

The Summary Care Record – Guidance from the General Practitioners Committee of the British Medical Association

The Summary Care Record (SCR) is being rolled out across a number of Strategic Health Authorities (SHAs) in England. It is important that you understand the implications of the SCR for both your practice and patients. This guidance represents the GPC's views and we hope that it will answer any questions you might have about the SCR. We also hope it will clarify the GPC's position and provide you with information about the BMA's and GPC's involvement and any action we are taking.

What is the Summary Care Record?

In 1997, Tony Blair announced that "if you live in Birmingham and you have an accident while you are, for example, in Bradford, it should be possible for your records to be instantly available to the doctors treating you." The Summary Care Record is the vehicle for delivering this vision and is a key component of the National Programme for IT, which is being delivered by NHS Connecting for Health.

The Summary Care Record (SCR) consists of an upload of medications, allergies and adverse reactions from GP records onto a central 'spine' or database. The SCR may be expanded to include significant medical history at the GP's discretion and then further "enriched" at the end of each patient consultation in discussion with the patient. NHS Connecting for Health has stated that software upgrades, to be implemented by GP suppliers by the end of the year, will automatically ensure that when GPs begin to "enrich" SCR's an agreed list of sensitive terms will not be included in the upload.

In the future, information will be added from other care settings and this will include inpatient discharge summaries, emergency department reports, outpatient clinic letters and out-of-hours reports. It may also include ambulance service patient reports, mental health documents, diagnostic imaging reports, admissions reports and NHS Direct documents.

The Summary Care Record will be made available to those working in unscheduled care settings for example, primary care out-of-hours services, emergency departments, walk-in-centres, in GP practices for treatment of GP temporary residents, patients requiring immediate necessary treatment and newly registered patients prior to their records being available. Access to the SCR is dependent on having an NHS smartcard and a legitimate relationship with the patient and should only happen with the patient's explicit consent.

What is the consent model for the SCR?

A 'consent-to-view model' is being adopted, which means that a SCR is created, unless a patient indicates they do not want one, during a minimum 12 week period. If a patient does not opt out, a SCR is created but it can be viewed only with the explicit consent of the patient at each episode of care unless it is an emergency situation and a patient is unable to state their preference. A patient can change their mind about having a SCR at any time. The Information Commissioner has advised that a patient can request the deletion of their SCR unless it has been used by a healthcare professional in the course of treatment or should have been used, in which case it will remain in the audit trail, but not accessible in a clinical setting. The consent-to-view model was one of the recommendations of the UCL independent evaluation.

The BMA's Annual Representative Meeting (ARM) policy 2009 is that it believes that explicit consent should be obtained prior to any upload of patient information. In accordance with ARM policy 2008 and following the recommendations of the independent evaluation, the BMA accepted the consent-to-view model as an appropriate way forward for further limited roll out and evaluation provided that there was a thorough evaluation of the public information programme and the new consent model was carefully piloted. This decision was taken following consultation with key members of the GPC and the BMA's Working Party on NHS IT and was informed by the situation in Scotland and Wales where a 'consent-to-

view model' had been adopted, with the support of the majority of doctors and benefits of their equivalent SCRs have been demonstrated^{1,2,3}.

The ethical position with regard to consent, as outlined in Medical Ethics Today is that 'consent may be expressed, or made explicit....consent may also be implied or assumed'....'implied is not a lesser, or valid form of consent. It must still be informed and based on real choice'. Regardless of whether consent is implied or explicit a patient needs to be offered a choice and sufficient information to make an informed decision and we wanted to see evaluation of the consent model and the Public Information Programme to ensure that consent for the creation of the SCR is informed.

NHS Connecting for Health has proceeded with a wider roll out prior to the publication of the independent evaluation of the SCR and therefore without publicised evidence of the impact of changes to the Public Information Programme and the consent model. The expedited roll out has also happened without consultation with the BMA.

In view of the number of patients who have already been sent information about the SCR, many of whom may wish to have a SCR and may also benefit from having a SCR, the GPC and BMA are not advising GP practices to boycott the SCR. We believe that there are potential benefits and the decision to have a SCR should rest with patients. Our focus is on ensuring that patients are fully aware and that implied consent is valid. We have urged the minister to evaluate the implementation and impact of the SCR in the areas, which have proceeded with Public Information Programmes before rolling out any further.

Is the Summary Care Record being rolled out in my area?

SCRs were uploaded initially in six early adopter areas, the first being in Bolton in October 2007. Following an independent evaluation⁴, roll out continued to 17 'fast-follower' PCTs in early 2009. To date there are over one million SCRs. SCRs are now being rolled out across a number of SHAs. Your Local Medical Committee (LMC) should be able to advise if you are unsure whether SCRs are currently, or soon to be, rolled out in your area.

In recent months there has been a push to speed up the roll out. In December 2009, the Department of Health announced that funding would be made available for regionally-based Public Information Programmes provided that the money is used by the end of March 2010. The NHS Informatics Planning document 2010/11 also required SHAs to agree timelines for the creation of SCRs.

The GPC and BMA are deeply concerned by this sudden acceleration in the roll out and feel that it is being rushed. We are very concerned by reports that GP practices feel unprepared and unsupported and LMCs are not being involved. The GPC and BMA have made it clear that roll out of the SCR should be a gradual process with proper evaluation. The final University College London evaluation report is due to report in spring 2010 and it would have been more appropriate to await publication prior to a wider roll out. The GPC and BMA have written to the minister to express these concerns. We recognise that there needs to be a critical mass of SCRs in order to evaluate the benefits properly; however, we have insisted that further evaluation must take place before commencing public information programmes in any additional⁵ areas.

¹ Informing Healthcare Programme Board meeting report, October 2008
(www.wales.nhs.uk/sites3/page.cfm?orgid=770&pid=34366)

² NHS 24 Pharmacist Festive Break Access to ECS 'Pilot' Project Evaluation, January 2006

³ ECS Accident and Emergency Pilot Project Implementation Evaluation for ECS Programme Board, March 2006

⁴ Summary Care Record Early Adopter Programme: An Independent Evaluation by University College London (<http://eprints.ucl.ac.uk/6602/>)

⁵ Additional to the SHAs where Public Information Programmes have already begun.

What information will patients receive?

When a SHA decides to go ahead with the SCR a regional Public Information Programme will begin. Patients will receive a letter from the local PCT, a SCR leaflet 'Changes to your health records', which includes details of the available options for patients and a form to request further information and an opt out-form if required. Patients are directed to a NHS Care Records Service information line (0845 603 8510) or a website (www.nhscarerecords.nhs.uk) if they require additional information.

The PCT letter can be tailored locally and therefore it is essential that Local Medical Committees are involved in reviewing the content. We are aware of cases where the PCT letter has been inappropriately tailored for example, by claiming support of GP practices in the area. Local Medical Committees should ensure that the PCT letter is accurate and balanced.

Should the GP practice play a role in informing patients about the SCR?

The GPC and BMA believe that patients should be provided with sufficient information to make an informed choice about the SCR.

The GPC and BMA are concerned about the effectiveness of the Public Information Programme. An independent evaluation of the pilots found that seven out of ten patients, in those areas, were not aware of the Summary Care Record. At the end of last year, in response to the findings of the evaluation, NHS Connecting for Health announced that the Public Information Programme would be carried out on a regional, rather than PCT, basis and that the documentation sent to patients had been changed to reflect the recommendations of clinicians and patients who were involved in the early adopters. The BMA would prefer a national publicity campaign but hopes a SHA-, rather than PCT-wide, campaign will help raise awareness. The effectiveness of a regional campaign has not been properly evaluated prior to wider roll out and this has been raised with the minister.

In view of this, GP practices play an important role in raising awareness including patients' rights to opt out of having a SCR. It is important that any information provided to patients is balanced and empowers them to make an informed decision. We do not support the provision of biased information, which attempts to persuade patients to opt in, or out, of the SCR.

We are also concerned that an opt-out form has not been included in the information pack which is sent to patients. Anyone who does not wish to have a SCR has to opt out by informing their GP or by completing a form either downloaded from the internet or requested through the national call centre. Opt-out forms were included in the early adopter patient information packs and NHS Connecting for Health has stated that this resulted in patients sending their completed opt-out forms to NHS Connecting for Health rather than their GP practice. It is essential that patients who wish to opt-out have the opportunity to do so and we recommend that practices make opt-out forms available in their practice.

What action should I take if the Summary Care Record is being rolled out in my area?

We recommend that you attend locally organised events so that you are informed about roll out of the SCR in your area. You then have the following options:

- You can decide, as a practice, to be involved. Your PCT should provide training and support. Prior to being involved you and your PCT need to be assured that your data are of an appropriate quality for sharing outside of your practice. This would have formed part of component 2 of the IM&T DES. Practices which have not been accredited under the DES should seek advice from their LMC and PCT before agreeing to upload patient data. Further information on data quality is available at: <http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/impguidpm/dq>
- Your practice can decline to be involved at this stage - if you decide not to be involved it is still important that you understand what the SCR is and any patient requests to opt out are recorded.

Will the Summary Care Record generate extra work?

The GPC is concerned that SCRs will generate additional work, which is not part of the GMS contract. It is envisaged that SCRs may create work in the following ways:

(i) Data Quality - The IM&T Directed Enhanced Service (DES) delivered financial support to practices to help them improve the quality of their data as part of a structured data accreditation programme. No data could be added to the SCR unless a GP practice had been accredited under the DES. This accreditation usually lasted for three years.

The IM&T DES ended at the end of March 2009, with a proportion of practices yet to be accredited. The robustness of accreditation has also varied between PCTs. The BMA is concerned that this will affect the quality of the information included in SCRs. Whilst all GP practices should ensure that their data are as accurate as possible, data that are an appropriate standard for sharing within the practice may not be of an appropriate format to share with other organisations. Therefore the GPC view is that this requires additional support. The GPC continues to negotiate for resources to support data quality work.

(ii) Explaining to patients about the SCR and adding information to the SCR following a GP consultation – Patients are being referred to a national helpline to minimise queries received by GP practices. The UCL independent evaluation found that the latter did not create a significant amount of additional workload. The initial extraction and subsequent uploads based on changes to medication, allergies and adverse reactions is automated with no workload for the practice. Workload implications of the subsequent enrichment of the SCR will need to be monitored and the GPC will take this forward as part of their contract negotiations.

(iii) The time taken to deal with returned mail and FP69 procedures

How have the BMA and GPC been involved in the development of the SCR?

The BMA was represented, by a member of the GPC, on the Ministerial Taskforce, which was set up in July 2006 to consider the ethical and practical issues around the implementation of the SCR. The BMA, including the GPC, campaigned for the right of patients to refuse to have SCR and was successful in securing agreement in 2006.

The BMA and GPC insisted that there should be a pilot of the SCR followed by an independent evaluation and supported moves to roll out the SCR gradually to six early adopter areas followed by an independent evaluation, which was conducted by UCL. A member of GPC represented the BMA on the Summary Care Record Independent Evaluation Advisory Group. The BMA's Working Party on NHS IT, which includes GPC representation, and the Joint GP IT Committee welcomed the report upon its publication in May 2008.

The consent model for the early adopters was an implied consent model for both upload and access. The BMA and GPC campaigned for an explicit consent model and following the publication of the UCL evaluation, NHS Connecting for Health agreed to change the consent model so patient information should only be accessed with explicit patient consent. As described above, this was accepted by the BMA, following consultation with members of the GPC, subject to an evaluation of the Public Information Programme and limited piloting of the revised consent model.

The BMA does not support, and has not been consulted about, the recent accelerated roll out particularly prior to the publication of the independent evaluation. We feel that this could jeopardise and counteract the preceding gradual implementation.