SUMMARY CARE RECORDS – PATIENT OPT-OUT

Introduction

This protocol sets out the procedure to follow where a patient requests that their records be excluded from the NHS Care Record held on the national database.

Today, records are kept in all the places where patients receive care. These places can usually only share information from records by letter, email, fax or phone. At times, this can slow down treatment and sometimes make it hard to access information.

Summary Care Records have been introduced to improve the safety and quality of patient care. Because the Summary Care Record is an electronic record, it will give healthcare staff faster, easier access to essential information about you, and help to give you safe treatment during an emergency or when your GP surgery is closed.

A Summary Care Record is an electronic record that's stored at a central location. As the name suggests, the record will not contain detailed information about full medical history, but will only contain important health information, including at the minimum:

- Whether the patient is taking any prescription medication
- Whether the patient has any allergies or has previously had a bad reaction to any medication
- The name, address, date of birth and NHS number of the patient

Patient may also choose to have additional information included in the SCR, such as details of long-term conditions, significant medical history, or specific communications needs.

Access to a Summary Care Record will be strictly controlled. The only people who can see the information will be healthcare staff who are directly involved in patient care and have a smartcard and access number.

Healthcare staff will ask permission every time they need to look at a Summary Care Record. If they cannot ask the patient, e.g. because they are unconscious, healthcare staff may look at the record without asking. If they have to do this, they will make a note on the patient record.

Patients are able to:

- Choose to have a Summary Care Record (SCR) without agreeing to let others have access to it. This is achieved by flagging the Patient Demographic Service with either "Consent to Share" or with "Dissent to Share" – this is achieved by "hiding" the record within the system.
- Choose not to have an SCR
- Limit the information available in the SCR.

However, unless a patient has actively opted out of the process, then currently they are "assumed" to have given consent. All children under the age of 16 years will automatically have a SCR created.

Central Process

Patients may elect to have, or not have, an SCR at any time. Patients may request not to have a record at all, and they may also have a SCR but request that it cannot be viewed by others, in which case it will only be made available to them.

At least 8 weeks before an area becomes “live”, patients over the age of 16 will receive a targeted letter with an information leaflet.

The options given to them will be:

- Not to have a Summary Care Record created. It's easy to opt out of having a Summary Care Record. Refer to the information pack posted to patients which will tell the GP practice that the patient wishes to opt out, by filling in the pre-addressed opt-out form in the pack and:
- return it by post; or
- hand it in the next time you visit your GP practice.

If a patient doesn’t have an opt-out form, simply:

- call the information line on 0300 123 3020 to get one posted, or
- print off a copy of the opt-out form (PDF, 514Kb) and hand it in at your GP practice.

These are the only ways you can opt out of having a Summary Care Record (SCR). You cannot opt out by email or on the web because your GP practice needs to know that it’s you opting out (and not someone else who might try to opt out for you).

To Have an SCR Created

- The patient is asked to validate the content of the record at the GP practice and inform them of any inaccuracies. Once the SCR process has been initiated, a further eight weeks will be allowed for patients to make the decision whether to:
    - Have an SCR fully accessible to their clinicians
    - Have an SCR only accessible within the initiating organisation
    - Not have an SCR. A blank record will be uploaded that indicates that the patient has withheld consent

If a patient has not expressed their views within eight weeks from initiation of the process, they will have a fully accessible SCR created automatically. NHS staff are required to seek patient consent each time they wish to access the record.

Practice Procedure

The practice will have “batch updated” patient records with the consent code below as part of the preparation procedure, excluding existing refusal patients as appropriate. All requests for refusal of consent must be received in writing using the form provided on the website above.

On receipt of a correctly completed form the following Read Codes will be keyed onto the patient record within the clinical system:

Where consent to an SCR has been given:	93C2
Where consent has been refused:	93C3

The request to opt out is to be scanned onto the clinical system.

IMPORTANT NOTE TO PRACTICES: Where consent is refused it is essential to positively delete code 93C2 where it exists and then add the refusal code 93C3. Code 93C2 must not be allowed to remain on the system for refusals or a SCR may be created regardless of the existence of the refusal code.

In addition, new registrations taken in the surgery between the date of the local mailing and the upload date must be given the publicity and option packs provided by the Care Records Service for this purpose.

Where there is concern over competency, undue influence or other issues that may affect the validity of the consent or dissent then the matter is to be referred to the practice Caldicott Guardian [*Insert name*].

The partners of the practice are the Data Controller for the purposes of the Data Protection Act and have a responsibility to correctly act on the wishes of individual patients. Where concerns exist these should be referred to the Caldicott Guardian in the first instance, who may decide to refer the query to the Digital Information Policy Team.

Where a patient has received their formal communication pack, it is essential that they follow the instructions carefully, including the options relating to opt-out, and go through the official established procedures to achieve the aim they wish.

Resources

digital.nhs.uk/summary-care-records
www.nhs.uk/NHSEngland
0300 123 3020 - Summary Care Record Information Line

Summary Care Record Patient Consent Preference Form (NHS Digital)
https://digital.nhs.uk/services/summary-care-records-scr/scr-patient-consent-preference-form

Appendix 1 - Patient Information Leaflet

IF I DO NOT HAVE A SUMMARY CARE RECORD – NHS Information

You have decided that you do not want to have a Summary Care Record. The NHS will do its best to provide you with safe, efficient care whether or not you have a Summary Care Record. The purpose of this information sheet is to ensure that you are clear what your decision could mean for your NHS care.

The Summary Care Record's purpose is to ensure that anyone treating you has basic but important information about you - especially when care is unplanned, urgent or during evenings and weekends. At first this would be limited to your current medications, known allergies and any bad reactions to medicines in the past. When you next see your GP, important information about conditions such as asthma or diabetes could be added if you agreed. Over time, you can choose to give consent to add other significant information such as referrals, discharges, and test results.

The information in your Summary Care Record could save you and the NHS time, but could also one day be lifesaving. The NHS has significant problems now with lost records and test results, treatment and prescribing errors.

With a Summary Care Record doctors and nurses would know at a crucial time:

- what medications you are taking, especially if they are many and complex
- what medications have not agreed with you in the past
- whether you have any allergies
- whether new medications they prescribe may react badly with things you are already taking
- that you have a condition that means you shouldn't have certain medicines

In addition, you would have the benefits of:

- peace of mind that wherever in England you needed care, anyone treating you would have essential information even if you were distressed or didn't remember details

And later on, as your Summary Care Record developed, you would be able use it to:

- see your test results as they come in
- check that your referral letters have been written
- remind yourself about important things said to you about your treatment
- inform NHS staff about your needs and how you want to be treated

RISKS AND PROTECTIONS

Staff disclosing information: The NHS already shares information widely and most NHS staff are honest and trustworthy. There are occasional problems with staff accessing records and disclosing information inappropriately. With the new NHS systems, the number of staff who will have an opportunity to look at your clinical records when they shouldn't will be greatly reduced. Only staff with special security cards can log onto the new NHS systems. This allows the NHS to track precisely who has done or seen what - and you can ask for this information

Hackers: Safeguards that will protect the Summary Care Record from hackers have been designed by security experts. They are far stronger than the safeguards in place anywhere within the NHS today.

Wrong information: It is important that the information about you is accurate. All data that goes into a Summary Care Record will have to pass quality controls. Once you could access it, you too could check it and point out any remaining errors.

Access by government organizations: No other part of government would have direct access to your Summary Care Record. As now, any information from your record that the NHS gives to others, such as the police, would be very strictly limited by law. In fact, the Summary Care Record gives the opportunity to improve things by ensuring that any such disclosures follow consistent procedures and are recorded and monitored.

More control by the patient: The greatest safeguards for your Summary Care Record are that you will be able to see it yourself, know who else has seen it, and have more control than ever before over what it contains and who has access. You can ask for it to appear as a blank screen, or ask for information to be removed or not added in the first place. Later on, additional controls will allow you to let staff see some parts of your Summary Care Record, but not others.

The majority of patient Summary Care Records are now live.

We hope that the information provided has made clear the practical results of your decision. Please be assured that the Department of Health is committed to honoring your decision and doing all it can to ensure you receive the best healthcare possible. You can, of course, change your mind at any time. We ask that you to review your decision from time to time.

If you feel unsure about whether or not to have a Summary Care Record, or would like further information, please make an appointment to discuss it with your GP.