# The Spine and Confidentiality

Standard Note: SN/SP/4584
Last updated: 10 January 2008
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This note is designed to help Members who have received queries from constituents about the National Care Records Service database. It aims to provide some background information, with a brief non-technical outline of the current state of play, focusing on issues of confidentiality and patient consent.

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# A. Origin

The creation of the NHS Care Records Database is one of the major strands of the NHS IT strategy in England. It came to life in December 2003 when John Reid, then the Secretary of State for Health, announced that that a 10 year contract to set up and run the national NHS Care Records Service had been awarded to BT. In his announcement he also said that by 2010 every NHS patient in England would have an individual electronic NHS Care Record.

The press notice issued by the Department of Health about the announcement said:

> The NHS Care Records Service will provide all 50 million NHS patients with an individual electronic NHS Care Record, which will detail key treatments and care within either the health service or social care. For the first time, information about patients will be mobile - just like patients themselves - and not remain in filing stores in the buildings where treatment or care has been received.
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> The NHS Care Records Service will connect more than 30,000 GPs and 270 acute, community and mental health NHS trusts in a single, secure national system.
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> Health Secretary John Reid said:
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> "This is a key part of reform of the NHS and will help make the NHS a truly responsive service, which provides patients with more choice. To help patients make these vital choices they will need access to more information about the NHS and their own personal health and care history than ever before. This system will equip the NHS to provide that.
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> "At present, most patients have a number of different paper and computer based records that cannot be quickly transferred around the system. There is no central record containing all their health and care information. Currently, our hospitals hold millions of paper records that have to be manually retrieved when patients need treatment or see a consultant. In the 21st century, this is clearly not an efficient way to store health information.
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> "The NHS Care Record will completely revolutionise the way that information is accessed and will make available efficient, secure and integrated records to the right people at the right time. Patient records will be available 24 hours a day, seven days a week to ensure that vital information about an individual's health and care history can be available instantly to health professionals who have authorised access. This will be of particular use to A&E staff who can access information about emergency patients and help to diagnose them more quickly."
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> The care records will also cut down on time wasted by NHS staff and the patients who turn up for appointments and find that their records are not ready or are in the wrong place in the hospital or clinic.
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> Two further contracts have been awarded to the Local Service Providers (LSPs) in the North East and London regions, which will deliver essential infrastructure and connect to existing systems in the NHS. They will underpin the delivery of both the NHS Care Record and the Electronic Booking Service, which was announced in October this year.

> BT has been awarded a 10 year contract, worth £996million to provide systems to access and use the service and IT support at a local level in the London region.
>
> Accenture has been awarded a 10 year contract, worth £1099million, to provide systems to access and use the service and IT support at a local level in the North East region.
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> Further LSP contracts will be awarded by the end of the year for the remaining regions: North West & West Midlands, Southern and Eastern.
>
> By late 2004, patients will begin to benefit from new NHS Care Records that will contain basic patient information and health details. The information on the NHS Care Records will grow over time and eventually the public will be able to access their NHS Care Record themselves. This will mean that patients will have access to all their health information and can be more involved in making decisions about their own care and treatment.[1]

A brief history of policy developments up to that point, as described in the press notice's *notes to editors,* is set out below:

> 1. The principle underlying the NHS Care Records Service was initially presented in the 1998 Department of Health strategy *Information for Health*, which committed the NHS to provide life-long electronic health records for everyone, with round-the-clock, on-line access to patient records and information about best clinical practice for all NHS clinicians.
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> Following the development of the NHS Plan, a supporting document *Building the Information Core: Implementing the NHS Plan*, was published in January 2001. This outlined the information and IT systems needed to provide the patient-centred care that the NHS Plan promises to deliver.
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> The Wanless Report, published in April 2002, also made several key recommendations for IT in the NHS, including:
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> - doubling the IT budget and ensuring that IT funding was not used to subsidise other services
> - stringent, centrally-managed national standards for data and IT
> - better management of IT implementation in the NHS, including a national programme.
>
> The Wanless Report coincided with the publication of *Delivering the NHS Plan*. This set out the vision of a patient-centred service that would empower patients and offer them more choice, such as where and when they would be treated. In June 2002, the Department of Health published its new strategy for developing IT - *Delivering 21st Century IT Support for the NHS - a National Strategic Programme*. This gave rise to the founding of the National Programme for IT.
>
> 2. The design and roll-out of the NHS Care Records Service has been organised into two parts. Services that are common to all users nationally will be the responsibility of

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[1] Department of Health Press Notice, "Every patient to get electronic patient record," December 2003: http://www.dh.gov.uk/en/Publicationsandstatistics/Pressreleases/DH_4062888

> the National Application Service Provider (NASP). Services delivered at a more local level will be the responsibility of five Local Service Providers (LSPs). Together, they will ensure the integration of existing local systems and implement new systems, if necessary. The NASP and the LSPs will make IT work across the NHS to support the creation of the NHS Care Records Service. LSPs will provide the systems to use the NHS Care Record as well as support services at a local level. The National Programme for IT has grouped England's strategic health authorities into five implementation groups known as clusters. They were set up to ensure that the national applications can be delivered locally, while maintaining standardisation.[2]

## B. The NHS Care Records Service and The Spine

The NHS Care Records Service is running well behind the original schedule and a Health Select Committee report, *The Electronic Patient Record*, published in September 2007, suggests that elements of its future development are still uncertain.[3] However, it appears from information provided to the Health Select Committee and from Government Written Answers that the project includes the following:

- The Personal Demographics Service, which involves a national database, already in use, containing basic demographic details about every NHS patient (name, address, date of birth, NHS number and current GP);
- A Summary Care Record, to be included on the national database and currently being piloted in a few Primary Care Trusts, which would contain key clinical information, including allergies, prescriptions, summary medical history, operations and procedures;
- A Secondary Uses Service, which would provide a single point of access to aggregated data for a range of purposes, for example, management, commissioning, clinical audit and research.
- A Detailed Care Record, an electronic record holding significantly more detailed clinical information than the Summary Care Record, which would be available locally and which would combine information from existing local systems, but not necessarily all of it;
- Local record systems containing comprehensive patient records, which have always existed and are now either on paper or in electronic form, which would continue to be stored in hospitals, GP surgeries and other organisations;

Most of the controversy so far has centred on the “spine” and the uses to which it might be put although there has also been some more general concern about the use of electronic records. The “spine” is the colloquial name given to the national database, which will consist of the first two of the items on the list set out above. The third item also concerns the spine as it involves the use of the data on it for secondary purposes. The spine already contains demographic data. Summary Care Records are due to be uploaded onto it at some point but according to Government statements, Detailed Care Records will not be uploaded onto the spine.[4]

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[2] As above.

[3] House of Commons Health Select Committee, *The Electronic Patient Record*, Sixth Report of Session 2006-07 HC 422-i-iii, 13 September 2007; and the Government’s response to it published 12 November 2007, Cm 7274.

[4] See, for example, HC Deb 14 March 2007 c441W

## C. Confidentiality and Patient Consent

Major issues relating to the spine have been confidentiality and patient consent, in particular whether patients may or may not opt out of the system. In 2006 the Guardian newspaper ran a campaign encouraging readers to write to their GPs asking them to ensure that their records were not put onto the new database[5] and recent newspaper articles suggest that many doctors have serious concerns about the security of data on any large scale electronic database.[6]

### 1. Issues

Issues relating to confidentiality and patient consent were discussed in the report of a Taskforce on the Summary Care Record set up in July 2006 by Lord Warner, then Minister at the Department of Health. The Taskforce, chaired by Harry Cayton, met four times and published a report in December 2006.[7] In his covering letter to Lord Warner, the chairman said:

> In our report we acknowledge that there are differences of opinion and approach between GPs, secondary care doctors, nurses, and patients. These are based on differences of view about the practicality, ethics and value of creating a Summary Care Record. Nevertheless the Taskforce is united in believing that a national care record service is desirable for patients, clinicians and the Health Service and that the Summary Care Record, cautiously implemented, in line with our recommendations, will bring real benefits in safety, quality, efficiency and coordination of care.

On the issue of patient consent and related issues, the report said:

> 4.2. In particular we acknowledge the clear difference of view between both the BMA and the Ethics Committee of the RCGP [Royal College of General Practitioners] on the one hand and the Department of Health, its advisors and many Royal Colleges on the other, over issues of consent. Concerns about data quality in clinical records compounded the issue. We hope that our recommendations will allow these differences to be explored and resolved during the early adopter phase of the Summary Care Record.
>
> 4.3. It is worthwhile describing briefly two ethical positions on the most appropriate model of consent to be adopted for the Summary Care Record. This concerns the question of whether the creation of a Summary Care Record for a particular patient should require that patient's explicit consent, or whether, following a public information programme consent should be assumed and the Summary Care Record

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[5] See "From cradle to grave, your files available to 250,000 NHS staff", Guardian 1 November 2006 and a letter written by the Chief medical Officer to doctors in response to the article, which is available on the Department of Health's website: http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_063045

[6] See, for example, "Four out of five doctors believe patient database will be at risk", The Times 31 December 2007, "Records safe with us, says NHS chief" The times 26 December 2007; and the BMA website: http://www.bma.org.uk/ap.nsf/Content/EPRpublic. The BMA has also written a briefing on the issue: BMA http://www.bma.org.uk/ap.nsf/Content/ncrs2

[7] Report of the Ministerial Taskforce on the Summary Care Record chaired by Harry Cayton, 6 December 2006: http://www.connectingforhealth.nhs.uk/resources/care_record_taskforce_doc.pdf

created unless the patient makes an explicit decision for this not to happen (or for it to be deleted at some future point). These two positions are often referred to as the opt-in and the opt-out models and each has strong ethical arguments in its favour (These are set out in paragraphs 4.4 and 4.5 below). A third approach, that of making the summary compulsory (as electronic records are in say the Veterans Health Administration in the USA), has not been considered or proposed by the Taskforce or by the Department of Health.

4.4. The explicit consent (or opt in) model is considered by its advocates to be preferable to implied consent (or the opt-out) model. This is because it requires an explicit decision made by the patient and therefore makes it possible to be confident that information will not be available on the Summary Care Record where the patient does not wish this. An explicit decision about particular information would also make it possible for patients to check the accuracy of data and to discuss with their GP any sensitive issues, prior to their information being made available for sharing. For the advocates of the opt in model, explicit consent is real consent and it is a fundamental ethical principle of medicine that practice should be guided by consent. Explicit consent reinforces the relationship of trust between a GP and patient.

4.5. The implied consent (or opt out) model is considered by its advocates to be preferable because reliance on an explicit model of consent will mean that significant sections of the population, probably the most vulnerable, for example the elderly, will not benefit from the improvements in care accruing from the availability of health care information in emergency situations. Most people would wish to benefit from such information in an emergency. Thus, the advocates of opt out consent argue, the opt in model fails to take seriously the wishes of significant numbers of patients. This could also be seen to be unjust because it would disproportionately affect the most vulnerable. The advocates of the opt-out model point out that implied consent is already standard practice in much of medicine. They are also concerned that the time and resources required to obtain explicit consent from the whole population individually will mean many years' delay in realising the benefits of the Summary Care Record and would not make best use of valuable health care resources.

4.6. We also recognise the context in which the NHS Care Records Service is being created. Clinicians, especially GPs, have a long history of IT use and many have developed significant expertise in the use of electronic record systems and see themselves as protectors of patient information. IT systems in primary care have been created bottom-up and, within their limitations, work well for individual practices. The case that the Summary Care Record is essential for modern clinical care is not yet universally accepted. The Taskforce noted the successful implementation of summary records in Scotland and a part of Wales.

4.7. Many patients and patient organisations recognise the potential benefits of the Summary Care Record. These range from the simple practical advantage of less frequent repetition of basic personal information to a variety of healthcare professionals, through to improved care and safety especially when accessing care in a new and unfamiliar environment. Many patients express concern about lost paper records, inefficient appointment systems and unnecessary repetition of tests. Whilst they may be worried about confidentiality they recognise that with proper management the benefits of the Summary Care Record will be considerable. The Taskforce also acknowledges that for a small number of individuals an electronic shared care record is unacceptable.

> 4.8. The content of the Summary Care Record has been a matter for debate. It must be made clear to patients that the handling of particularly sensitive data, including medications, will be agreed with them. Broadly speaking, until it is possible to seal off parts of the record, content should be limited to non-sensitive information. The Taskforce discussed the proposal that the initial summary should contain only current medications, adverse reactions and allergies. The Taskforce is in agreement with this proposal but were clear that as the system matured the content should become more complete and include individual care plans.

The Taskforce made 14 recommendations. These included the creation of a Summary Care Record Advisory Group to oversee the issues arising from the early adopter sites. It recommended that this Group should include patients as well as clinical and managerial users in the NHS and that one of its roles would be to consider how best to address the issue of individuals (expected to be few) who did not wish to have a Summary Care Record in any form. It also said that it was essential that there be a public information programme before any information was uploaded. The programme should give a clear and realistic timetable to allow patients to view their proposed Summary record and to set limits on sharing, should they wish to do so as previously announced.[8]

On 18 December 2006, the Department of Health issued a press notice responding to the Taskforce report. It announced that it was setting up an advisory group on the implementation of the Summary Care Record and that it was accepting the other recommendations of the Taskforce.[9] This was interpreted as a climbdown by some of the press, in particular the Taskforce's suggestion that patients would be able to refuse to have their health records uploaded on to the system at rather than simply being able to stop them being shared.[10]

## 2. Current guidance about consent

At the moment Summary Care Records are only being created in some "early adopter" sites. A leaflet for patients explains the National Care Records Service including the options open to patients.[11] More detailed guidance to the early adopter sites on managing requests from patients who do not want a Summary Care Record to be created for them is also available. The document says that the guidelines that it contains will be monitored during the Early Adopter Programme and modified as appropriate. An extract is reproduced below.

> ….Initially a Summary Care Record will contain information on allergies, adverse reactions and current medications extracted from the patient's GP record. Over time it

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[8] Report of the Ministerial Taskforce, as above.

[9] "Way clear for next steps on electronic patient record" Department of Health Press Notice 18 December 2006: http://www.gnn.gov.uk/content/detail.asp?ReleaseID=251128&NewsAreaID=2&NavigatedFromSearch=True

[10] See previous Department of Health Press Notice on the issue dated 26 October 2006, "Health Minister sets out electronic patient record details": http://www.gnn.gov.uk/environment/fullDetail.asp?ReleaseID=237651&NewsAreaID=2&NavigatedFromDepartment=False For press commentary, see, for example, "How patients' protests forced a rethink on NHS computer records…" *The Guardian* 16 December 2006

[11] The NHS Care Records Service, Better information for better, safer care: http://www.nhscarerecords.nhs.uk/patients/what-do-i-need-to-do-now/nhs-crs-summary-leaflets/summary_leaflet_online.pdf

will become a richer record as more information is added from the GP record and later from the records held by hospitals etc where the patient receives treatment.

Patients can request that the information in their Summary Care Record is not made available and can only be viewed by themselves through Healthspace.

Patients can request not to have a Summary Care Record at all.

We believe that if patients are concerned about who can see their Summary Care Record, the most appropriate option is to choose the “dissent to sharing” position. This means that although the information in the Summary Care Record is not normally available, on the request of the patient it could be readily made available to clinicians who are treating them. Patients can make this choice at any time and will be able to view their “consent to sharing” status through Healthspace as it becomes available.

*Process*

A minimum of eight weeks before Summary Care Records are created in an area a Public Information Programme will target those people in the area who are aged 16 and over. A leaflet will be given to them which explains the purpose of a Summary Care Record, how to obtain a copy of the Care Record Guarantee, and their options, which are:

- To have a Summary Care Record, in which case they need do nothing more. In doing this the patient is only agreeing to the initial upload of allergies, adverse reactions and medications from their GP record. The addition of diagnoses from their GP record will occur with the patient’s consent thereafter at an appropriate consultation with their GP.

- Not to have a Summary Care Record created, in which case they must complete a form and should discuss the matter with any member of the clinical team who is available at their GP practice to ensure that they understand the implications of their decision. This discussion should also clarify that the NHS will continue to endeavour to provide people who do not have a Summary Care Record with the best services, and will not discriminate against those who do not choose to have a Summary Care Record.

An example form is enclosed. The Department of Health recommends that Practices should require those who do not want to have a Summary Care Record to obtain a copy of the form from their GP practice and complete and sign it. This will provide a clear record of their decision.

- To allow the process for creating the Summary Care Record to be initiated and to look at the content by, for example, obtaining a print out from their GP practice.

Other means for patients to look at the content are being explored during the early adopter process. Once the Summary Care Record process has been initiated people have a minimum of a further eight weeks to decide to either:

- Have a Summary Care Record which is accessible to those who are providing them with care or treatment.

- Have a Summary Care Record but not allow anyone to see the information outside the organisation which created it i.e. set their flag on PDS to “dissent to sharing”.
- Not have a Summary Care Record and follow the process described above to achieve this. Following this a blank record will be uploaded which contains no clinical information and solely indicates that the patient has chosen not to have a Summary Care Record.

If a patient does not express their wishes within the 8 weeks after the Summary Care Record process is initiated then their Summary Care Record will become accessible to clinicians providing them with care or treatment.

Patients can change their decision at any time. However, once a Summary Care Record has been created and has been relied upon by those who provide an individual with care, there are important medico-legal reasons which require the information contained within the record to be preserved. The Department of Health is consulting on the circumstances and required processes for managing requests for amendment and/or deletion of information held within health records.

Keeping good records when the Summary Care Record is discussed with a patient is clearly important. It has been agreed that the Read code 93C3 will be used to record that a patient does not wish to have a Summary Care Record and 93C2 can be used to record that that the patient has indicated to a member of the practice clinical team that they want a Summary Care Record created. These codes can be applied at any time up to the time when the Summary Care Record is created.

Where a patient was known to be either absent during the period leading to the creation of their Summary Care Record, or was considered to lack capacity under the Mental Capacity Act 2005 during this period, it is recommended that you revisit the decision with the patient, or anyone holding a Lasting Power of Attorney under the Mental Capacity Act 2005 for the patient, at the next appropriate consultation.

Where a child is competent, the decision to request not to have a Summary Care Record rests with the child, not the parent as the request is made under the Data Protection Act which looks to competence rather than age. Where a child is not competent, the decision rests with the parent but the Department of Health recommends that GPs should not agree where it might put the child at significantly increased risk, or would prevent existing risk from being significantly reduced. Any questions should be referred to your local Caldicott Guardian or Data Protection Manager.

### *Consent, Data Protection and Legal Points*

The advantages and disadvantages of seeking explicit consent, even though it is not a legal requirement, have been debated at length by many groups advising the National Programme for IT.

The Ministerial Taskforce on the Summary Care Record, which was established in late 2006 to look at the issues surrounding the introduction of the Summary Care Record and included representatives from the RCGP, BMA, RCN, organisations representing patients, and the College of Emergency Medicine, proposed the process described earlier and this was accepted.

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.
> - 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.
> - Potentially result in complaints and litigation where health outcomes would have been improved if a Summary Care Record had been created.
>
> Summary Care Records cannot be created without the agreement and cooperation of GP Practices who are currently the Data Controllers for the records from which the required data will be copied. The Department of Health can only recommend that Practices follow its advice in line with the points raised above.
>
> The Department has sought and received robust legal advice to the effect that the creation of Summary Care Records is lawful. Individuals must be told about the change in the way their records are held and this requirement will be fulfilled through the public information programme. There is however no requirement in law for their consent to be obtained.
>
> However, having been told, people do have a legal right to have objections to the creation of their Summary Care Record considered, as provided under section 10 of the Data Protection Act 1998 (http://www.opsi.gov.uk/ACTS/acts1998/80029—b.htm#10). As the current Data Controller for GP records, each Practice is legally responsible for responding to these objections, which are referred to as section 10 notices. It is expected that the response will be to agree that a Summary Care Record will not be created. However, should you have any concerns about not creating a Summary Care Record, or have any questions about section 10 notices or other Data Protection issues, you can seek advice from the Digital Information Policy Team, your Caldicott Guardian or your professional bodies…. [12]

## 3. Access to the spine

This note does not examine all the technicalities of the scheme that may affect confidentiality, such as “sealed envelopes”, particularly as some of these still have to resolved but the following Question and Answer is reproduced below to illustrate some of the security aspects concerning access to the spine.

> Mrs. Gillan: To ask the Secretary of State for Health who is able to gain access to the NHS medical records of individuals; what procedures are involved in assessing those records; and how his Department monitors access.
>
> Mr. Bradshaw: holding answer 28 November 2007]: Local national health service organisations have the responsibility for determining which of their staff may access the detailed care records they hold, and for establishing the working practices that

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[12] NHS Conneccting for Health, *Guidance on managing requests for no summary care record during the period of the early adopter programme*: http://www.nhscarerecords.nhs.uk/nhs/publications/gpguidance.pdf

> effectively deliver the confidentiality required ethically, and by law. Guidance on required practice for those who work within or under contract to NHS organisations about the safeguarding of confidentiality, and patients' consent to the use of their health records, exists in the form of the "NHS Confidentiality Code of Practice", published in November 2003.
>
> Local organisations are and have been responsible for the procedures that are followed, which differ from organisation to organisation and also according to whether the record concerned is held electronically or on paper.
>
> The security measures controlling access to electronic medical records held on the NHS Care Records Service are set at the Cabinet Office standard e-Government interoperability framework level 3, with access further restricted to only those with a legitimate relationship with the patient, and further role-based access restrictions to specific information.
>
> Tools are provided by NHS Connecting for Health to enable organisations to control access to records held in the new information technology systems and services deployed under the national programme for information technology. To access patient records staff will need to:
>
> - have been issued with a smartcard following rigorous identity checks;
> - log on to a system with their card and pass code;
> - have been assigned a role profile that permits them to use system functions that allow record access and;
> - have their membership of a team involved in a patient's care confirmed by a check against central records or
> - have special authorisation to satisfy statutory requirements or other exceptional reasons for accessing records.
>
> System audit trails will enable organisations to monitor access and the Department has made it clear that misuse must not be tolerated. The Department will monitor how well NHS organisations adhere to standards rather than the details of access.[13]

# D. Progress

## 1. Personal Demographics Service

The Personal Demographics Service has been up and running for some time, as explained in the following Written Answer:

> Derek Wyatt: To ask the Secretary of State for Health whether general practitioners and hospital computer systems share a common address base for their patients. [116306]
>
> Caroline Flint: National Health Service patient address and other demographic information has historically been compiled in individual local records held by general practitioners and hospitals. Information, including changes of address, is sometimes

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[13] HC Deb 5 December 2007 c1322W

> shared in the course of referrals, but data held by one NHS body may not always reflect changes notified to another.
>
> Over time, a single authoritative source of patient demographic data, known as the Personal Demographics Service (PDS), will be used by all general practitioners and hospital computer systems in England. Access to the PDS will reduce clinical risks arising from a failure to match patients with their clinical record, and help minimise cases of correspondence and documents being misdirected. Early evidence from one trust has shown a six-fold reduction in misdirected mail addressed using PDS-held data.
>
> The PDS, which first went live in June 2004, already contains information for all the patients within England, and is currently accessible across the NHS, with over 310,000 users, and receives over 26 million inquiries per month. the volumes are growing over time, with increasing patient benefits and efficiency improvements.
>
> There will be no physical or electronic links between the PDS and other non-NHS databases, and other Government departments and public agencies will not be able to access the data that it contains.[14]

Although more attention has focused on the Summary Care Record, there have also been questions about creating demographic records, as illustrated by the following Parliamentary Question and Answer:

> Stephen O'Brien: To ask the Secretary of State for Health whether patients can opt out of having their demographic details held on the NHS national data spine.
>
> Caroline Flint**:** Patients registered with the National Health Service will not be able to prevent their basic demographic and contact details from being held within the NHS care records service (NHS CRS).
>
> The NHS has maintained registers of its service users from the earliest days of its existence to support the delivery of healthcare. A record is also kept of which general practice each patient is registered with, and reasons of efficiency and probity require this to be held centrally, for example to prevent multiple general practitioners from being paid for the same patient, and to ensure that the correct commissioning body meets the cost of care provided. A register is also needed to enable the Secretary of State to meet the obligation to provide healthcare, free at the point of contact, for those patients who are ordinarily resident in England.
>
> While for these reasons it is not practicable to give patients choice about whether their demographic details will be held in the system, safeguards have been built into the NHS CRS personal demographics service (PDS) which allow an individual's contact details to be hidden from NHS staff if patients request this level of protection. Access to the PDS is controlled by a member of staff's relationship with the patient, and by what they need to see to do their jobs, and is dependent on their having a current secure smartcard and a valid pass code.[15]

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[14] HC Deb 5 February 2007 c719W

[15] HC Deb 12 June 2007 c1005W

## 2. Summary Care Records Service

Progress on uploading the Summary Care Record onto the spine was given in a Written Answer in January 2008 in response to a question from Andrew Lansley about when the full implementation of the Summary Care Record was expected to take place. Ben Bradshaw, Minister at the Department of Health replied:

> There are no current plans to implement the summary care record (SCR) beyond the existing early adopter programme. The Department is working with both the Summary Care Record Advisory Group and the independent evaluators based at University College London to ensure that all significant learning from the early adopters is taken into account as soon as it is available. The evaluation will draw from extensive fieldwork done to capture the views and experiences of general practitioners, practice managers, nurses, other National Health Service clinical and management staff, and patients. The results of the evaluation will be incorporated into future deployment plans for the SCR.[16]

An earlier statement by Caroline Flint, previously Minister at the Department of Health, on progress in introducing the Summary Care Record, which explains what the contents of the Record in early adopter sites is reproduced below:

> A key element of the national programme for information technology is delivery of a national summary care record. The first phase of this service will allow a summary of information held on general practitioners' systems to be uploaded to a national database to allow other clinicians to view it. Information is loaded onto the database from different systems via a transaction messaging system, which processes and routes data messages.
>
> Introduction of the summary care record has now begun at so-called early adopter sites. In the first instance it is expected that the service will be predominantly of use in unscheduled care settings where knowledge of allergies, medicines and major diagnoses will improve patient care and safeguard patient safety. It is expected that the service will be extended in due course to include information from other care settings. Implementation and the future development of the summary care record will be overseen by an advisory group, including clinical, patient and manager stakeholders, chaired by Professor Martin Marshall, the Department's Deputy Chief Medical Officer.[17]

A press notice issued by NHS Connecting for Health (an agency of the Department of Health responsible for computer systems and services) says that evaluation of the early adopter sites will last one year, staring from April 2007.[18] For an example of an early adopter site, see the website of Bradford and Airedale Teaching PCT, which is an 'early adopter' of the NHS Care Records Service.[19]

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[16] HC Deb 7 January 2008 c114W

[17] HC Deb 10 May 2007 c418-9W

[18] http://www.connectingforhealth.nhs.uk/newsroom/news-stories/awardofcontract250407

[19] http://www.bradfordairedale-pct.nhs.uk/NR/exeres/3A59A8FB-5325-4B60-A570-1DE3C440BF9F,frameless.htm?NRMODE=Published

Below is another Written Answer, which distinguishes Summary Records from those held locally:

> Stephen O'Brien: To ask the Secretary of State for Health whether all patients will be able to opt out of having their (a) summary and (b) detailed care record put on (i) the Spine and (ii) any other database other than that of their GP.
>
> Caroline Flint: Patients will be able to ask their general practitioners to prevent a summary care record being created for them on the spine, though the Department advises patients to think carefully before requesting this as the summary care record will enable improved national health service care and reduce clinical risk.
>
> Detailed care records, however, are held locally within health communities and are not held on the spine. Clinicians are required to keep adequate records for clinical governance and medico-legal reasons and will generally do so within detailed care records systems. As is currently the case, patients will not be able to specify how or where local detailed records are held, though the new systems will enable patients to place restrictions on how these records may be shared or accessed.
>
> In some circumstances it may be possible for clinicians to agree to keeping records outside of the detailed care records systems if to do otherwise would cause substantial distress. However, some forms of care, for example blood tests and x-rays, will in future automatically generate records within the detailed care records systems, and if care is dependent upon use of these systems there can be no flexibility for those who receive that care.[20]

## 3. Secondary Users Service

The following question is about the Secondary Users Service:

> Dai Davies: To ask the Secretary of State for Health what controls she plans to put in place to ensure that patient records entered on the electronic care record database are not misused by researchers using the secondary users service.
>
> Caroline Flint: The primary purpose of the National Health Service care records service (NHS CRS) is to support the delivery of care to patients. However, the aim is that data extracted from NHS services supporting direct patient care, including the NHS care records service, choose and book and electronic transmission of prescriptions, will be made available either in aggregate form or, where detailed information is provided, in anonymised or pseudonymised form, via the so-called secondary uses service.
>
> The use of consistent pseudonym enables individual cases to be tracked. Identifiable information will be available only where patient consent has been formally given or where specific permissions apply. Permission is required from the Patient Information Advisory Group (PIAG), set up under the Health and Social Care Act 2001. The PIAG assesses each application to test that the use of patient information is justified, taking into account issues of confidentiality and consent.

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[20] HC Deb 19 February 2007c423-4W (406-7W)

> Access to the secondary uses service requires each user to be formally registered and to use individual smart card access, just as for other systems in the national programme for information technology. Each user is allocated a role which determines what reports, and what organisations or geography of data they may access. Key user activities, including logon and extraction of data, are recorded. The Secondary Uses Group set up by the Care Record Development Board to advise on the ethical use of patient data and how the potential for research, statistics and management can be realised without compromising confidentiality or security, is due to report shortly.[21]

The report mentioned was published in August 2007.[22] The Care Record Development Board has closed down and the National Information Governance Board for Health and Social Care will take responsibility for monitoring the implementation of the recommendations in the report.

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[21] HC Deb 25 June 2007 c261W

[22] Report of the Care Record Development Board Working Group on the Secondary Uses of Patient Information, August 2007:
http://www.connectingforhealth.nhs.uk/crdb/workstreams/secusesreport.pdf