should be noted that whilst the reporting of patient safety incidents to the NRLS is becoming more established practice, and is now a core standard the NHS is expected to adhere to, the figures are still likely to underestimate the full scale of such patient safety incidents.

[20] *A Safer Place for Patients*: National Audit Office, HC 456 Session 2005–06.
[21] *A Spoonful of Sugar: medicine management in NHS hospitals*: Audit Commission 2001.
[22] *Building a Safer NHS for Patients: Improving Medication Safety—Department of Health 2004.*

Personal Demographics Service—Right Patient, Right Care:

Use of the NHS number as the unique identifier in all healthcare interactions in England will, when fully achieved, make a major contribution to patient safety.

Currently, an individual patient has different identifying numbers in different NHS organisations and sometimes even within the same NHS organisation.

The dangers of this are well illustrated by information extracted from the NRLS which shows that between November 2003 and May 2006 there were 600 patient safety incidents reported which related directly to patients' identifying numbers. Furthermore, the NRLS also reveals that between January 2006 and December 2006 alone there were 7,984 patient safety incidents reported where the incident type was "Patient Incorrectly Identified".

In this respect, the Personal Demographic Service (PDS)—which allows authorised NHS health and social care practitioners accurately and efficiently to trace patients against the patient's most up to date demographic details; thus identifying the patient's unique NHS number will make a key contribution to patients' safety benefits.

PDS underpins all current and future NHS Connecting for Health products and, with approximately 50 million demographic records for everyone in England stored on the database, it is already supporting the delivery of the Choose and Book Service (potentially benefiting over 45 million patients with in excess of 17,500 bookings daily) and the Electronic Prescription Service (potentially benefiting about 15 million patients with in excess of 185,000 prescription messages daily).

The PDS is of course central to realising the ultimate goal of delivering high quality and safe care across different health care organisations through the NHS Care Record Service. But even now, over 1.5 million patient records are successfully retrieved from the PDS every day, helping to correctly identify patients.

NHS Summary Care Record:

The Summary Care Record (SCR) forms the national element of the NHS Care Record Service and will provide authorised health care professionals with access to key clinical information about a patient anywhere, at any time.

The record will grow over time but will go live from this year under the Early Adopter Programme before moving to full national roll out. In the initial stages, the record (subject to patient consent) will contain the following information held on the GPs record:

- Known allergies
- Known adverse reactions
- Medications—acute prescriptions in past 6mths and repeat prescriptions in past 18mths
- Significant diagnoses and problems (+ any other significant issues, treatments, operative procedures etc)

This information was provided as part of the HSC oral evidence session on 26 April 2007.

Future phases of the SCR will see it hooking up with the Electronic Prescription Service to provide a richer view of medications, and the Choose and Book service to provide referral information as well as capturing information from secondary care such as discharge information, outpatient letters and emergency care reports.

The importance of having access to this basic patient information is highlighted by the following information obtained from the NRLS (England only) between January and December 2006:

- 1,678 reported patient safety incidents where the patient was allergic to the treatment given.
- 916 patient safety incidents where the patient suffered an adverse drug reaction (when the drug was used as intended).
- 1,147 reported patient safety incidents where the treatment given was contraindicated in relation to drugs or conditions.
- 821 patient safety incidents reported where the primary cause given for the incident was "missing / inadequate / illegible referral letter".
- 28,875 patient safety incidents reported relating to "documentation" eg missing / illegible / misfiled (See footnote for specific search filters)[23]

[23] NRLS Search Filters = "Documentation- no access to" + "Documentation- missing / inadequate / illegible referral letter or healthcare record / card" + "Documentation- delay in obtaining healthcare record / card" + "Documentation- misfiled".

Electronic Prescription Service (EPS):

With around 1.3 million prescriptions now being issued every working day in England, and this figure expected to rise by 5% each year, the development of the EPS (which replaces a paper based system with an electronic one which is more efficient and consistently accurate) is absolutely critical to providing health care professionals with up to date and accurate information about the range of medications a patient might be taking at any point in time.

In a study of older people at the University Hospital of North Durham, a structured review of patients' medication was conducted after admission. An average of almost one drug per patient was found to be inappropriate and stopped and an average of approximately one drug per two patients was started following identification of omissions in the drug history.[24]

The importance of having up to date medication information for older patients is further illustrated as follows[25]:

— As people get older, their use of medication tends to increase. Four in five people over 75 take at least one prescribed medicine, with 36% taking four or more medicines.

— Adverse reactions are implicated in 5%–17% of hospital admissions for older people.

— While in hospital, 6%–17% of older inpatients experience adverse drug reactions.

— Older people who are taking four or more medicines have increased risk of suffering an adverse reaction to a medicine and being readmitted to hospital as a result.

The EPS has been designed to provide medication data to the NHS Care Record. The NHS Care Record, populated by data from the EPS will, over time, provide a single, authoritative point of reference for the medication a patient has been prescribed and dispensed and has the potential to lead to a significant reduction in medication errors caused by a lack of instantly available medication information.

Already, over 4,825 pharmacies and 5,778 GP practices have EPS technology benefiting a potential 9.1 million patients. To date, over 26.5 million prescription messages have been issued electronically, with the weekly count exceeding 900,0000.

Details of the status of Pharmacy Systems Suppliers can be found on the NHS CFH web site at "http://www.connectingforhealth.nhs.uk/systemsandservices/eps/supplierstatus/pharmacysystemsuppliers"

E-Prescribing:

Whereas the patient safety benefits of the Electronic Prescription Service lie principally in providing clinicians with up to date information about a patient's medications through links to the NHS Care Record, the benefits of e-Prescribing systems lie in reducing actual prescribing errors and administration errors often associated with prescribing.

A study[26] into the incidence of adverse drug events and potential adverse drug events reviewed 4,031 patient records and found an incidence of 6.5% actual and 5.5% potential errors. Of these:

— 56% related to errors at the ordering stage

— 34% related to administrative errors

— 6% were transcription errors

— 4% were dispensing errors

The Agency for Health Care Policy and Research (USA) published a research in action paper claiming that computerised medication order entry (also known as e-Prescribing systems) has the potential to prevent an estimated 84% of dose, frequency and route errors in prescribing. This report cites numerous other research studies, which claim safety benefits from computerised medication order entry systems or e-prescribing systems.[27]

NHS Connecting for Heath is providing the functional specification to be incorporated into the local detailed record solutions being developed by the Local Service Providers and will allow for:

— Computerised entry and management of prescriptions.

— Decision support, aiding the choice of medicine and other therapies, with alerts covering, for example, drug interactions, contra-indications, allergic reactions and other safety-related issues.

— Knowledge support, giving users immediate access to up-to-date drug information such as the British National Formulary.

[24] *Building a Safer NHS for Patients: Improving Medication Safety—Department of Health 2004.*

[25] *A Spoonful of Sugar: medicine management in NHS hospitals*: Audit Commission 2001.

[26] Bates DW, Cullen DJ, Laird N, Petersen LA, Small SD, Servi D, *et al. Incidence of adverse drug events and potential adverse drug events*. JAMA 1995; 274: 29–34.

[27] *Reducing and Preventing Adverse Drug Events to Decrease Hospital Costs. Research in Action*, Issue1 AHRQ Publication Number 01–0020 March 2001. Agency for Healthcare Research and Quality, Rockville .MD. http://www.ahrq.gov/qual/aderia/aderia.htm

— Electronic links between hospital wards/departments and pharmacies.

— A robust audit trail for the entire medicines provision process.

E-Prescribing systems will be underpinned by the Dictionary of Medicines and Devices (dm + d), a dictionary containing agreed unique identifiers and associated textual descriptions for medicines and medical devices. The dm + d will help make e-Prescribing systems interoperable with other NHS IT systems, enabling safe and reliable exchanges of information on medicines and devices and effective decision support through linkages of data.

Of course, others of the many products and initiatives being developed and deployed by NHS Connecting for Health will also contribute to improving patient safety.

Enclosure to Annex 5

Supporting Evidence

Bates and Gawande 2003. The conclusions of the work by Bates, *et al*. reports the following benefits:

— Information technology can substantially improve the safety of medical care by structuring actions, catching errors, and bringing evidence-based, patient-centred decision support to the point of care to allow necessary customisation.

— The use of decision support for clinical decisions can also result in major reductions in the rate of complications associated with antibiotics, and can decrease costs and the rate of nosocomial infections.

— 53%–83% reduction in serious medication errors.

Bates, D W and Gawande, A A, *Improving Safety with Information Technology. New England Journal of Medicine 2003*, 348:2526–34
(http://content.nejm.org/cgi/content/short/348/25/2526)

The Agency for Health Care Policy and Research (USA) published a research in action paper claiming that computerised medication order entry has the potential to prevent an estimated 84% of dose, frequency and route errors. This report cites numerous other research studies, which claim safety benefits from computerised medication order entry systems.

Reducing and Preventing Adverse Drug Events to Decrease Hospital Costs. Research in Action, Issue1 AHRQ Publication Number 01–0020 March 2001. Agency for Healthcare Research and Quality, Rockville .MD.
http://www.ahrq.gov/qual/aderia/aderia.htm

The LEAPFROG Group for patient safety Rewarding Higher Standards (USA) quotes the following examples of safety benefits from physician order entry systems:

(i) A study by David Bates, MD, Chief of General Medicine at Boston's Brigham and Women's Hospital, demonstrated that their Computer Physician Order Entry (CPOE) system reduced error rates by 55% from 10.7 to 4.9 per 1,000 patient days.

Bates DW, Leape LL, Cullen DJ, Laird N, *et al*. Effect of computerized physician order entry and team intervention on prevention of serious medication errors JAMA. 1998;280:1311–6.

(ii) Rates of serious medication errors fell by 86% in a subsequent study by the same group. The prevention of errors was attributed to the CPOE system's structured orders and medication checks.

Bates DW, Teich JM Lee J Seger D, Kuperman GJ, Ma'Luf N, Boyle D, Leape L *The impact of computerized physician order entry on medication error prevention* JAMIA. 1999;6:313–21

(iii) John Birkmeyer, MD, a surgeon and health services researcher at Dartmouth Medical School, estimates that implementation of CPOE systems at all non-rural US hospitals could prevent over 500,000 serious medication errors each year.

Birkmeyer JD, Birkmeyer CM, Wennberg DE, Young MP. *Leapfrog safety standards: potential benefits of universal adoption*. The Laepfrog Group. Washington DC: 2000

E-prescribing report prepared by First Consulting Group for California Healthcare Foundation claims patient safety benefits from e-prescribing and references a Movement championed by the Institute for Safe Medication Practices, calling for the universal adoption of e-prescribing and the abandonment of hand written prescriptions by 2004, for the improvement of prescribing safety.

Kilbridge Peter, MDE & Gladysheva Katy, First Consulting Group, *E-Prescribing prepared for California Healthcare Foundation 2001*.

A report on the prevention of medical errors by First Consulting asserts that it is through understanding and altering the processes by which complex systems operate that quality is best achieved and improved. Healthcare quality requires, perhaps more than anything does, access to reliable information at the point of medical decision-making. As such, the provision of clinical care is an information-dependent process.

Two principal kinds of information management support care quality. The first is collection of and access to real-time clinical data at the point of care. What did this patient's X-ray reveal? What medications is she receiving? Access to point-of-care information assists the clinician in treating the patient "here and now." A second kind of information is aggregate data on populations of patients. This data can be retrospectively examined to identify practice patterns, incidence of disease or complications, and the like. It can also be used to target specific practitioner behaviours for improvement.

Both types of information management are required as part of any coherent strategy to measure and improve the quality of healthcare delivered. Implementing evidence-based medicine in a healthcare delivery organization requires a substantial investment in rethinking and fine-tuning clinical processes across the continuum of care. Moreover, creating more reliable and effective clinical processes and practices necessitates introducing information technology into the hands of physicians and other caregivers.

Classen D and Kilbridge P—*Health quality and the prevention of medical errors*, First Consulting Group June 2000.

Smart tags and packaging are already saving lives, preventing illnesses and sharply reducing costs in healthcare. The Protti World Review Report 14 cites examples of radio frequency identification technology and its benefits in healthcare.

Radio-frequency identification: Its potential in Healthcare. Health Devices 34(5), May 2005:149–60 (no Authors listed)
(http://www.connectingforhealth.nhs.uk/worldview?searchterm = Protti)

Right patient, right blood new advice for safer transfusions—NHS Connecting for Health has supported the National Patient Safety Agency in the development of new measures to improve the safety of blood transfusions, including photo ID cards and electronic tracking systems for patients and blood.
(http://www.npsa.nhs.uk/display?contentld = 5354)

Protti World View Report 8 is the first of two reports providing an overview of clinical information technologies that are helping to save lives and improve the quality of life for patients. This report includes references to the benefits of Picture Archiving and Communications Systems (PACS) such as improved speed and accuracy of diagnosis.
(http://www.connectingforhealth.nhs.uk/worldview?searchterm = Protti)

Protti World View Report 3 shows how the value of computers in healthcare can be about improving decision-making. This report includes references to the benefits of computerised electronic patient record systems. It suggests that electronic systems enable physicians and nurses to make better, quicker decisions with the aid of on-line access to evidence-based results, assistance in placing orders, detecting drug interactions, and receiving alerts after abnormal test results. This delivers more efficiency with fewer errors.
(http://www.connectingforhealth.nhs.uk/worldview?searchterm = Protti)

Protti World View Report 2 specifically focuses on how the use of computers in healthcare can reduce errors, improve patient safety and enhance the quality of care. Incomplete information in records and the difficulty that clinicians have in keeping up with the rapidly growing clinical evidence base are significant problems that can be mediated by IT. The US Institute of Medicine—Quality Chasm report 2001 is quoted "The current care systems cannot do the job. Trying harder will not work. If we want safer, higher-quality care, we will need to have redesigned systems of care, including the use of IT to support clinical and administrative processes.
(http://www.connectingforhealth.nhs.uk/worldview?searchterm = Protti)

The Audit Commission report "a spoonful of sugar—medicines management in NHS hospitals—2001" reported that:

- Electronic prescribing reduces medicine errors significantly by providing timely, legible information. One study concluded that improved information systems could contribute to the prevention of 78% of transcription errors leading to adverse medicine events.
- Computerised systems containing rules to prevent incorrect or inappropriate prescribing have also reduced the incidence of errors and increased the appropriateness of medicine treatment.
- Computerised prescribing linked with electronic health records will radically alter the way in which care is provided and will deliver significant improvements in the quality of patient care (Ref. 86). The introduction of these systems, which ultimately need to be accessible by primary care and other hospitals, is vital to provide access to common clinical data. It is one of the biggest challenges currently facing the NHS.

(http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/E83C8921-6CEA-4b2c-83E7-F80954A80F85/nrspoonfulsugar.pdf)

Annex 6: *NHS existing systems suppliers that have obtained work under the National Programme*

Existing Systems Compliance Programme (Technical Authority to Deploy at 13 June 2007).

ESP Programme

Patient Administration Systems

C&Bv1—McKesson Totalcare

C&Bv1—iSOFT Clinicom

C&Bv1—Harrogate (Silverlink/Anglia)

C&Bv1—Capula Elan Oasis

C&Bv1—iSOFT iEXPRESS

C&Bv1—Silverlink ICS

C&Bv1—IMS Maxims BLKHEARTS

C&Bv1—York Trust ICE/In house PAS

C&Bv1—Ascribe (HEIS) eCamis

C&Bv1—iSOFT IPM

C&Bv2—Cerner Millennium

C&Bv1—IMS Maxims Hammersmith

C&Bv2—EDS SWIFT

C&Bv2—iSOFT iiEXPRESS

C&Bv2—ATOS Origin SemaHelix

C&Bv2—System C Medway

C&Bv2—Royal Marsden Anglia/In house

C&Bv2—iSOFT Clinicom

C&Bv2 prov—Ascribe EPEX

C&Bv2—Silverlink ICS

C&Bv2—Royal Devon&Exeter SWIFT

C&Bv2—iSOFT IPM

C&Bv2—McKesson Totalcare

C&Bv2—Filetek Magic

C&Bv2—McKesson Star

C&Bv1—Misys CPR

C&Bv2—UCLH (GE Healthcare)

C&Bv2—IMS Maxims PAS/CAB

C&Bv2—Norfolk & Norwich

C&Bv2—Ultragenda

Community Pharmacy Systems

ETPv1—AAH

ETPv1—Hadley Healthcare Eclipse (Local/FDB)

ETPv1—Cegedim Pharmacy Manager

ETPv1—Enigma Nexphase

ETPv1 -System Sol QicScript

ETPv1—Lloyds PMR

ETPv1—Positive Solutions PSL ETP

ETPv1—Pharmacy Plus

ETPv1—Enigma Mediphase

ETPv1—RX System Proscript

ETPv1—Boots Smartscript EPS

ETPv1—Hadley Healthcare Eclipse (Local/HHPD)

ETPv1—Cegedim Central Message Broker

ETPv1—Lloyds Compass

General Practice Systems

C&Bv1—Seetec GP Ent
C&Bv1—InPS Vision
ETPv1—The Phoenix Partnership SystmOne
ETPv1—InPS Vision
C&Bv1—The Phoenix Partnership SystmOne
ETPv1—Seetec GP Ent
C&Bv1—EMIS LV
C&Bv1—Microtest—Evolution Practice Manager
GP2GPv1.0-EMIS LV
C&Bv1—iSOFT Synergy
C&Bv1—iSOFT Premiere
ETPv1—EMIS LV
ETPv1—EMIS PCS
ETPv1—iSOFT Synergy
ETPv1—iSOFT Premiere
ETPv1—Microtest Practice Manager
C&Bv1—EMIS PCS
GP2GPv1.0-InPS Vision
GP2GPv1.1-InPS Vision
C&Bv2—Seetec GP Ent
C&Bv2—iSOFT Synergy
C&Bv2—iSOFT Premiere
GP2GPv1.1-EMIS LV
ETPv1—EMIS PCS

Independent Sector Treatment Centre

C&Bv1—Cambio Cosmic
C&Bv2—iQ System Serv iQUTopia
C&Bv2—Streets Heaver Compucare
C&Bv2—Cambio Cosmic

QMAS & RFA (Level 0 GPSoC)

QMAS v7—Microtest
QMAS v7—In Practice
QMAS v7—EMIS GV
QMAS v7—EMIS PCS
QMAS v7—EMIS LV
QMAS v7—Ascribe Protechnic Exeter
QMAS v7—iSOFT
QMAS v7—The Computer Room
QMAS v7—Seetec
QMAS v7—The Phoenix Partnership
QMAS v7—Healthy Systems
QMAS v8.5 (R10)—Microtest
QMAS v8.5 (R10)—EMIS LV
QMAS v8.5 (R10)—EMIS GV
QMAS v8.5 (R10)—EMIS PCS
QMAS v8.5 (R10)—The Phoenix Partnership
QMAS v8.5 (R10)—Healthy Systems
QMAS v8.5 (R10)—InPS Vision 4

QMAS v8.5 (R10)—iSOFT
QMAS v8.5 (R10)—In Practice
QMAS v8.5 (R10)—Ascribe Protechnic Exeter
QMAS v8.5 (R10)—Seetec
QMAS v8.5 (R10)—iSOFT Synergy Enterprise
QMAS v9—iSOFT
QMAS v9—Microtest
QMAS v9—EMIS LV
QMAS v9—Ascribe Protechnic Exeter
QMAS v9—EMIS GV
QMAS v9—EMIS PCS
QMAS v9—In Practice
QMAS v9—The Phoenix Partnership
QMAS v9—Healthy Systems
QMAS v9—Seetec

Secondary User Service

SUS—Indigo4
SUS—Ardentia
SUS—Iuvo
SUS—NHSIA Exeter
SUS—Anglia
SUS—McKesson
SUS—NHSIA Exeter

Summary Care Record

SCRv1

Annex 7: *LSPs provided the following examples of their experience in delivering systems and services as those required under the National Programme*

Fujitsu: Usha Mullapudi Cardiac Centre (UMCC), Hyderabad

Implementation of a Hospital Management System to a 150-bed cardiac hospital equipped with four operating theatres, three catheterisation labs, a blood bank, a modern pathology lab, a spiral CT scanner and a pharmacy unit.

The EPR maintained the overall patient medical history including past and present clinical findings, treatment details, medication details and progress notes. In-patient EPRs contained chart monitoring, test results, ward movement, discharge summary and visit details. The workflows generated by patient activities were mapped to modules for different hospital departments and functions: Reception; Wards; Billing; Pharmacy; Laboratory; Operation Theatre; Blood Bank; Electronic Patient Records; Financial; Accounting and Payroll; Stores; Duty Roster; Security and Administration; House Keeping and Laundry; Diet and Kitchen; Equipment Interface; Fixed Assets and Pathology Lab.

Fujitsu: The Southern Derbyshire Acute Hospitals NHS Trust

Development of a Trust Workforce Plan making effective use of information technology, suitable for internal and external purposes, to be integrated with service and financial planning and able to accommodate future changes.

The Trust has a total of 1,147 beds across 44 wards and serves a population of over half a million people through Southern Derbyshire. The Trust employs approximately 5,500 staff from medical and nursing staff to ancillary staff within an annual budget of around £200 million.

Accenture:Andalusian Heath Care Service, Spain

Design, build and run of a System and Technology Management centre serving the region and the management of the infrastructure to support "smart card" based electronic patient records as part of an ambitious modernization programme. The Andalusian Healthcare service is the largest public healthcare service in Spain with 75,000 employees including 14,000 physicians serving 7.3 million citizens. It has a complex health network made of 32 hospitals, 1300 primary health centres and over 100 specialized health centres.

In November 1997 Accenture won a public offering to carry out the project, which consisted of building an Information Technology Management Centre in six months. This centre would assume the management of the health centres environment for the next three years, starting as of July 1st 1998.

Accenture:The Milwaukee County Medical Centre

The Milwaukee County Medical Centre is a 450-bed acute care hospital with a Level 1 trauma centre for the region. Its integrated delivery system includes 30 outpatient clinics, an eye institute and links to the Medical College of Wisconsin, Curative Rehab Hospital and Milwaukee County Behavioural Health Facility, a 600-bed psych, alcohol and drug treatment facility.

Accenture served as the total outsourcing provider (all IT functions, including computer operations, technical services, help desk, WAN / LAN, desktop support and applications support, and all strategic planning, budgeting, etc.) since 1991. In 1996, the County sold the acute care facility. From 1996 to present, Accenture has provided Applications Management services to the remaining County-owned facility, Behavioural Health.

CSC: 40 Danish Counties

CSC Scandihealth is the largest supplier of healthcare IT software and services in Denmark and Scandinavia and the leading provider of electronic patient records systems to Danish hospitals.

CSC: St Vincent's Catholic Medical Center, New York

The St. Vincent's Catholic Medical Centers (SVCMC) comprises seven facilities including acute centres and ambulatory clinics. In 2001, CSC has been awarded two contracts within the health system. The first outsourcing contract calls for supplying all aspects of the IT management for the duration of five years; the second, calls for creation of an integrated software and hardware platform for the Patient Management, Patient Accounting, Hospital Procurement and Accounting functions.

CSC: Children's Hospital Los Angeles (CHLA)

Management of business and clinical information systems, including mainframe and midrange computers, desktop computers, helpdesk operations, voice and data communications, and applications maintenance and development.

BT: NHS Information Authority, NHSNet Broadband Upgrade

BT is delivering 256Kbps NHS Net upgrades to 6,536 GP surgeries.

BT is delivering 2Mbps NHS Net upgrades to 223 Hospitals.

BT is providing the intensive programme management to upgrade 30 GP sites per day.

The upgrade process takes 40 days, therefore BT is concurrently managing delivery to 1,200 sites at any one time.

Contract value is in the region of £168 million, with rollout having commenced in December 2002. BT is currently rolling out 600 sites per month, and committed to complete by March 2004.

BT: Salford & Trafford Health Authority

This health authority serves around one million patients. It includes 113 GP practices, two major hospitals and a community NHS trust.

BT partnered with the customer to assess current levels of equipment at its 113 sites and then developed an appropriate and cost-effective solution, which would meet the individual needs of the GP Primary Care Groups.

BT implemented reliable electronic communication between all GP practices through a standard communications network.

BT delivered, trained and supported 250 desktop PCs (and 84 network connected printers, with access to BT managed email services and web browsing of the NHSnet and Internet, for users at GP practices.

BT ensured that all existing GP System software (from the 3 clinical application suppliers) could be used on the desktop PCs.

BT provides end-to-end service ownership, helpdesk and Service Level Guarantees for the end-to-end service.

BT remotely accesses PCs to ensure maximum availability, optimum problem fix time and software downloads.

BT:Walsall Trust

Walsall Hospitals NHS Trust is responsible for the Manor Hospital—a 600-bed full acute hospital with A&E, maternity, dermatology, oncology, etc—and the nearby 120-bed non-surgical Goscote Hospital

BT was prime contractor for the delivery of the Clinical Image Management Service 2000–01. The initial scope was for PACS storage for new CR in A&E Imaging. This included diagnostic and referential workstations for the Imaging and A&E Department, with potential to have web referential views across the extended campus.

CSC: Scandihealth

CSC's EMEA public sector business was initially focused in the Nordic region, where CSC acquired Datacentralen, a state-owned IT service firm, and Scandinavian Healthcare Informatics.

The Scandihealth business (with 300 professionals provides healthcare solutions to 70% of hospital beds in Denmark) was the starting point of CSC growth in healthcare in Europe. Nowadays the portfolio includes the full range of system integration, application development, consulting and operations management services, as well as vertical specific solutions, such as hospital information systems, laboratory systems and home care systems based on various partner platforms; for instance Oracle HTB is the key development and integration platform used in Denmark and CSC intends to leverage it in other countries too (eg Norway, Sweden, and Italy).

National Switch Point (LSP) for the Dutch healthcare sector

The National Switching Point enables healthcare players throughout the country to exchange patient information in a fast and safe way. With this initiative, CSC has built the foundations for the countrywide roll-out of a reliable Electronic Patient Record.

The LSP is at the heart of the National Information Infrastructure (called Aorta) for the healthcare sector and enables parties in the sector to exchange patient information safely and quickly. This 'mission critical control' handles the access to patient information. Through the LSP, healthcare providers can ask for up-to-date patient information from systems of other hospitals, pharmacies and general practitioners.

CSC's Healthcare Experience outside the NHS NPfIT contract

The Department of Health's aim is to improve the health and wellbeing of the people of England. Its work includes setting national standards and shaping the direction of the NHS and social care services, and promoting healthier living. Health and social care services are delivered through the NHS, local authorities, arm's length bodies and other public and private sector organisations.

In 2002 CSC was awarded a seven-year IT outsourcing contract. The contract has since been extended for a further two2 years, the agreement will now run until 2011 and now includes an innovative new Managed Print Service. CSC's service to DH comprises provision of a full infrastructure outsource, a number of areas of application support and development, as well as targeted consultancy provision.

CSC and the Department have created an IT partnership which will support and enhance the Department of Health's information and communications investments. Since the beginning of the relationship CSC has been involved in many projects to deliver new and improved services to the Department of Health, examples range from technology refresh programmes, to provision of flexible hosting services and innovative managed service solutions.

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