

***GUIDANCE FOR THE NHS
ABOUT ACCESSING PATIENT
INFORMATION IN NEW AND
DIFFERENT WAYS AND
WHAT THIS MEANS FOR
PATIENT CONFIDENTIALITY***

Linked electronic care records

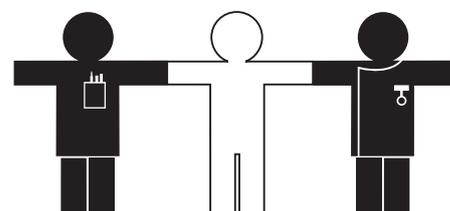
How they will affect your work and patients

Information to help you explain them to patients

Guidance on your responsibilities and how to
implement *The Care Record Guarantee*

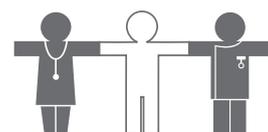
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I Linked electronic care records



1. Why this guidance is needed

This guidance is being made available to all NHS frontline staff (i.e. those directly involved with patient care) in England. It applies equally to existing electronic record systems and the developing NHS Care Records Service (NHS CRS). It explains:

- The implications of increased access to patient information by electronic means.
- What the introduction of the NHS CRS will involve.
- The impact that increasing electronic access to patient information will have on your job and patient care.

Please note:

- The term 'NHS Care Records' applies to all electronic records for individual patients, including the developing NHS CRS.
- This guidance only applies to England. Scotland, Northern Ireland and Wales are developing their own electronic records systems and they will issue separate guidance to their own staff.
- The term 'patient' is intended to cover all users of health and other care services.
- The term 'staff' includes GPs.

The NHS CRS will be introduced gradually in stages across England over several years from 2007. This guidance describes what safeguards need to be in place generally when information is accessed by electronic means and what safeguards the NHS CRS will enable nationally, once it is fully up and running. Until consistent national safeguards are available, it looks at differing local safeguards (see section II).

Beginning in 2007 there will be a rolling programme throughout England to raise public awareness about linking electronic medical records and what it means to them. But even before that, systems are beginning to change. You may find that patients are already starting to ask questions about how their records are stored and accessed. This guidance will help you prepare for any resulting questions from your patients by also explaining:

- Your responsibilities in terms of ***The Care Record Guarantee*** (www.connectingforhealth.nhs.uk/crdb) which sets out the rules that will govern information held in the NHS CRS.
- Patients' choices.



- Your responsibilities as NHS staff in terms of protecting patient confidentiality.
- How to answer frequently asked questions and address patient concerns.

You will receive further information and training as the NHS CRS is introduced in your organisation.

Further information is also available on the website www.nhscarerecords.nhs.uk.

2. *The NHS Care Records Service*

The NHS Care Records Service will allow the NHS to move away from its current organisation-centred patient records, to records that are centred on the patient. This will make caring for patients across organisational boundaries safer and more efficient. It will also give patients themselves access to a record that covers care across organisations.

Over time, NHS organisations will increasingly keep care records on computers that link together, allowing them to access information in a safe and secure way. This is being introduced to support the NHS in delivering safer and higher quality care for patients. Introducing it will take several years and will bring a number of improvements. Linked electronic records will mean better access for health care staff to reliable information about patients they are treating. Linked records will support the delivery of better health care. In due course, patients too will have 24 hour access to an essential summary of their records if they want it.

The NHS CRS will support these improvements. Health care providers from many disciplines have been consulted in the design of the NHS CRS, to ensure it meets the needs of the professions and to provide guidance on effective training. Patients have also been consulted, particularly about confidentiality and content of the record.

The NHS CRS will use the strongest national and international security measures available for handling patient records. These measures make sure that patient information is stored safely, stays private and is accessed appropriately.

Every patient who participates in the new NHS CRS will, over time, have records linked in two ways:

- a) A Summary Care Record - for providing access as needed throughout England.
- b) Detailed records of care given by local organisations, which will be linked for local access.



a) Summary Care Record

Patients can, over the next few years, have a Summary Care Record, which will be available to authorised health care professionals treating them anywhere in the NHS in England. At first, the information in the Summary Care Record will come from their GP record. Later, it will come from other parts of the NHS as well.

Initially, the Summary Care Record will contain only 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, summaries of care and clinicians providing care, may be added to the Summary Care Record.

As anyone adds new information, they should inform patients of those additions, on admission or in the course of a consultation. This will allow patients to request that sensitive information, for example relating to mental or sexual health, certain infections or other matters that individuals consider sensitive, is handled in a way with which they are comfortable (see Section II.4 [page 13] for further information on limiting access).

An **Early Adopter Programme** will learn lessons for the roll out of the Summary Care Record across England. A Ministerial Taskforce was established to recommend how best to implement the Summary Care Record in the Early Adopter Programme. It reported to Ministers on 6 December 2006 and its recommendations are being implemented. The Taskforce included representation from a variety of organisations including clinicians, hospital managers, patients and the ambulance service.

The Early Adopter Programme will focus on the General Practice element of the Summary Care Record, enabling access by appropriate health care professionals within a Primary Care Trust (PCT) area. Various options for limiting participation will be explored. The Early Adopter Programme will be fully evaluated, including an independent evaluation, before roll out begins.

The full roll out of the Summary Care Record will follow from the Early Adopters. It will be several years before the Summary Care Record is rolled out across England.

b) Detailed records

Records containing information about a patient's medical care exist now in a variety of places, for example, at their GP surgery or at hospitals where they have received treatment.

Over the next few years, as the NHS CRS develops, instead of having separate records in all the different places where a patient receives care, NHS organisations which normally work together in a local area, such as hospitals, clinics and GPs, will develop and begin to link and access detailed electronic records for each patient. These groupings will be determined locally, by need and technical capability. A patient who has attended NHS organisations in different areas may have more than one set of linked detailed records.



All detailed records will be kept electronically to be accessed locally. Detailed electronic records will typically contain:

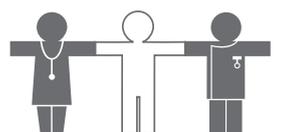
- Name, address, date of birth and NHS number.
- Details of any medicines, allergies, results of tests and X-rays.
- Details of any health conditions, such as asthma or a heart problem.
- Notes about any treatments, diagnosis or operations that the patient has had; and proposed plans or reminders.

They will sometimes include other information the patient has shared (for example, about family or work) but only where this is relevant to the patient's health care.

Linked detailed electronic records will be developed gradually over several years and that process has already started in some places.



II What is *The Care Record Guarantee* and how do you comply with it?



What is The Care Record Guarantee and how do you comply with it?

The introduction of linked electronic records understandably raises issues about confidentiality, security and access. *The Care Record Guarantee*, launched by ministers in 2004, sets out the commitments that will govern information held in linked electronic record systems. It has been drawn up by the **Care Record Development Board (CRDB)** and is reviewed at least every twelve months. The CRDB is an independent multi-disciplinary group established by the Department of Health to advise on matters of policy and ethics. As well as people from health and social care, it includes patients and members of the public and is chaired by Harry Cayton, the National Director for Patients and the Public at the Department of Health. More information about the CRDB can be found at www.connectingforhealth.nhs.uk/crdb.

The Care Record Guarantee covers people's access to their own records, controls on others' access, how access will be monitored and policed, options people have to further limit access, access in an emergency, and what happens when people cannot make decisions for themselves.

All frontline staff need to understand *The Care Record Guarantee* and how to implement it. You can get a copy by visiting www.connectingforhealth.nhs.uk/crdb, or from your NHS organisation.

Answers to some of the key questions around access, confidentiality and patient choices are set out on the following pages.

1. How will staff access to patients' records be controlled?

The NHS CRS will ultimately provide a standard set of safeguards that will help staff comply with the commitments to patients in *The Care Record Guarantee*. However, the nationally deployed safeguards will take some time to deliver.

Until consistent safeguards are available using national systems, NHS organisations are reliant upon the safeguards provided by their local systems, which will differ by locality. These will often be a combination of local system controls and managerial controls. They should be equivalent to – or an improvement over – controls that have applied in the past. Details about local interim controls should be available locally and should also be explained during local training and implementation activities.

Local access controls will build up step-by-step and their development will be an integral part of the information governance processes and policies of the local NHS organisation.

Data sharing agreements between organisations can document the controls that are in place and provide clarity on how they will operate, but on their own they do not provide a lawful basis for sharing confidential patient data.



When the NHS CRS is fully implemented, standardised controls, based on the commitments in *The Care Record Guarantee*, will be in place across England:

- Access will only be possible if you have registered with your local **Registration Authority** to obtain an NHS **Smartcard**, with a Passcode. However the point at which you get a Smartcard will vary depending on where in England you are located and your organisation's implementation of new electronic services.
- Access to the NHS CRS will only be allowed following appropriate training. More details will be given to you by your trust.
- You will only be able to access a patient's record on the NHS CRS if you are involved in that patient's care (this is called a **legitimate relationship**).
- Access will depend on your role (**role-based access**). Roles and access privileges will be defined centrally and given locally by people designated to do this in each organisation.
- Every time someone accesses a patient's record, a note will be made automatically of who, when and what they did (an **audit trail**). Patients can access this information through a formal 'data protection subject access request'.
- Alerts will be triggered automatically both to deter misuse of access privileges and to report any misuse when it occurs. When access is not justifiable, someone in the NHS organisation responsible for overseeing patient confidentiality – sometimes known as the **Caldicott Guardian** - will take action, which may include disciplinary procedures, and telling the patient where appropriate.

How the NHS CRS will affect you as a hospital doctor

“The NHS CRS will provide a massive benefit for hospital doctors. It ensures we always have the clinical notes and results for our patients available whenever and wherever we need them.” Dr Simon Eccles, NHS

Connecting for Health **national clinical lead** for hospital doctors and consultant in emergency medicine at Homerton University Hospital NHS Trust, London.

- The immediate ability to check a patient's current medications, adverse reactions and allergies. This ensures that both GP and hospital clinicians are referring to the same information.
- In the future the ability to review all past and future appointments within your organisation and/or network. This reduces duplication of effort and saves time and resources.
- Faster access to diagnostic results. It will allow quicker ordering of tests, especially frequently ordered groups of tests.
- Facility for inter hospital/discipline consultation - for example X-rays, digital photos and ECGs - can be discussed with a radiologist based elsewhere in the NHS in England, using secure communication.



2. Will patients have access to their own electronic records?

Patients have a right to see their records whether they are paper or electronic. They need to apply directly to the NHS organisation where they received treatment, using subject access procedures under the Data Protection Act.

However, it is planned that they will have the option to view their Summary Care Record at any time using a protected NHS web service called **HealthSpace** (www.nhs.uk/healthspace). They will be able to check it for accuracy and add information, for example their communication preferences.

If someone believes that there is an inaccuracy in their record, they have the right to ask for it to be changed or, if agreement cannot be reached, to ask that a statement be added saying that they disagree with their record.

There are currently no plans for detailed records to be made available to patients through HealthSpace. To gain access to detailed records, patients must still follow procedures laid out by the Data Protection Act - i.e. make an application in writing or, if that is not possible, by some alternative method. They may have to pay a small charge.

3. How will patients be informed about the changes, their options for participation and what they need to do?

Patients will be able to choose how fully they want to participate in linked electronic care records enabled by the NHS CRS. It is therefore essential for them to understand their options for limiting access to all, or parts, of their records. They must also be aware of the potential effects of doing so (see later sections on how to record those concerns and what to do next).

The process for introducing Summary Care Records in the Early Adopter sites will be agreed before they go live, and will take account of recommendations made by the Ministerial Taskforce on the Summary Care Record. The NHS Connecting for Health (NHS CFH) Connected Patient project will work with GP practices in the Early Adopter areas to find out what is needed to make the new arrangements work. A group chaired by the Deputy Chief Medical Officer will advise NHS CFH during the Early Adopter phase.

Lessons learned in the Early Adopter areas will be applied to further roll-outs of the Summary Care Record and this guidance changed accordingly.

Current thinking is that people will receive information about their options in a number of ways. As detailed records are linked locally, at the point of care patients should be given handouts about the different ways their information is being held and accessed and the implications for their care and their personal health information.



Before their Summary Care Records **'go live'**:

- They will receive a letter from their PCT explaining what will happen, and the implications.
- Details about the different ways information will be accessed will be set out in an accompanying information leaflet.
- Other information will be given to patients and the public as the Summary Care Record service is rolled out.

People do not need to do anything if they are happy with the new arrangements for linking and accessing their records.

People who would like more information can:

- Ask for a copy of the leaflet – *Your health information, confidentiality and the NHS Care Records Service. Answers to your questions.* Available from www.nhscarerecords.nhs.uk.
- Ask for a copy of *The Care Record Guarantee* available from www.connectingforhealth.nhs.uk/crdb
- Visit the website at www.nhscarerecords.nhs.uk

People who would like to speak to someone in person, or over the telephone, can contact:

- A helpline for the public. Details of this will be provided as soon as the number is available.
- Their local Patient Advice and Liaison Service (PALS) either by contacting their local service or by visiting www.pals.nhs.uk.

In the Early Adopters for the Summary Care Record, people who have reviewed all the information and decided they do not want it uploaded, or decided to limit access to their record, will need to speak first to a clinician or someone else trained to explain the implications for their health. Processes for doing this will be tested in the Early Adopters.

How the NHS CRS will affect you as a nurse, health visitor or midwife

“For nurses, health visitors and midwives, the NHS CRS is immediately appealing because it will save time... but the most important benefit it offers is even safer, higher quality care.” Barbara Stuttle CBE, NHS CFH national clinical lead for nursing and executive nurse, South West Essex PCT.

- Immediate access to key information in an emergency.
- Reduced administration, less chasing of information and repetitive form filling.
- Access to hospital discharge notes and other patient information in the community, enabling improved follow-up care.
- In the future, test results will be available 24 hours a day, 7 days a week, allowing integrated care across primary and secondary care.



4. What are a patient's options for limiting access?

A three month consultation on how to meet the needs of people who do not want electronic records is being conducted by the Department of Health, from January 2007. Policy and practice will be adjusted to take account of its findings.

Below is the current thinking by the Department of Health.

It is good practice to agree with patients how information is expressed in the record and how it will be accessed, particularly if the information is likely to be sensitive. Patients can ask for information not to be included and this will be a matter for a clinician's professional judgement.

The NHS is required by law to keep a record of the GP practice with which each patient is registered. Patients do not have a legal right to prevent demographic data (such as name, address) being held in the **Patient Demographic Service (PDS)** and **Patient Administration System (PAS)**. The NHS must have basic administrative information to manage their care. However, if needed, steps can be taken to prevent address details from being displayed to staff and, in extreme cases, for example if someone is in a witness protection programme, an alias can be created.

If a patient requests that no demographic data is held, you should seek advice from the person in your organisation responsible for protecting the confidentiality of patient information (sometimes known as a Caldicott Guardian), who may in turn need to seek advice from the Department of Health.

Patients have a right to limit access to their *clinical* data. Over time, as records are increasingly linked through the NHS CRS, it is planned that people will have several ways to limit access should they feel it necessary:

- **No accessing of records across organisations** - clinical information is only accessible to authorised people in the legal organisation that created it and to which the treating clinician is accountable (which is almost always their employer). Examples are a Primary Care Trust or NHS trust. A decision to limit access in this way can be taken before wider access begins and can be reversed by the patient at any time. The decision will apply to both the nationally available Summary Care Record and also detailed records. The exception is information received from another organisation as part of clinical communication (e.g. a referral) to which the patient has consented. Dissent does not interfere with these communications.
- **Partial access** – as the new service develops, but not right away, patients will be able to limit access to elements of their record by asking that certain information in the record is hidden from normal view. This will be known as a **patient's sealed envelope**. Hidden information will only be accessible with the person's express permission, except in exceptional circumstances (see section II.8 [page 17]).



In the future, patients will have two options for sealing information:

a) Seal - if a patient 'seals' the information, it can only be accessed with the patient's agreement, except in exceptional circumstances (see section II.8 [page 17]). Those outside the core team that created the information will see a flag indicating that information is missing.

b) Seal and lock – if a patient 'seals and locks' information, no one can have access to it outside the team that created it, even in an emergency. There will not be a flag to indicate that the information is missing.

Having no NHS CRS electronic records

Patients can request that their Summary Care Record not be uploaded.

In some circumstances a patient may request that the clinical data in their local detailed records be recorded either on paper or within a separate IT system without links to the NHS CRS. Basic administrative data will still need to be held electronically. In practice, many types of care are dependent on clinical data being held in the main NHS systems and there are strong patient safety reasons for holding clinical data where it can be checked.

How the NHS CRS will affect you as a community care professional

“Members of a care team, for example in primary care and mental health trusts, will be able to refer to one set of records no matter where they are. This will lead to safer care and more efficient use of services”.

Martin Baggaley, consultant psychiatrist and clinical lead NHS CFH, London

- All members of the care team will be able to refer to the same information simultaneously from different places.
- The opportunity and incentive to address a number of issues that need more clarity:
 - Managing access to records for those who may be adversely affected by reading information in them.
 - Consent to record sharing for those with learning difficulties.
 - Linking information in children's and their parents' records, without allowing access.
 - Sharing information in child protection cases.



The practicalities of this option will be explored in a Department of Health consultation. The findings will inform plans for the wider roll out of the NHS Care Records Service.

This guidance will be regularly updated to reflect the evolving plans, policy guidance and growing knowledge of best practice.

Local arrangements

Until a consistent set of technical data access controls is available nationally through the NHS CRS, patient controls on access will differ from location to location, but they should include some combination of the following:

- Organisational boundaries enforced at the patient's request.
- Records flagged or other ways of capturing patient dissent, for example a code in the record.
- Managerial controls to ensure dissent is acted upon.
- Physical restrictions on access.

Each NHS organisation must have a plan for meeting the needs of people who dissent. The plan should include both current procedures and how the organisation will move to a mainly technological solution.

At all stages, frontline staff will need to be able to inform patients about the local measures and their options for limiting access to their data. To help you do this, a range of materials, such as posters and handouts, will be made available to SHA and trust Chief Executives for local tailoring and distribution.

How the NHS CRS will affect you as administrative staff

“For administrative staff the NHS CRS will mean less paper, more time and better communication between hospitals, GPs and clinics.” Bronwen Thomason, vice chair, British Society of Medical Secretaries.

- Reduced need to search for notes and chase other hospitals or departments for return of notes, test results or X-rays. Eventually most information will only have to be entered once.
- Over time, the ***GP-to-GP transfer service*** will enable the full set of GP notes from the former practice to be available within minutes of a patient registering with a new surgery. Data will not have to be photocopied and posted at one practice and keyed in again from hard copy.
- In the longer term, job redesign could mean more time spent helping patients and supporting clinicians.



5. What are the implications of a patient limiting access?

Organisational boundaries

If a patient decides to limit access by imposing organisational boundaries, each organisation, whether it is a Primary Care Trust or hospital, will only be able to access the information created by, or sent to, its own health care professionals. They will not be able to access the Summary Care Record. They will not be able to access the linked records for local organisations that would normally form the detailed record. Thus the patient will not benefit fully from the advantages of the NHS CRS.

Imposing organisational boundaries should not impact on the normal one-off electronic flow of information that supports care and takes place with the patient's agreement. However, you will need to advise that, where restrictions are in place, information access (discharges etc.) will happen as it does now - for example by letter, telephone, secure e-mail or electronic reporting. Relying on this type of communication could well affect the speed and efficiency with which care can be offered, particularly for those receiving care from multiple organisations that need to access information.

Not holding information in NHS CRS systems

Patients who do not want their Summary Care Record uploaded will not gain the benefits of having essential information available throughout England for their care. This may affect care out of hours, in an emergency, or outside of the local area. Local detailed records will still be available for local care.

Where it has been agreed that clinical information not be held at all within the NHS CRS, it is essential that:

- A complete record of all clinically relevant information is kept locally on paper or within independent IT systems. Local clinical governance leads must be informed of the circumstances and appropriate arrangements made to ensure patient safety.
- A clinician is involved in explaining the likely consequences to the patient, as providing the best modern treatment often requires the use of computers (e.g. radiography, blood tests and hospital in-patient stays need to create records in new systems to provide care). The patient also needs to be aware that no information will be available in an emergency.
- The patient is given the name of a designated contact within the trust for any ongoing questions or concerns.
- Any clinical data is only removed from systems in line with Department of Health guidance.

Local processes will need to be put in place to respect the patient's wishes with the minimum practicable impact on the patient's care. This needs to be done while, at the same time, meeting the need of the NHS to fulfill all legal obligations to disclose information, for example, if stipulated by court order (see section II.8 [page 17] for more examples).



The best way for the NHS to respond will emerge from consultation and testing. In the interests of patient safety, clear procedures must be followed whenever a patient's request not to upload data is agreed.

6. Which staff will be able to advise patients on limiting access?

Your NHS organisation will designate and train staff to advise patients about limiting access to their electronic care records and to register their preferences in the system.

7. How do you record a patient's wishes?

Patients who decide to limit participation in the NHS CRS will be able to pre-register their wishes with a local clinician. Depending on what is available locally, they can register their wishes in several ways.

A 'flag' can be changed on the Patient Demographic Service.

- Initially, the flag in all patient records is set to 'No Record' indicating that that patient has not expressed dissent or consent. A 'No Record' designation will be treated exactly the same as if the patient has registered explicit consent.
- If a patient dissents from giving access, the flag should be set to 'Dissent'. A decision to limit access in this way will apply to the whole of the patient's NHS Care Record.
- A patient can also choose to register explicit consent to information access, in which case the flag will be set to 'Consent'.
- Some GP systems limit access to Choose and Book unless the consent flag is set to 'Consent'. As Choose and Book is unrelated to the NHS CRS this link between the systems will be changed so that patients can choose to 'Dissent' (limit access to their clinical records) but will still be able to use the Choose and Book service.

If the local system is not yet enabled to access the flag in the Patient Demographic Service, the clinician can add a code to the record or record the patient's request in some other way.

Instructions on pre-registering patients should be given locally, in advance of the launch of the new NHS CRS in each area.

8. Can a patient's request to limit access to their record be overridden?

When data becomes part of NHS CRS systems, a patient's request to limit access to all or parts of their electronic care records may only be overridden in exceptional circumstances by health care professionals who have a legitimate relationship with the patient. This will automatically trigger an alert to the designated local contact in the trust who oversees patient confidentiality.



Where a patient has the mental capacity to be asked for consent to access their records and they have refused, overriding the patient's wishes will only be justifiable in the public interest, where legislation allows, or where a disclosure is ordered by a court. This decision should never be made by one member of staff alone and should always involve the person in the NHS organisation who is responsible for protecting the confidentiality of patient information (sometimes known as a Caldicott Guardian).

Where a patient lacks the mental capacity to make such a decision, it is good practice to consult family and carers. Local procedures will need to take account of new legislation such as the Mental Capacity Act.

Unjustifiable access to confidential patient information against a patient's express wishes is a breach of confidentiality and can be subject to disciplinary action, including dismissal.

How the NHS CRS will affect you as a GP

"The NHS CRS will transform NHS efficiency. Patient information will be instantly accessible wherever it is needed in the NHS. This won't happen overnight but we need to get there as soon as possible." Dr Gillian Braunold, NHS CFH national clinical lead for GPs, based at Kilburn Park Medical Centre, London.

- Immediate access to patients' main diagnoses, prescriptions and letters, as well as to accurate and complete patient demographic information.
- A GP-to-GP transfer service will provide a full set of GP notes very soon after a patient registers with a new surgery, avoiding the need to re-input data from hard copy or send it through the post.
- In time, a ***Secondary Uses Service*** will provide data that does not identify individual patients to inform planning, management, commissioning/strategic decisions and approved research.

9. Do clinicians have the right to limit patients' access to their records?

As now, clinicians can only keep information from patients permanently in very exceptional circumstances, such as where there is a clear danger that the information may cause serious harm to the patient or to someone else, or if it contains confidential information about other people. It is intended that in these circumstances, clinicians can seal information from a patient's view but the process of achieving this is still being considered.



They may also, with the patient's agreement, hold back information until they can discuss it with the patient, e.g. an upsetting test result. This will be particularly relevant in the future when it is intended that patients will be able to access their own Summary Care Record via HealthSpace.

The Data Protection Act exempts clinicians from revealing the information which they have kept from patients for lawful reasons.

How the NHS CRS will affect you as an allied health professional

"The key benefit for allied health professionals will be having the right information, at the right time, in the right place. The introduction of the NHS CRS provides an opportunity to question old traditions, re-visit the way we work and review old practices. The benefits of accessing a single accurate record amongst all relevant staff caring for the patient are enormous." Jan Laidlow, NHS CFH national clinical lead for allied health professionals and clinical services manager for the radiology directorate at Southampton University Hospitals NHS Trust.

- For many community-based allied health professionals, the NHS CRS will bring access to IT for the first time and the ability to update notes, and communicate instantly with a team, or with other teams treating the patient.
- More effective working across disciplines. It will reduce the isolation for those working in the community by enabling them to be connected to their colleagues.
- Easier contact with previous clinicians for more detailed information. People with complex needs will not have to 'tell their story' to many different professionals, reducing duplication as well as administrative delays.



III What is expected of all NHS frontline staff?



What is expected of all NHS frontline staff?

As a member of the NHS frontline staff, you have two key responsibilities with regard to patient confidentiality:

1. To maintain a confidential service in the new electronic environment in line with your legal and professional obligations and employment contracts

All NHS staff handling health or other sensitive information about patients have a legal duty of confidentiality. Patients' rights and the NHS commitment to protect patient privacy are set out in detail in *The Care Record Guarantee* - you can get a copy by visiting www.connectingforhealth.nhs.uk/crdb, or from your NHS organisation. The law also protects the public's rights through data protection, human rights legislation and common law.

You can protect patients' rights to confidentiality by:

- Having procedures in place to ensure all staff, contractors and volunteers understand their responsibilities regarding confidentiality.
- Recording patient information accurately, consistently and promptly.
- Keeping patient information private and secure.
- Disclosing and using information with appropriate care.
- Avoiding misidentification by using the NHS number as the unique patient identifier, e.g. on prescriptions, test results and referrals.

You should therefore:

- Help patients to understand that when they present themselves for care, they need to provide their correct name, date of birth, address, and - if they know it - their NHS number, and let staff know of any changes.
- Make clear notes, bearing in mind that patients could have access to them and will need to understand them. Make discussing health care records a routine part of any consultation.
- Respect patients' rights to access their own health records.
- Be familiar with legal requirements and guidance on confidentiality, as set out in *The NHS Code of Practice*. You can get a copy from www.dh.gov.uk.
- Be familiar with information governance requirements, as defined in *What you should know about Information Governance*, available from NHS Connecting for Health, Reference No 3453. It can be downloaded from www.connectingforhealth.nhs.uk/infogov/publications.



2. *To advise patients and answer their questions*

- Inform patients of the changes. One way is to ask them if they have seen and understood the information leaflet on the NHS CRS which will be given to patients, either sent to their homes or made available in health care settings, as the Summary Care Record rolls out. If not, you should offer them a copy and/or someone to discuss it with. Additional copies of the leaflet will be available to read or download from the NHS CRS website www.nhscarerecords.nhs.uk.
- Information for patients in electronic format for local tailoring is being made available at the same time as this guidance and your local NHS communications lead will be able to advise you about this.
- If patients have concerns about confidentiality, explain their choices for limiting access to their record and what this means – or refer them to the designated contact in the organisation who oversees patient confidentiality.
- Make clear to patients when recording their information that their health care records may be accessed by others involved in their care.
- Regard all medical records as ‘already known’ information rather than ‘complete’ information. Always ask patients to confirm significant details such as medication they are taking.
- Answer concerns directly or tell patients where they can get more information or advice.



IV What do you need to do now?



1. Take part in your local NHS CRS training when appropriate

If you have not already had training, it will be provided locally at the appropriate time to enable you to use the new service. You will not be able to use the NHS CRS until you have completed your training.

2. Register as a user of the NHS CRS

As a staff member, you will be asked to register to use the NHS CRS. You will be given appropriate access once your identity and status have been confirmed. Your organisation will keep you informed about the timetable for registration in your area, and when and how to register to receive your Smartcard and Passcode. If you are registered to use the Choose and Book service, you will already have a Smartcard and Passcode – you will also use these to access the NHS CRS.

Once you have been given a Smartcard, you must:

- Carry it whenever you may need to access the NHS CRS.
- Keep it safe and secure. Treat your Smartcard like your credit or debit card.
- Never tell or share your Passcode.
- Never allow anyone to use your Smartcard - checks on access will be made and you will be held responsible for all patient data recorded and accessed using your Smartcard.
- Never leave your Smartcard unattended.
- Never leave your Smartcard in the Smartcard reader when you are not actively using it.
- Report the loss, theft or damage of your Smartcard immediately to your **Sponsor** (local member of staff who confirmed your identity) and local Registration Authority so that they can cancel and replace it as soon as possible.

You will be advised what to do if your Smartcard is lost or stolen, your Passcode forgotten, or your Smartcard locked due to an incorrect Passcode being entered three times.

If you have further questions please speak to your local designated NHS CRS contact:



V What other questions may patients have?

This section covers a range of other questions which patients may ask and suggested responses.

The answers have been written so that you can respond directly to them, i.e. the 'you' in the answer refers to the patient.



THE NEW SYSTEMS

WHAT ARE THE BENEFITS OF THE NEW NHS CRS?

1. Improvements for you as a patient

- Assurance that the right information for diagnosis, treatment and care planning is available when and where it is needed.
- Fewer lost records and test results.
- Improved safety by reducing transcribing errors.
- Improved protection of your confidentiality and more control by you over how information is accessed.
- Eventually, 24 hour secure access by you to your Summary Care Record and ability to add information so that those providing care know your needs and preferences – e.g. if you have communication preferences or need wheelchair access.

2. Improvements for NHS health care professionals

- Secure, more efficient access to up-to-date information, 24 hours a day, seven days a week, including diagnostic images such as scans, X-rays and test results.
- Ability to access a patient's health care records in more than one place at one time.
- Fewer lost records and test results.
- Better and easier communication between health care providers, including highlighting who has been involved in caring for a patient.
- Increased safety, with the system checking for errors and possible treatment conflicts.
- Over time, knowledge-based software to help clinicians with decision making and choosing the right pathway of care for their patients.

3. Improvements for the NHS

- A linked-up NHS able to offer safer, higher quality care.
- Cost and time savings from increased efficiencies.
- Ability to plan staff and resources according to patient demand, leading to improved performance.
- Better quality and more easily anonymised information for planning, audits, research, fraud detection and performance management.
- Early detection of disease clusters or outbreaks.



HOW ARE MY HEALTH CARE RECORDS USED?

Like paper records, your new electronic records will be used as follows:

- With your name included, to provide you with care and check the quality of that care.
- With your name and other identifying details removed (to protect your confidentiality) to:
 - Find out what the NHS does well or needs to improve.
 - Compare treatments to see what works best.
 - Carry out research.
 - Manage and plan NHS services and finances.
- In very limited circumstances allowed by law, information identifying you can be used without your permission. For example a doctor must tell your local authority if you have food poisoning or information could be used for important medical research involving thousands of patients, where contacting each one for permission would not be practical.



SECURITY & CONFIDENTIALITY

HOW SECURE IS THE NEW NHS CRS?

- All health records are private and personal, so it is our top priority to make the process of accessing your electronic information secure.
- Every person registered with the NHS has a unique identifier - your NHS number - which is used for administrative purposes. It will be used to link all your health information together and ensure that your information is put into the right record.
- The new Service will use the very strongest national and international security measures to make sure your information remains confidential. These measures make sure that your information is stored safely, stays private and is accessed appropriately. The key standards that the NHS CRS meets are:
 - ISO 27000 (old BS7799) is the defining Information Security standard. Information can be found at: www.iso27001security.com/html/iso27000.html.
 - Federal Information Processing Standards (FIPS) is the standard with regard to cryptography. Information can be found at: <http://csrc.nist.gov/publications/fips/index.html>.
 - The electronic Government Interoperability Framework (eGIF) standards are used for secure registration and authentication. The eGIF defines the technical policies and specifications governing information flows across government and the public sector. Information can be found at: www.govtalk.gov.uk/interoperability/egif.asp.
 - The Common Criteria standard details the EAL or Evaluation Assurance Levels of Information Technology hardware and software. For example, we advocate EAL4 firewalls be used to separate corporate networks from N3. Information can be found at: www.commoncriteriaportal.org/.
 - The Communications and Electronic Security Group (CESG) is part of GCHQ, and provides the programme with ITSEC Assurance levels, and advice on the security of the Critical National Infrastructure. Information can be found at: www.cesg.gov.uk/.



COULD MY RECORD BE ACCIDENTALLY DELETED OR LOST?

- When the NHS CRS is fully up and running, there will be very strong protection to prevent any information from being lost, even if the system temporarily stops working. It has been designed to recover as quickly as possible.
- All information that is stored will be constantly updated and copied to a separate, secure site. If something causes the system to stop working, for example a power failure, automatic processes should recover the information as soon as possible.

WHAT ARE MY RIGHTS REGARDING CONFIDENTIALITY AND MY NHS RECORDS?

- You have the right to expect your health information to be kept private.
- You have rights to confidentiality under data protection and human rights legislation and the common law. In every place where you are treated by the NHS there are people who are responsible for ensuring your rights to confidentiality are protected (sometimes known as a Caldicott Guardian).
- Your rights to privacy and our commitment to protecting them are detailed in the leaflet entitled - *The Care Record Guarantee: Our Guarantee for NHS Care Records in England*. You can get a copy by visiting www.connectingforhealth.nhs.uk/crdb or from your local NHS organisation.



LEGAL RIGHTS AND LIMITING ACCESS

WHAT DOES IT MEAN IF I LIMIT ACCESS TO MY ELECTRONIC CARE RECORDS?

- You can limit the information that can be accessed, but this would mean that you won't be able to take advantage of the full benefits of the new service.
- If you decide to limit access to your clinical records across NHS organisations, this will affect access to your whole NHS Care Record.
- At first your Summary Care Record will contain only basic information such as current medications, adverse reactions and allergies. It is designed to be available to those giving you out of hours or unplanned care across the NHS in England.
- Your detailed records are designed to enable those giving you NHS care locally, particularly long-term care, to access information about you and do other things such as order tests and manage complex treatments.
- If you are sent to another part of the country or to a nearby hospital for care, those treating you will have to rely on the information provided by your GP in the referral, rather than having automatic access to fuller information. When you leave hospital, records about your outpatient and inpatient treatment will not automatically be available to your GP but must be sent by post or fax. It will also mean that records made by your GP about the management of any long-term conditions will not automatically be available to those looking after you in hospital or in the community.

CAN I LIMIT PARTICULAR ITEMS OF SENSITIVE INFORMATION BEING ACCESSED IN VARIOUS PLACES WHERE I RECEIVE CARE?

- Any time you have care, you can discuss how sensitive information will be recorded.
- You can ask for your information only to be accessed by people in the organisation that created it, such as your Primary Care Trust or local hospital trust. If other NHS organisations need access to your information, it will have to be sent by letter, telephone, e-mail, electronic reporting, or fax, as they do now. This would mean, however, that you won't be able to take advantage of the full benefits of the service.



- As the service develops, although not right away, you will also be able to ask that certain information is hidden from normal view. This will be called a patient's sealed envelope.

You will have two options for sealing information:

- a) **Seal** - if you 'seal' the information, it will only be accessed with your agreement, except in exceptional circumstances. Those outside the care team that created the information will see a flag, showing that information is missing.
 - b) **Seal and lock** - if you 'seal and lock' information, no one can ever have access to it outside the team that created it, even in an emergency. There will be no flag to show that the information is missing.
- If we find that anyone in the NHS has accessed any information that you have restricted without good reason, we will inform you and, where appropriate, take disciplinary action. This could include dismissal.

CAN I CHANGE MY MIND?

- A flag in your record that tells the computer system about accessing information can be set at your request to "access" or "no access". You can ask to have the setting changed at any time. Where this is not available yet, there will be other ways to record your preferences.
- Once sealed envelopes are available, you can seal and unseal information at any time with a clinician.

WILL OTHER PEOPLE OUTSIDE THE NHS BE ABLE TO ACCESS MY RECORDS?

- Sometimes your health care team might include people from social services, education or a private hospital. You should be informed if this is the case.
- In the future, other health care professionals who are treating you, such as dentists, or pharmacists located in your high street, may have access to parts of your records. You should be informed when this happens. They will be covered by similar confidentiality arrangements.
- When it could be best for your care for organisations outside the NHS to have access to your health information, such as private or voluntary sector organisations that care for you, this will need to be agreed with you first. If you do not agree, you will need to discuss the possible effects on your care and alternatives available. Anyone caring for you outside the NHS who in the future will be given access to NHS Care Records must meet defined standards of confidentiality and security.



- As a competent individual you may grant others - for example solicitors - the right to see your records, but it should be ensured that you understand what you are agreeing to. You may wish to limit access to just part of a record. In addition, people with powers under mental health legislation may have access to records of a non-competent adult.
- The NHS will only give information to other parties without your permission if required or allowed to do so by law, for example, if a court order has been issued.

CAN PARENTS ACCESS A CHILD'S RECORD?

- Parents or legal guardians have the right to access the records of a child unless the child has requested that access be denied, or has provided information with the expectation that access would be denied. However, even where the child has denied access, a clinician may provide information to parents or legal guardians where the public good in doing so outweighs the obligation of confidentiality to the child.

CAN I STOP INFORMATION BEING PUT INTO MY RECORD?

- No. Health care professionals are required to make accurate, relevant records of the care provided. You can discuss what is recorded, where it is recorded, and how it is expressed, but you cannot prevent a health care professional from making some record of relevant information.

CAN I ASK TO SEE WHAT A CLINICIAN MAY HAVE SEALED FROM MY VIEW IN MY RECORD?

- No. Just as now, the Data Protection Act exempts clinicians from revealing the information which they have kept from patients for lawful reasons. However, there are only very exceptional circumstances when a health care professional may keep information from you. It might be allowed if:
 - In a health professional's judgment, seeing the information is likely to cause serious harm to your physical or mental health, or that of someone else.
 - The information has been provided in confidence by someone other than a health care professional caring for you. An example would be information provided by a family member who asks your doctor or carer not to tell you.
- A health care professional may also agree with you to hold back information until they can discuss it with you, for example a potentially upsetting test result. This will be particularly relevant when you can access your own Summary Care Record by computer.



WILL THE NHS ASK MY PERMISSION TO CREATE MY ELECTRONIC CARE RECORDS?

- You will be notified in advance by your Primary Care Trust when your Summary Care Record is about to be introduced. You will have several options for limiting access to all or parts of your Summary Care Record. The details of the options available will be worked out in the Early Adopters, following the recommendations of the Ministerial Taskforce on the Summary Care Record.
- The detailed records of your care will gradually be linked together so that organisations that normally work together can access them. Where this happens, you should be given information the next time you receive care in a participating organisation, including what to do if you want to limit access to your records.
- If you are happy for your NHS Care Records to be accessed by those caring for you across NHS organisations, you do not need to do anything.
- If you have reviewed all the information available and decided to limit access to your Summary Care Record or local detailed records, you should see a health care professional such as your GP, who can register your choices. You can make this decision and change it at any time.
- The full range of choices for limiting access will be refined over time through testing and consultation.



ACCESS TO YOUR OWN CARE RECORD

CAN I CHANGE OR ADD INFORMATION TO MY NHS CARE RECORD?

- You cannot change information written by others.
- Eventually, you will be able to add information to your Summary Care Record such as access needs and treatment preferences – e.g. the need for wheelchair access. You can also specify people you would like to have access to your health record such as a carer.
- Any changes you make to your record will be noted in the same way as changes made by a health professional.



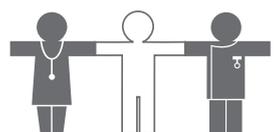
WHERE YOU LIVE

WHAT HAPPENS IF I LIVE IN ENGLAND AND RECEIVE CARE IN WALES/SCOTLAND, OR VICE VERSA?

- Computer systems in England, Wales, Scotland and Northern Ireland are in different stages of development and may be linked in the future.
- Therefore, if you live outside England but receive care here, you will have electronic care records covering your treatment in England. When you return home, information about your care in England will be sent back, as now, by letter, secure e-mail, phone or fax. This may change in the future as electronic record systems become available elsewhere.
- When you are referred to another country for treatment, you should be provided with information about how their health care records work.



VI Glossary of Terms



Audit trails – register all accesses to a patient’s record – who, when, what they did. Patients can also ask to see this information through a subject access request.

Caldicott Guardian – staff in NHS treatment locations, who are responsible for ensuring that patient rights to confidentiality are protected.

The Care Record Development Board (CRDB) – an independent body established by the Department of Health, it brings together patients and service users, the public, and social and healthcare professionals within a single forum that helps to set the new model for care. It works with NHS Connecting for Health to enable access to information, scheduling and processes across traditional boundaries.

Care Record Guarantee – the commitment of the NHS in England to patients that it will use records about them in ways that respect patient rights and promote patients’ health and well-being. The Guarantee covers people’s access to their own records, controls on others’ access, how access will be monitored and policed, options to further limit access, access in an emergency and what happens when someone cannot make decisions for themselves.

Early Adopter Programme – sites that link GPs and secondary care to test the systems for the Summary Care Record during 2007.

Frontline staff – staff who are directly involved in patient care.

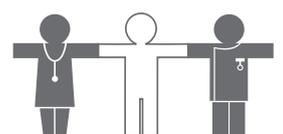
GP-to-GP transfer service – system used for transferring electronic patient records when a patient registers with a new GP practice. A secure way of transferring patient records from one GP practice to another.

Go live – for the purposes of communications with the public, go live is when electronic care record systems enable information to be linked so that it can be accessed by people in different organisations, e.g. a hospital can access information created by a GP.

HealthSpace – HealthSpace is a secure website which can be found at www.nhs.uk/healthspace which provides an on-line personal health organiser for patients. In time it will provide patients with full access to elements of the NHS CRS such as viewing a history of personal health information and treatment, and the ability to set personal preferences such as communication preferences or transport requirements. Access to chronic disease management support will also be available.

Legitimate relationship – limits access to a patient’s record to staff involved in the patient’s care.

National clinical lead – NHS Connecting for Health has national clinical leads for nurses, GPs, hospital doctors and allied health professionals. They work closely with the clinical professional organisations and other organisations as well as the chief clinical officers at the Department of Health. They make sure that clinicians are involved at every stage in designing the new systems and developing new working practices.



NHS Care Records Service – the computer software and electronic store of over 50 million care records which can be accessed by health professionals where and when they are needed. It will also give patients secure internet access to a summary version of their own electronic care records.

NHS Code of Practice – sets out the basic principles underlying public access to information about the NHS. It reflects the Government's intention to ensure greater access by the public to information about public services and complements the Code of Access to Information which applies to the Department of Health. It is available from www.dh.gov.uk.

Patient Administration System (PAS) – an administrative system, typically used in hospitals, that contains essential non-clinical data (for example, patient attendance lists, appointments, waiting times etc).

Patient Demographic Service (PDS) – this is a service that holds information nationally such as name, address, date of birth, preferred communication language, patient password and consent information.

Patient's sealed envelope – allows a patient to place restrictions on access to components of their records – begins in 2008.

Registration Authority – the organisational structure within an NHS organisation that is responsible for registering and verifying the identity of NHS health care professionals/workers who need to access the NHS CRS. After proving their personal identity and being vouched for by a sponsor, staff are issued with a Smartcard and Passcode with an approved level of access to patient information, by the Registration Authority. This is essential to protect the security and confidentiality of every patient's personal and health care information. For example, a consultant should be allowed to record clinical information while a receptionist should only see relevant information needed to process appointments, not full clinical records.

Role-based access – restricts what a member of NHS staff can see and do in a patient's record to what is appropriate to their role in a patient's care.

Secondary Uses Service – a system designed to provide timely, patient-based data and information, with identifying details removed, for management and clinical purposes other than direct patient care. These secondary uses will include functions such as health care planning, commissioning, public health, clinical audit, benchmarking, performance improvement, research and clinical governance.

Smartcard – is a plastic card containing an electronic chip (like a chip and pin credit card) that is used to access the NHS CRS along with a Passcode. The chip does not contain any personal information, providing only a secure link between the NHS CRS and the database holding the user's information and access rights. The combination of the Smartcard and the Passcode together, issued by a Registration Authority, help protect the security and confidentiality of every patient's personal and health care information. It is printed with the user's name, photo and unique identity number.



Sponsor – sponsors are staff appointed by the organisation’s Executive team to vouch for members of staff to be entitled to receive access to the NHS CRS through a Smartcard.

Sponsors will usually be a member of staff’s operational head, manager or administrator within a practice, clinic, ward or department. They may also be a member of the HR/personnel department.

