

## NHS CONNECTING FOR HEALTH

# THE INITIAL GENERATION AND CONTINUING REFRESHMENT OF THE GP SUMMARY CARE RECORD: THE WAY FORWARD

This document describes the way in which the General Practice contribution to the Summary Care Record – a key element of the NHS Care Record Service – will be implemented. At first the General Practice summary will be the main or only active part of the Summary Care Record; in time it will be supplemented by other contributions.

This document is not intended as a description of the full Summary Care Record, let alone the NHS Care Records Service. Other documents set the fuller context. It is a guide to how the General Practice component of the Summary Care Record will be implemented. The pilot study described here is genuinely intended to improve understanding and thus to influence the full implementation of the General Practice Summary. So the final description may differ from that given here.

### Background

After extensive consultation and reflection, the Care Records Development Board, on the advice of its Ethics Advisory Group, advised the National Programme Board that an assumption of patient consent to information sharing should be adopted. The introduction of the care record would be preceded by an information campaign nationally and then locally when the introduction was imminent. People would be able to decide not to take part – the so-called opt-out. This was agreed by the National Programme Board and by Ministers

Concerns have been expressed by the BMA Ethics Committee and General Practitioners Committee and by the Royal College of General Practitioners' Ethics Committee and Health Informatics Standing Group. These concerns focus around data quality and checking, and patient rights. Some in the mental health field had pointed out that the original proposals risked stigmatising mental health. Finally, the technologists with *NHS Connecting for Health* observed that the original proposals were complex and difficult to implement.

On March 8<sup>th</sup> 2006 a key senior group within *NHS Connecting for Health* met to consider these views and to decide on policy for the initial and continuing Summary Care Records from general practice. This document sets out the way forward decided then.

## **Before general practices contribute to the summary care records**

Before information from a general practice is placed into NHS Care Record Service Summary Care Records the practice's database must conform to technical CFH standards including being hosted in an approved data centre, and must satisfy a data accreditation process.

The Public Information Campaigns will alert people to the plan to undertake the generation of Summary Care Records. There will be functionality for a putative summary to be printed for a patient to view. If a patient does not wish a Summary Care Record at this initial or later stages, this will be recordable on PDS using the "no share" flag.

## **The initial generation of a summary**

As each practice goes live a text-only Summary Care Record<sup>1</sup> will be extracted from the GP database for each patient on the database. For all those people who have indicated dissent (opted out) their summary will not be available for viewing. The text-only Summary Care Record will include all repeat prescriptions currently in the GP record and issued in the past 18 months, acute prescriptions issued within 6 months with date of issue, and suspected adverse and allergic reactions to medication. It will not contain any diagnoses or problems. There will be no "tailoring" of this summary – if there are prescriptions that a patient does not want shared then there will be no sharing of any prescriptions or allergies.

This text-only Summary Care Record, when viewed, will have a clear statement that it is an un-validated initial text upload with the date of upload.

## **The subsequent Summary Care Record**

Subsequently, a coded Summary Care Record<sup>2</sup> will be uploaded to replace the text-only Summary Care Record. Until a coded summary is uploaded the text-only summary will be available for that patient, but it will become increasingly out of date. The coded Summary Care Record will contain significant and recent diagnoses and problems, with date of onset, all repeat prescriptions currently in the GP record and issued in the past 18 months, acute prescriptions issued within 6 months with date of issue, and suspected adverse and allergic reactions to medication.

A compliant GP system will indicate to a clinician what would normally be included in a summary and offer the ability to easily mark/unmark entries for inclusion or exclusion

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<sup>1</sup> The text will be a textual representation of the coded data for prescriptions and allergies

<sup>2</sup> By "coded" it is meant that the data are transmitted and stored as codes, but the person viewing the record will only see the rubrics derived from those codes. There will be the capacity for some text within a coded summary (uncodable data such a name of carer or limited character length code expansions to add context to disease or problem codes), but it will be predominantly coded data. A second part of the coded summary will contain a text representation of the coded section.

from the Summary Care Record. This will allow data quality to be improved and the content of the Summary Care Record to be refined for that patient.

At consultations after the text-only summary has been generated the doctor or nurse will be presented with (probably) four options:

- To generate a coded summary
- To defer the decision
- To print out a coded summary for patient view
- To record refusal to a the sharing of a Summary Care Record

In the latter case, no summaries will subsequently be visible except under exceptional circumstances (similar to those in which a sealed envelope can be opened). The patient can choose to change their PDS sharing flag in consultation with an appropriate health professional.

After a coded summary has been uploaded, if a change is made to repeat prescribed medication, new acute medication is prescribed, a new problem is classified as significant, a new suspected adverse or allergic reaction to medication is recorded, or any data items in the summary are unmarked as being suitable for the summary, then a new coded summary care record will be uploaded. The GP System will offer a global option of checking each time a new coded Summary Care Record is generated or, by default, accepting summaries. It will offer the capacity for clinician and patient preference for checking uploads to be respected.

At any time the PDS flag can be set to “no data sharing” and the Summary Care Record for that patient will no longer be visible to clinicians outside the practice.

The presentation of the Summary Care Record to the using clinician will offer a generic reminder that it may not be complete; there will be a message to distinguish between a absent summary due to personal choice and a summary with no clinical content; and there will be blank (or other indication) line for each medication or suspected adverse or allergic reaction to medication not included.

### **People limiting their participation**

The mechanism described here offers three ways for a patient to limit their participation in the Summary Care Record. They can ask for no initial summary to be generated, in which case the PDS flag is changed to “no sharing” and their Summary Care Record will not be visible. They can subsequently agree with their GP or practice nurse that certain items (diagnoses, prescriptions, suspected adverse or allergic reactions to medication) are not included in their Summary Care Record. In this case, if the patient has initially set their flag to “no sharing”, it would need to be reset to “sharing” before the summary was generated. Thirdly, they can choose to set or leave their flag in PDS to “no sharing” in which case there would be no summary visible and, in time, no sharing of the Detailed Care Record outside the organisation, in this case the practice.

These options are necessary until sealed envelopes are implemented. Once they arrive, the options for limiting participation will be:

1. Agree with a clinician that clinical data will be recorded in a non-CfH system (paper or non-CfH electronic form)<sup>3</sup>
2. Set PDS to “no sharing”, in which case no Summary Care Record or Detailed Care Record will be visible outside the authoring organisation (e.g. the general practice or Acute Trust)
3. Place items within their electronic record in a sealed envelope which can only, except in very restricted extreme circumstances, be opened with their explicit consent

### **Next steps**

These decisions will be incorporated into the drafting of the revised version of “The Clinical Development of the NHS Care Records Service” paper.

The pilot uploading of GP Summary Care Records will be undertaken in a limited geographical area in late 2006 and early 2007. This pilot will be evaluated – a process for identifying an independent evaluation team will start shortly. Professional representatives will be involved in advising on the pilot and its evaluation. The first full implementations of the Summary Care Record will occur about one year later and will be informed by the experience of the pilot.

### **Version 14 May 2006**

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<sup>3</sup> A patient cannot choose not to have demographic data in PDS. Potentially sensitive parts of some people’s entries in PDS will be hidden from view – the so called “stop noting”