

***GUIDANCE ON MANAGING
REQUESTS FOR NO
SUMMARY CARE RECORD
DURING THE PERIOD OF
THE EARLY ADOPTER
PROGRAMME***



Background

Summary Care Records are being implemented as part of the National Programme for IT in the NHS.

They will initially be created in Early Adopter sites and then, following the incorporation of lessons learnt during the Early Adopter Programme, throughout England.

You will have seen the attention given to Summary Care Records in the media and it is likely that some of your patients will have concerns about their Summary Care Record. This document provides you with key facts that will help answer patients' questions.

These guidelines will be monitored during the Early Adopter Programme and modified as appropriate.

The Department of Health believes that Summary Care Records are a necessary component of care in the 21st century and that they will prove to be essential for better, safer out of hours and urgent care provision.

Key Facts

Initially a Summary Care Record will contain information on allergies, adverse reactions and current medications extracted from the patient's GP record. Over time it will become a richer record as more information is added from the GP record and later from the records held by hospitals etc where the patient receives treatment.

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

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

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

Process

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

- To have a Summary Care Record, in which case they need do nothing more. In doing this the patient is only agreeing to the initial upload of allergies, adverse reactions and medications from their GP record. The addition of diagnoses from their GP record will occur with the patient's consent thereafter at an appropriate consultation with their GP.
- Not to have a Summary Care Record created, in which case they must complete a form and should discuss the matter with any member of the clinical team who is available at their GP practice to ensure that they understand the implications of their decision. This discussion should also clarify that the NHS will continue to endeavour to provide people who do not have a Summary Care Record with the best services, and will not discriminate against those who do not choose to have a Summary Care Record.

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

- To allow the process for creating the Summary Care Record to be initiated and to look at the content by, for example, obtaining a print out from their GP practice. Other means for patients to look at the content are being explored during the early adopter process.

Once the Summary Care Record process has been initiated people have a minimum of a further eight weeks to decide to either:

- Have a Summary Care Record which is accessible to those who are providing them with care or treatment.
- Have a Summary Care Record but not allow anyone to see the information outside the organisation which created it i.e. set their flag on PDS to "dissent to sharing".
- Not have a Summary Care Record and follow the process described above to achieve this. Following this a blank record will be uploaded which contains no clinical information and solely indicates that the patient has chosen not to have a Summary Care Record.

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

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

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

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

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

Consent, Data Protection and Legal Points

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

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

Concerns over an explicit consent approach have been that it would:

- Take considerable time to implement and therefore delay the delivery of the benefits associated with having a Summary Care Record.
- Disadvantage the most vulnerable members of society who may benefit most from the new record but may not be provided with one for a considerable period, or who may be difficult to contact to gain consent.
- Require everyone to take action when, based on the experience of other countries who have implemented similar electronic records, only a very small minority will request not to have a Summary Care Record at all.
- Potentially result in complaints and litigation where health outcomes would have been improved if a Summary Care Record had been created.

Summary Care Records cannot be created without the agreement and cooperation of GP Practices who are currently the Data Controllers for the records from which the required data will be copied. The Department of Health can only recommend that Practices follow its advice in line with the points raised above.

The Department has sought and received robust legal advice to the effect that the creation of Summary Care Records is lawful. Individuals must be told about the change in the way their records are held and this requirement will be fulfilled through the public information programme. There is however no requirement in law for their consent to be obtained.

However, having been told, people do have a legal right to have objections to the creation of their Summary Care Record considered, as provided under section 10 of the Data Protection Act 1998 (<http://www.opsi.gov.uk/ACTS/acts1998/80029—b.htm#10>). As the current Data Controller for GP records, each Practice is legally responsible for responding to these objections, which are referred to as section 10 notices. It is expected that the response will be to agree that a Summary Care Record will not be created. However, should you have any concerns about not creating a Summary Care Record, or have any questions about section 10 notices or other Data Protection issues, you can seek advice from the Digital Information Policy Team, your Caldicott Guardian or your professional bodies.

Further Information

An example leaflet which explains the risks of not having a Summary Care Record which you can copy and hand to concerned patients is also enclosed. The NHS Care Record Guarantee for England which sets out how patient information is used and also how it will be protected from misuse, can be found at http://www.connectingforhealth.nhs.uk/crdb/docs/crs_guarantee from which you can access the CRS guarantee.

The Digital Information Policy Team can be contacted via nhscarerecords@nhs.net

Gateway reference 7940

