

Introducing the electronic Summary Care Record

In March this year NHS Connecting for Health launched a public information programme in the first of a series of "early adopter" Primary Care Trusts (PCTs). Patients in Bolton became the first in England to receive information telling them about the introduction of the new electronic Summary Care Record. The Summary Care Record forms the national element of the NHS Care Records Service which will see an electronic record being created for every person in England who does not opt-out by 2010.

Since that time, four other PCTs have followed suit in Bury, South Birmingham, Dorset and Bradford & Airedale. So far, just over half a million patients have been written to in order to tell them about its introduction, and by the end of the early adopter phase, this may rise to almost two million.

What is the Summary Care Record?

The Summary Care Record will eventually be available across England and is designed to improve patient care by making essential clinical information available to all doctors, nurses and appropriate healthcare staff involved in a patient's care as they move across the various organisational boundaries within the health service. Dealing with the NHS can be incredibly frustrating. At present we have a system that pushes around millions of pieces of paper every day, many of which inevitably get lost or are not available when a patient is presented for treatment. Electronic records will be available in the right place, at the right time, which will make patient care safer, quicker and better.

A patient's Summary Care Record will be made up of extracts from their usual GP clinical records made when they attend the Health Service. It is NOT the entire GP record but the essential elements that will help ensure safer care in all care settings. This means that when a patient presents themselves in A&E, or is seen by a locum GP out of hours, the doctor treating them will have access to crucial information about their medical history. This will help to avoid those 1 in 10 people currently in hospital because of a wrong prescription or treatment.

During 2007/8, these early adopter areas are starting to populate patients' Summary Care Records with limited but important clinical information from their GPs' records. Patients are informed about the coming changes and are given four months to find out more and determine the extent of their participation. Following the four month period, the practices will upload a limited part of the record, namely a list of recent drugs, allergies and adverse reactions only. This will only apply for those patients who have not declined to have a Summary Care Record. After this first upload of information to the central database (or "Spine"), significant medical history and other key information will only be added after discussion with the patient and with their agreement. How this is done effectively for both the GP and patient is being tested in a variety of ways in the early adopter areas.

Access to records will be controlled

Access to patient records will be strictly controlled. There is a strong registration process compliant with the government standard eGif level 3 which means the user has to initially appear in person to prove their identity before access is assigned by the "Registration Authority" governed by NHS Connecting for Health.

NHS Staff will have to pass three tests to access a patient's records. They will have to be registered as NHS staff and be issued with a Smartcard and passcode (which works like a chip and PIN bankcard); they have to be recognised by the system as providing care or treatment to you (what we call a Legitimate Relationship); and, they will only be able to see the sorts of information they need to give you that care or treatment (what we refer to as Role Based Access). This means that only staff who have need to see clinical information as part of their job will have access to it.

Full audit trails of who has accessed a record is made possible by the unique identity associated with each smartcard. These are available to patients on request, as well as to staff charged with checking for system misuse by authorised staff. It will be up to individual privacy officers (Caldicott Guardians) to investigate where inappropriate access to records may be suspected. This "footprint" is a considerable advance on what exists now with either paper or electronically held records.

The Summary Care Record is being made available to support unscheduled care in A&E Departments, the general practice out-of-hours service and ambulance services. Additionally and under the same rigorous controls, access will be available to registered and authenticated community staff to the Summary Care Records of the patients with long-term conditions for whom they provide care.

Patients have choices

Patients have choices. They can decide whether or not to have a Summary Care Record and, if they decide to have one, whether or not it is shared. They can change their mind at any stage.

Patients have three choices that they can make once they are informed of the opportunities available to them, as outlined in the table below:

STORE ✓	STORE ✓	STORE X
<p>Clinician - via SCR:</p> <p>A Summary Record (SCR) is, visible to an authorised user who has a Legitimate Relationship with that patient.</p> <p>Patient – via HealthSpace:</p> <p>The patient's Summary Care Record is visible to them.</p>	<p>Clinician - via SCR:</p> <p>A Summary Care Record will exist but will not be automatically visible to any authorised user. <i>The patient may give a Clinician permission to view the record at any time.</i> The status can only be overridden without the patient's permission according to the Law.</p> <p>Choosing not to share also means that a patient's detailed record from one organisation will not be accessible in another organisation.</p> <p>Patient – via HealthSpace:</p> <p>The patient's Summary Care Record is visible to them.</p>	<p>Clinician - via SCR:</p> <p>A blank summary is created, stating that the patient did not want to have a summary record. No data is available to be viewed, regardless of the sharing status.</p> <p>Patient – via HealthSpace:</p> <p>No clinical data is available. A note confirming this choice is visible.</p>
SHARE ✓	SHARE X	NO SCR TO SHARE

Patients can choose to have a Summary Care Record created (stored) and choose to share it routinely. Alternatively, any patient who does not wish to have a Summary

Care Record made (not store) does not have to have one made and can dissent to one being made by contacting their GP during the 16 week period. They can of course also decide at a later time to not have a record if they so wish.

As the figure demonstrates patients with any misgivings about the Summary Care Record can also decide to have a Summary Care Record created but not to share it routinely – the “amber box”. Should a patient then wish to allow a clinician to see their Summary Care Record then they can give permission to the clinician and ask that the permission exists only for the period of that consultation. Every subsequent viewing of the record will also need their express consent.

This setting allows the patient to give consent to a clinician who they see on a one off basis. When this happens, an alert will be sent to the information guardian. These choices are underpinned by the Care Record Guarantee which is the commitment that patient records will be used in ways that respect patient rights and promote patient health and well being.

After 2008, patients will be able to choose what is routinely shared and what is not by using “sealed envelopes”; until that time they can choose what items other than medications and allergies are included. Sealed envelopes are being developed to enable items of clinical data to be hidden from clinicians, and only made available to them with patient’s explicit consent.

Patient access to their own Summary Care Record

The first patients in Bolton and Bury PCTs are now able to see their own Summary Care Record through HealthSpace, a website with strict registration and access controls. Patients need to register for an “Advanced Account” to get access to their HealthSpace record. This will provide patients with the opportunity to read their record and flag up any corrections which might need to be made by their GP.

HealthSpace enables patients involvement in the sharing and therefore in the use of their record in a variety of ways. They will be able to print out a copy of their Summary Care Record from within HealthSpace. They will also be able to share their record by logging in to their HealthSpace account whilst in the company of a clinician using their own access controls (especially useful when outside England or, in the short term, in areas where the Summary Care Record has not yet been adopted). If the patient chooses to have a Summary Care Record but not to share it (the amber box) he or she will be able to view the Record though HealthSpace even though no-one else can without their permission. They will also be able to view their consent status.

HealthSpace is of course available now. It provides patients with a personal health organiser capable of storing: personal details, medications (including Over the Counter); health details (height, weight, blood group, blood pressure, cholesterol, blood sugar level, heart rate, peak flow); lifestyle details (alcohol and tobacco consumption); NHS contact details (e.g. GP, pharmacy, optician, hospitals, clinics etc); a calendar for scheduling events and reminders; local NHS services search; and, access to the Choose and Book online booking system.

During 2008, some important additions will be made to HealthSpace. It will allow patients to list and update their nominated pharmacy to support the roll-out of electronic prescribing. Patients will also be able to record faith/spiritual preferences; any disability/access requirements; any dietary requirements; and, other comments

related to their care and treatment. In time it is planned for patients to be able to store “living wills” and other important documents.

Evaluating the programme – making sure we do the sensible thing

The early adopter phase will continue until the Spring of 2008. Throughout this phase the programme is being independently evaluated to make sure that learning and best-practice are captured ahead of rolling out the availability of the Summary Care Record to the rest of England.

The evaluation team at University College London (lead by Professor Trisha Greenhalgh, Professor of Primary Health Care and Director of the Masters Programme in International Primary Health Care at UCL and herself a practising GP), have been conducting their study since April 2007.

The evaluation of the early adopter phase will broadly cover the following areas:

- Usability, usage and functionality of the Summary Care Record
- Impact and benefits of the Summary Care Record
- Patient access to their own Summary Care Record (particularly via HealthSpace)
- Evaluation of the Public Information Programme
- Evaluation of the consent/dissent model

The evaluation team are conducting extensive fieldwork within the early adopter Primary Care Trusts (PCTs), immersing themselves in the reality of implementation and usage of the Summary Care Record on the ground. The views and experiences of GPs, nurses, patients and the public, practice managers and other clinical and administrative staff using the Summary Care Record are being captured. The final report of the evaluation's findings will be published in the summer of 2008 with any emerging findings influencing the continued rollout of the Summary Care Record.