NHS CRS - Summary Care Record, Implied consent model and Permission to view			
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Summary Care Record

Implied Consent Model and Permission to View

Contents

1 About this Document

1.1 Purpose

The purpose of this document is to define and explain the Summary Care Record consent model.

1.2 Audience

This document is for those involved with the implementation of the Summary Care Record.

1.3 Content

This document comprises the following sections / topics

- What is the Summary Care Record
- The Summary Care Record Consent Model
- Enriching Summary Care Records
- Access to Summary Care Records

1.4 Related documents

This document should be read in conjunction with the following documents which are all available on the Summary Care Record website at:

http://www.connectingforhealth.nhs.uk/systemsandservices/scr/

- Principles for Implementing Permission to View for the Summary Care Record to support the diversity of care settings in the NHS: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/documents/principles.pdf
- Summary Care Records Scope Document: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/scrscopel.pdf
- Independent Evaluation of Summary Care Record: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/evaluation
- Summary Care Record Public Information Programme Toolkit: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/comms/pip
- Documentation on Implied Consent and Permission to View using current GP System functionality:

http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/Implied-Consent.pdf

- Guidance for GPs on managing requests for patients wishing to opt out of having a Summary Care Record: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/gpguide

- The NHS Care Record Guarantee for England: www.nigb.nhs.uk/guarantee

- A confidentiality publication providing information for patients about how their health information is held and how it can be accessed: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/confidentiality.pdf

- FAQs, including FAQs for clinicians: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/faqs/mpsfaqs

2 What is the Summary Care Record

2.1 Background

Patients can, over the next few years, have a Summary Care Record which can be available to authorised healthcare staff treating them anywhere in the NHS in England.

The Summary Care Record is intended to assist in urgent and unscheduled care services such as Out of Hours, Walk in Centres and Emergency departments with information to support their consultations.

The initial content of the SCR will be the GP Summary and will use data sent from patients GP Record, specifically Medications, Allergies and Adverse reactions.

Over time additional information such as diagnoses, discharge summaries and outpatient letters can be added to the Summary Care Record.

Patients have the option to decide whether they want to have a Summary Care Record or not. Patients can also decide who can view their record.

For a full definition of the scope of the Summary Care Record please refer to the Summary Care Record Scope document.

3 Summary Care Record Consent Model

Summary Care Records are being implemented across SHAs and PCTs within England. Patients are able to decide what level of involvement they wish to have with the Summary Care Record. Therefore before any records can be created patients need to be informed about the record and their options in relation to it. Patients are informed under a Public Information Programme. A personally addressed letter and leaflet will be sent to each patient registered with a GP which explains the purpose of a Summary Care Record, how to obtain a copy of the NHS Care Record Guarantee, and their options, which are:

To have a Summary Care Record, in which case they need do nothing more.

Not to have a Summary Care Record created, in which case they must complete an opt-out form and read the accompanying information to ensure that they understand both the risks and benefits before making their choice. 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.

Please refer to the Summary Care Record Public Information Programme Toolkit for further information.

3.1 Implied Consent Model

Summary Care Records are being uploaded under a model of informed implied consent. The model has the support of the Information Commissioner’s Office who have been engaged throughout the programme. It is the same model used for creating shared and emergency patient records across Scotland, Wales and other parts of the world and helps to create a critical mass of records.

Under an informed implied consent model, patients are assumed to be happy to for their records to be created unless they specifically opt out

3.2 ‘Permission to View’

Patients are asked for their permission on every occasion before any healthcare professional views their record. This explicit request for permission to view a record is in line with recommendations from the independent evaluation of the Summary Care Record undertaken by University College London.

For full information about the independent evaluation please refer to the full report.

The revised consent model involves a “permission to view” step, simplifying the decision patients have over who accesses their records without lessening their control or removing the choices available.

When the patient presents for care, they will be asked for their permission to view their Summary Care Record. If the patient is happy to share the content they can say yes. If they do not feel that the information in their SCR is relevant to that Clinical encounter, they can say no.

There are certain limited occasions where a patient may not be asked for their permission to access the record:

- Clinical emergency - this can be used when the patient is unable to give permission or when the clinician needs to act in the patient's best interests.
- Access made in the Public Interest
- Access required by statute, including subject access requests made under the Data Protection Act 1998
- Access required by Court Order

3.2.1 Ask Every Time / Don't Ask Me Again

It is recognised that with the introduction of Permission to View, it is possible that certain patients with long term or multiple conditions may be asked for their Permission to View frequently.

If a patient decides that they do not want to be asked every time, and are happy for all healthcare professionals involved in their care to be able to access their Summary Care Record, they can request – Don't Ask Me Again. This setting can be recorded within the SCR application and held on the Spine and will allow users to trace a patient's record and then (assuming they have the appropriate permissions) they will be taken directly into the patients record rather than being presented with the screen which asks if they have requested patient permission.

This option should be used with care and patients must understand fully that if they are setting this option, it applies to all healthcare staff with appropriate access permissions – not necessarily just the clinicians they are currently familiar with.

For further guidance on the principles of implementing Permission to View refer to the document Principles for Implementing Permission to View for the Summary Care Record to support the diversity of care settings in the NHS

3.3 Summary Care Record for Children

The Public Information Programme is designed to inform patients aged 16 and above of their options. Summary Care Records will automatically be created for children under 16.

If a child under 16 decides they do not want a SCR, or the parents of a child under 16 do not want the child to have a record, they can approach their GP and ask for their wishes to be considered.

In accordance with current working practices relating to children, the GP will decide if the child is deemed to be Gillick Competent[1], and if so, accept the child's choice on having a record.

If the child is not Gillick Competent, the GP can consider either the child or the parent's request and must act in the child's best interest as to whether to agree with the request or not. They will use their clinical judgement and knowledge of the patient to make this decision in line with their current working practices.

Use of the Summary Care Record does not alter any existing models of NHS practice and GPs continue to be bound by their professional code of ethics in relation to the decisions they make in the treatment of minors.

3.4 Limited Capacity

The Mental Capacity Act 2005 provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. It makes it clear who can take decisions, in which situations, and how they should go about this. It enables people to plan ahead for a time when they may lose capacity. The Act replaces previous statutory schemes for Enduring Powers of Attorney and Court of Protection Receivers with reformed and updated schemes.

As detailed in the "Principles for Implementing Permission to View for the Summary Care Record to support the diversity of care settings in the NHS", existing procedures must apply where the patient is a minor or is of limited capacity.

There are also legally defined situations where permission does not need to be obtained Clinicians should continue to follow their professional guidance as in Principle 6

"Principle 6: Permission to view does not apply where the patient is unable to give permission to view and the clinician acts in the patient's best interests."

3.5 Can patients change their mind?

Patients can change their mind and decide to opt-out of having a Summary Care Record at any time. The record is then suppressed and is not available for clinical use. In exceptional cases, patients can also request that their record is permanently deleted.

However if the record was accessed as part of someone's healthcare, it needs to be kept, though not accessible for care, in case there was a subsequent investigation of the performance of a clinician or a dispute about the facts.

3.6 Compliance with Data Protection Act 1998

The Information Commissioner has confirmed on numerous occasions that proposals for the roll out of the Summary Care Record comply with the Data Protection Act 1998. The

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[1] **Gillick competence** is a term used in medical law to decide whether a child (16 years or younger) is able to consent to his or her own medical treatment, without the need for parental permission or knowledge.

creation of a Summary Care Record is clearly a medical purpose as defined in the Act and so long as people are informed about proposals there is no requirement in law for explicit consent to be obtained.

In addition advice has been sought and received from the GMC. The GMC shares the broadly-held understanding of the law – that is, that there is no legal requirement to gain a patient's explicit consent before up-loading data to the SCR. It is the GMC view that patients have the right (albeit qualified in some cases) to control how identifiable information about themselves is disclosed or accessed, but have no right to determine the form or place in which that information is stored.

4 Enriching records with additional information

Following the initial automatic upload of the core data set of Medications, Allergies and Adverse reactions from GP systems to the SCR clinicians can add significant medical history to the updates sent to the SCR – i.e. they can enrich the records.

Practices already have summaries of the main clinical conditions that the patients suffer from such as asthma, epilepsy and diabetes that can be added to the SCR. It is also possible to include treatment plans such as end of life care and mental health care plans.

The GP system software enables the clinician to switch on the sending of additional information to the SCR on an opportunistic basis. It is not possible to automate the sending of summaries to an entire practice population in bulk.

It is not required to take explicit consent from patients before adding the richer content to their records. It is acceptable to inform patients that you intend to add the information under implicit consent as per the core data set; however clinicians may wish to take explicit consent from patients before adding further information beyond the core data set.

The GP system software has been built in such a way as to allow clinicians to enrich records at their own pace and do as they feel most comfortable.

Because the updates to SCR go individually, it enables the clinician to check the message for sensitive items before it is send. They have the opportunity to exclude any such sensitive items.

This can then 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 excluded from the information that is sent to the SCR. It is not possible to exclude any individual elements of Medications, Allergies and Adverse reactions.

As it is not possible to exclude any individual elements of Medications, allergies and adverse reaction, any patient who doesn’t wish this information to be available should be advised to opt out and not have a SCR

GP System supplier functionality offers methods of automatically selecting specific types of information, therefore where a local policy exists for what should be added (enriched) to the

SCR, methods of automating the process may be are possible. Further information on the functionality to do this, should be sought from the specific GP system supplier.

For refer to case studies showing of how records have been enriched to support end of life care plans.

5 Access to the Summary Care Record

In order to safeguard the content of a patient's record, access to the information contained within the Summary Care Record is strictly controlled and only those with a legitimate relationship with the patient may access the record. Some users may only need access to Demographic information, where others need access to Clinical information.

Use of the record is conducted within an audited environment. Searching for records, accessing them and making any alterations to the content, are all actions which will be audited and may trigger an alert to an organisation's Caldicott Guardian or Privacy Officer. Abnormal activities will be investigated and patients will be notified if there is any inappropriate access to their record.

For further information please refer to the confidentiality publication providing information for patients about how their health information is held and how it can be accessed.

5.1 Controlling access to the Summary Care Record

The Summary Care Record Programme operates under the NHS Care Record Guarantee for England. The NHS Care Records Service uses the strongest national and international security measures for storing and handling patient information. These include:

- Smartcards to access applications
- Role Based Access Controls (RBAC)
- Legitimate Relationships

Clinicians are also bound by a Professional Code of Conduct when accessing confidential clinical data.

Users of the records also have a responsibility to be bound by the rules of working with the record (such as not sharing their smartcards with other users)

5.2 Role Based Access Control

In order to access the SCR application, order access systems integrated with SCR for viewing of records users need to be set up appropriately in the NHS Care Records Service via the Registration Process.

A key element of the Registration Process is to create one or more role profiles for a user, each of which consists of:

- An organisation (required) – e.g. The Whittington Hospital NHS Trust
- An NHS Job Role (required) – e.g. Consultant
- Area of Work (optional) – e.g. Secondary Care
- Additional activities (optional)

Access to functionality within the Summary Care Record application is controlled by activities only. These activities are either included within a Job Role (known as baseline activities) or added separately to one of the user's existing roles.

5.3 Patient control

'Permission to View' is the patient's way to control who has access to the content of their record. When the patient presents for care, they will be asked for their permission to view their Summary Care Record. If the patient is happy to share the content they can say yes. If they do not feel that the information in their SCR is relevant to that Clinical encounter, they can say no.

There are certain limited occasions where a patient may not be asked for their permission to access the record:

- Clinical emergency – This can be used when the patient is unable to give permission or when the clinician needs to act in the patient's best interest.
- Access made in the Public Interest
- Access required by statute, including subject access requests made under the Data Protection Act 1998
- Access required by Court Order

Accessing the Summary Care Record in a clinical emergency will result in an alert being sent to the Privacy Officer (staff involved in safeguarding the privacy of patients). All alerts should be investigated and Clinicians will be accountable to their professional bodies for any Emergency Access that they make. There are text fields for clinicians to enter reasons why they used emergency button which aids investigation.

Commitment 4 and page 7 of The Care Record Guarantee provides further information about the circumstances where information may be shared without asking permission.

5.4 Storing of patient's consent preferences

Currently GPs are recording patients' wishes to opt-out using locally held Read Codes on GP System. A centrally Spine-held flag has now been provided as a means of recording opt-out wishes that ensure no clinical data is added on the Summary Care Record from any source. This will ensure that a patient only needs to have their opt-out wishes recorded once and it will be respected in all care settings. Further guidance will be provided on the process for updating the central Spine flag.

For further information about setting patient consent preferences please refer to Guidance for GPs on managing requests for patients wishing to opt out of having a Summary Care Record.