

	<b>Shared Care Record Review Document</b>			
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Version for feedback

## THE CLINICAL DEVELOPMENT OF THE NHS CARE RECORD SERVICE

### Introduction

The NHS Care Record Service is central to the *NHS Connecting for Health's* National Programme for Information Technology. Now that the architecture has been commissioned, designed and is being built, there is a need for clarity concerning how it will be used by clinicians and patients. The NHS Care Record Service is an essential element in the vision of the National Programme for IT that will enhance patient experience, improve patient care and support better outcomes from health care.

This report is the outcome of the review of the NHS Care Record Service by the National Clinical Leads in *NHS Connecting for Health* and the Care Record Development Board. It sets out how the vision for a patient care record, compatible with the commissioned architecture and the NHS Care Record Guarantee, can be achieved. It describes an incremental approach that will build public and professional confidence, establish working practices and allow for the effective evolution of the whole NHS Care Record Service. Such evolution must be firmly based on experience, with time to learn and apply lessons from the early phases.

The NHS Care Record Guarantee (appendix) is a key policy document governing the NHS Care Record Service. It pledges that “we will aim to share only as much information as people need to know to play their part in your healthcare” and that “under current law, no one is able to make decisions about sharing health information about you on your behalf<sup>1</sup>”. The development of the NHS Care Record Service must be compatible with these aims.

The NHS Care Record Service will have at its core the electronic health care records used to deliver direct patient care, the Patient Clinical Record. In addition there will be a National Summary Record for supporting urgent and emergency care.

This report describes the Patient Clinical Record and then considers the National Summary Record. It then summarises access controls, makes recommendations on governance and gives details of how to comment on this document in the feedback process.

### The Patient Clinical Record

As at present, health professionals will continue to generate clinical records for encounters or episodes of care. Currently such clinical records are available to and shared with the immediate team, such as a surgical team or the doctors and nurses in a single general practice.

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<sup>1</sup> At present, the only exception to this is parents or legal guardians who may decide on behalf of their child. This may change if the Mental Incapacity Bill becomes statute.

As the NHS Care Record Service allows linkages the possibilities of sharing information are greatly increased, with a parallel prospect of enhanced patient care and safety. This is accompanied by an increase in the risks to patient confidentiality. The controls on access to these clinical records (see below) will help to ensure confidentiality and only appropriate access; but also the record architecture needs to ensure patient protection. The proposals in this document are designed to gain most patient benefit within the requirements of security and confidentiality.

If, unusually, a person is receiving care from only one health service – their general practice or their dentist, for example – they will only have one active record and that will be the full extent of their Patient Clinical Record. Most people receive care from a range of health professionals – say, their general practice team (general practitioner, practice nurse etc), an optician, a pharmacist, a community nurse, a dentist and a consultant in out-patients. The records of those health professionals involved in on-going care for a patient will collectively comprise that patient's Patient Clinical Record. This is independent of where those health professionals are geographically located, or where their records are stored.

Each health professional will have access to their own records and aspects of the other parts of the Patient Clinical Record as determined by their role based access (see below). Health professionals will join the Patient Clinical Record for an individual patient through implied consent and explicit consent. The former will apply with a patient is registered with a general practice or referred – for example when a general practitioner refers a patient to an orthopaedic surgeon then, until the patient is discharged from follow up, that surgeon and their clinical team will normally be part of and party to the areas in that patient's Patient Clinical Record that their role permits.

The concept of explicit consent occur when a patient approaches a health professional without referral, an optician for example, and wishes them to have access to a part of their Patient Clinical Record, perhaps because they have diabetes. They will give consent to that health professional being party to their Patient Clinical Record as long as they continue to consult them. Only health professionals with appropriate authentication for access using a smart card can become party to a Patient Clinical Record.

There is a third group of patients, those with complex or multiple health conditions. They will additionally have a "pathway of care" which is a record structure available to a specific group of health professionals who already have access to their Patient Clinical Record but who can also access and contribute to a shared record that allows coordinated care regardless of location. A pathway of care includes:

- Past and planned care relating to their conditions including aims of treatment
- Roles and responsibilities of the health professionals
- Communications (inter-clinician, inter-agency and with the patient)
- Patient inputs

It is central to this vision that patients can limit the information that is included in their Patient Clinical Record. At present, some clinical records are not shared at all, for example those made by psychologists or in counselling, and this will continue to be an option. So a patient can ask that the records of a health professional are not sharable in their Patient Clinical Record or even within that health professional's group.

A patient can decide not to allow access to their Patient Clinical Record to any health professionals involved in their care. In further developments of the Patient Clinical Record patients will be able to request that specific clinical items in their record are not available to specific individual health professionals or groups.

## **The National Summary Record**

The purpose of the National Summary Record is to act as a source of information to support first contact care, for example out-of-hours, in accident and emergency, temporary residents, on first registration with a new surgery and on acute admission. It will be used before a patient

consents to a health professional or health care group being party to their Patient Clinical Record or when a patient does not wish to set up such an arrangement.

It must, therefore, contain significant aspects of a patient's care, such as major diagnoses, procedures, current prescriptions and allergies; and it must accumulate new key aspects of a patient's care as time goes by. However, it must only contain clinical data that is necessary for the purpose of enhancing safe patient care on first contact.

For a very small group of patients who are not registered with general practitioners and who use health services in an unstructured fashion, the National Summary Record will, as far as these patients allow, be the best record available. This will be a considerable advance on the current recording system for these people.

As a clinical database becomes compliant with (using an LSP supported program and meeting inter-operability and hosting requirements) and joins the NHS Care Record Service, and after its data quality has been validated, the National Summary Record will be populated by an extract from that database. In reality, because most electronic clinical data is currently on a patient's general practice electronic record, most of the initial population of the National Summary Record will be from the primary care record. We will be seeking views and reporting separately on the detailed methodology and content of the extract from the Patient Clinical Record, but our current thinking is that it should contain:

- Major diagnoses<sup>2</sup> and surgical procedures
- Allergies and adverse reactions
- Recent and current prescriptions

These data will be clearly marked to identify the origin, the date of upload and the fact that it came as part of an original mass upload.

Once a patient's National Summary Record is in place, it will be added to by:

- All electronic prescribing records from all settings<sup>3</sup>
- Significant diagnoses/procedures/allergies that the patient and clinician agree shall be added<sup>4</sup> to the National Summary Record<sup>5</sup>
- Clinical documents such as medical referral letters and medical discharge summaries<sup>6</sup>
- Patient comments, preferences and views (entered through Healthspace or discussion with their clinician; in this space the patient may enter statements such as their views on access to their record; living wills; organ donation etc)

All entries to the National Summary Record will be transmitted and recorded as SNOMED CT codes. There are important issues that will need to be addressed in time concerning changed diagnoses, conflicts between recordings in different settings and obsolescence of data. These issues are still to be addressed.

Each entry in the National Summary Record must identify its author (person and organisation) and date. This then becomes an index of health professionals caring for that patient and informs a health professional accessing the National Summary Record of who else is, or has

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<sup>2</sup> We propose that the diagnoses would be those on a pre-defined list of "significant" conditions, but excluding potentially sensitive mental health diagnoses, sexual health episodes or infections. This will be part of the separate discussions concerning uploading etc

<sup>3</sup> Initially from primary care but in time from all health care settings as the information becomes available

<sup>4</sup> When the patient and the clinician agree not to submit an important clinical event to the National Summary Record, there will be a flag on the national record to indicate that it is incomplete

<sup>5</sup> Initially these will be mainly in primary care; however in time entries will be generated in hospitals and other settings

<sup>6</sup> The addition of referral letters and discharge summaries must be compatible with the person's right to limit participation. This will be included in the discussions with the professions and the public

been, delivering health care to that patient. It also will allow, if and when the patient consents, for the new health professional to join that patient's Patient Clinical Record.

The Patient Clinical Record must enable a clinician and their patient to identify which entries are on the National Summary Record; and patients should have access in time to their own National Summary Record through Healthspace. Both these features will facilitate feedback to improve data quality in the National Summary Record.

As with the Patient Clinical Record, people will be able to limit their participation in the National Summary Record. They will be able to ask for individual items, such as individual diagnoses in their Patient Clinical Record, to not be sent to or to be removed from the National Summary Record. As clinical databases become compliant with the requirements of the NHS Care Record Service and uploads to the National Summary Record are proposed, there must be a public information and engagement initiative in order to inform people of their right to limit their participation.

In terms of the exclusion of prescription data from the National Summary Record, another working group will report separately on this after considering technical (the electronic transmission of prescriptions) and patient safety issues. Our current view is that, since all electronically transmitted prescriptions will be handled within a separate database, the National Summary Record can exclude drugs that a patient requests to be withheld while allowing interaction checks on all currently prescribed drugs.

## Access to the NHS Care Record Service

The acceptability of the NHS Care Record Service depends crucially on the controls around access. Briefly, there are two broad types of security:

1. Care professional centric security which includes role-based and workgroup-based access: authenticated health professionals are issued with personal smart cards which define their role and group, and through that define their access to clinical data within both the National Summary Record and the Patient Clinical Record.
2. Patient centric security: individual health professionals can only access a record for a patient with whom they have a legitimate relationship and within the constraints of patient consent.

An audit trail will document all accesses to patient data. Local data supervisors, called Caldicott Guardians, will be alerted on any inappropriate access to clinical data in the NHS Care Record Service.

## Governance

There must be adequate oversight and governance. There should be a Project Board and a Senior Responsible Officer. The content of the NHS Care Record Service must be agreed with the Care Record Development Board, and robust continuing information governance arrangements must be in place.

## Feedback

Comments on this document should be submitted to:

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## 1. Appendix: The NHS Care Record Guarantee: Our commitments to you

1. When we receive a request from you in writing, we must normally give you access to everything we have recorded about you. There are two exceptions: 1) confidential information about other people, or 2) information a health professional considers likely to cause serious harm to the physical or mental health of you or someone else. This applies to information in paper and electronic records. If you ask us to, we will also let others see health records about you.

Wherever possible we will make health records about you available to you free of charge or at a minimum charge, as allowed by law. We will provide other ways for you to apply to see your records if you cannot do so in writing.

We will provide information in a format that is accessible to you (e.g. in large type if you are partially sighted).

2. When we provide healthcare, we will share health records about you with those providing care or checking its quality. They must keep the information confidential, whether shared using the computer system or by other means (such as on paper).

We will aim to share only as much information as people need to know to play their part in your healthcare.

3. We will not share information outside the NHS<sup>7</sup> that identifies you for any other reason unless:

- you give us specific permission;
- it is required by the law;
- we have good reason to believe that failing to share the information would put someone else at risk.

Where, exceptionally, information is shared without your permission, we will ensure that the NHS Confidentiality Code of Practice and other national guidelines on best practice are strictly followed.<sup>8</sup>

4. Under current law, no one is able to make decisions about sharing health information about you on your behalf<sup>9</sup>. However, if you are unable to make decisions about information sharing, a senior healthcare professional involved in your care may judge it to be in your best interests for information to be shared. This judgment should take into account the views of relatives and carers and any views you have recorded in advance.
5. Sometimes your healthcare will be provided by members of a care team, which might include people from other services, such as social services or education, in addition to NHS staff. We will inform you where this is the case. When it could be in your best interests to for us to share health information with organisations outside the NHS, we will agree this with you before we proceed. If you don't agree, we will discuss with you the possible consequences for your care and alternatives.
6. You can choose not to have information in electronic care records about you shared. In helping you decide, we will discuss with you how this may affect our ability to provide you with care or treatment, and any alternatives open to you.

<sup>7</sup> Specifically, we will not share such information with other Government agencies.

<sup>8</sup> More information about existing guidelines can be found at [www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians](http://www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians).

<sup>9</sup> At present, the only exception to this is parents or legal guardians who may decide on behalf of their child. This may change if the Mental Incapacity Bill becomes statute.

7. We will deal fairly and efficiently with your questions, concerns and complaints about how we use information about you. All Trusts have a Patient Advice and Liaison Service which is able to answer questions, point people toward sources of advice and support, and advise on how to make a complaint. We will have a clear complaints procedure. We will use what we learn from your concerns and complaints to improve services.
8. We will take appropriate steps to make sure information about you is accurate. You will be given opportunities to check records about you and point out inaccuracies. We would normally correct factual inaccuracies. If you are unhappy with an opinion or observation that has been recorded, we will add your comments to the record. If you are suffering distress or harm as a result of information being held in your record, you can apply to have the information amended or deleted.

**We will make sure, through contract terms and staff training, that all who work in or on behalf of the NHS understand their duty of confidentiality, what it means in practice and how it applies to all parts of their work. Organisations under contract to the NHS, must abide by the same policies and controls as the NHS itself. We will enforce this duty at all times.**

We will take appropriate steps to make sure we hold records about you – both paper and electronic – securely and only make them available to those who have a right to see them.

We will keep a record of everyone who looks at the information held about you by the NHS Care Record Service. You will be able to request a list of all those who have looked at records about you and when they did so.

There may be times when someone will need to look at information about you without having been given authority to do so in advance. This may be justifiable, for instance if you need emergency care. Where the action cannot be justified, you will be informed.

**We will take action when records about you are deliberately looked at without authority or appropriate justification. This can include disciplinary action, ending a contract, firing an employee, or bringing criminal charges.**

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