

Londonwide LMCs' Practical Guidance to Practices on the rollout of the Summary Care Record (SCR)

We have produced this guidance as an adjunct to our support pack issued to practices on 24 February 2010, following the London rollout of the SCR by CfH, and following comments and concerns received.

The guidance covers four areas:

- 1. Patient awareness and informed decision-making**
- 2. Essential facts to clarify understanding**
- 3. Balancing risk and a practical approach to data uploads**
- 4. Further Information**

It is recommended that this guidance, which has the support of Connecting for Health (CfH), is read in its entirety by all members of your practice, in particular doctors, nurses and managers and understood by all practice team members who will be involved in your practice approach to SCRs.

1. Patient awareness and informed decision-making

a. Informed decision-making by patients:

It is important that patients are given sufficient information on which to base a decision to allow their SCR to be uploaded to the spine (the default position), or to actively choose to opt-out. There are arguments for and against which are not part of this practical guidance.

Raising patient awareness and providing good and appropriate access to information are crucial aids to informed patient decision-making.

b. Raising patient awareness and providing good and appropriate access to information – CfH's approach

The SCR is being rolled out to all patients with known addresses in the Capital by mailing a Patient Information Pack (PIP) to their known registered address. The purpose of the PIP is to raise awareness, provide information, and signpost patients to an advice line, further information and an online opt-out form.

c. Raising patient awareness and providing good and appropriate access to information – Our approach

Concerns have been expressed to us about the level of awareness and relevance of the PIP material to London's patients, of their engagement with it, and of the issues surrounding the SCR. These are complex issues and awareness and engagement will inevitably vary depending on factors such as an understanding of clinical risk, and in a capital city such as London, will especially include diversity issues such as ethnicity, language, personal

experience and trust in authority. GPs and practice teams therefore have a key part to play.

Irrespective of your personal view about the SCR, it is essential to put yourself in a position to be able to respond professionally to *your patients'* concerns and to be satisfied to the best of your ability that they have access to sufficient information to enable each of them to make an informed decision to opt-out should they choose.

We have already supplied you with a support pack containing a poster and information leaflet for patients which includes an 'opt-in opt-out' form. Watch out for future revisions to this material.

2. Some essential facts to clarify your understanding

CfH state that the 12 week period stated in their PIP is a MINIMUM period. It is not a deadline. There are no time limits and patients can change their minds.

- **No Time Limits**

There are no time limits within which practice sign-up and uploading must take place. CfH assure us that the 12 week period in the PIP is a MINIMUM duration.

There is therefore no deadline for practices to satisfy themselves that their patients have had access to sufficient information to make an informed decision re their SCR data.

Moreover, CfH assure us that there is no coercion to do so, and there is a strong wish to see high levels of patient awareness of their rights on the basis of an individual informed decision.

- **Patients Changing minds**

It is wholly possible for patients to change their minds either way at any time. As long as their record has not been opened, they can expunge it at any time. If it has been uploaded, they can 'cover it up' so no one else sees it. If they do so before the upload actually takes place, then it is simply a coding issue for the practice. If they do so after an upload has taken place, then until the individual record has been accessed outside the practice, the record can be expunged from the system. If there has been an access, the record can be sealed shut, and although it will remain on the system as there must be an audit trail of access for medico-legal reasons. CfH tell us that once sealed shut, it will not be possible to access it for any other purpose.

- **Consent to View**

The SCR system requires consent to view records being granted by the patient each time there is a need to access the record, except in an emergency such as an unconscious patient.

CfH state that uploads of patient data to the Spine can only take place if your practice is technically ready

- **To be considered as ready your practice will first**
 - a) need to be 'cleared' by the PCT as having records that are 'fit to send', ie your systems are paper-free and of satisfactory data quality
 - b) receive training before anything can happen
 - c) In any case not all systems are capable of uploading patient data.
- Currently the software is nationally compliant currently for Emis LV, In Practice Systems (Vision), TPP, and Isoft Synergy only.

3. Balancing risk and a practical approach to data uploads

The approach you adopt to uploading patient data will need to be informed by a) *how confident* you feel about your patients' level of awareness and access to key information as the basis to inform their decisions, and b) how much risk you wish to carry when you upload your patient data. The risks to be balanced are a) the risk you carry when a patient who had the opportunity to have data uploaded was denied the benefit of that upload during an emergency, against b) the risk you carry when a patient is denied the autonomy to opt-out of a data upload when you are in a position of control over that data.

Bearing in mind that a) your patients' data cannot be uploaded until your systems are considered 'ready' by the PCT and b) CfH sees the 12 week period as a MINIMUM time for patients to be informed and make choices, your approach to SCR can be governed by the principle of what is a reasonable period of time by which you feel you are in a position to balance the above risks for each of your patients.

Whilst it is open to you not to participate at all in the scheme, prolonged non-participation may be unwise in terms of balancing the above risks¹.

Equally, while it is open to you to upload all your patients to the default opt-in code, premature uploads may also be unwise in terms of balancing the above risks.

It therefore follows that spending a reasonable period of time ensuring you are confident that your patients' awareness has been amply raised and your risks have been balanced is an appropriate approach to take. To opt patients out simply enter the opt-out Read code 93C3.

The Opt-in/Opt-out form supplied to practices is designed to facilitate this approach, and can be downloaded from <http://www.lmc.org.uk/uploads/files/news/SCR/scrpatientfactsheetfeb10.pdf>.

It's different for NEW patient registrations

- ***The default opt-in does not apply to new patients. They can select to opt-in or out at the time of registration.***

Unsure Patients

- For unsure, undecided or undeclared patients, including new registrations or those for whom returned mail has been received (see below), practices can enter the opt-out Read code 93C3. It is essential to note that the SCR must be discussed with the patient at the next opportunity. This is achieved by the practice entering a free text/flag/diary entry to enter a discussion about the patient's choice when next seen.

If the patient then opts in, enter Read code 93C2. (Note – for technical reasons this may become 93C0 in due course). If they opt-out, leave as Read code 93C3 and delete diary entry. Clearly, once a patient's view is declared, confidence in awareness is achieved, and risks are balanced.

We are hoping to agree a modification to the GMS1 to make this more visible to patients.

4. Further Information

Raising Patient Awareness

As stated earlier, we believe that the current mailing being rolled out to patients may not be sufficient to deliver the confidence many practices with diverse populations need to enable them to be ready for uploading data. We are now working with CfH to explore other awareness-raising initiatives.

In the meantime, it may be that practices wish to be more proactive and contact patients directly, or via patient participation groups or meetings, via the practice website and via email and text systems if you have them.

Workload

There can be no doubt that a diligent approach to awareness and consent issues will involve practices in a surge of work at practice level. Whilst this needs to be recognised, it may well offset difficulties down the line. We will continue to work up simple materials to support practices on SCRs.

Opt-Out Forms

CfH state that there is no attempt from the centre to block patients choosing to opt-out and wish to facilitate this provided there is evidence of a patient signature.

CfH state that their opt-out forms are not sent in the pack to patients because there is evidence from the pilots that patients used the prepaid envelope in the PIP, (intended for them to request further information), to send all kinds of sensitive and confidential material including completed repeat script requests and their downloaded opt-out forms to the addressee – the PCT – instead of directly to their GP practices!

Yet it is imperative that signed opt-out forms *are presented to practices* for action since it is the practice which must enter the opt-out code to act upon a patient's wish to opt-out.

CfH are quite content for our form to be used by practices (<http://www.lmc.org.uk/uploads/files/news/SCR/scrpatientfactsheetfeb10.pdf>).

Opting out on behalf of others, including children

If a patient is requesting opt-out on behalf of a 3rd party the clinician must in any case check the records because they are responsible for acting in the best interests of that individual should they be incompetent. If competent they must make the request themselves, and for children Gillick competence is the key yardstick.

Returned mail

We have agreed with CfH how to avoid inappropriate FP69s arising from the SCR mail-outs, CfH will be directing NHS London and PCTs accordingly.

Information from Connecting for Health can be found at <http://www.connectingforhealth.nhs.uk/systemsandservices/scr>

Further sources of guidance from the profession:

1. MPS guidance can be accessed via <http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/mpsfaq>
2. RCGP guidance can be found at http://www.rcgp.org.uk/get_involved/rcgp_standing_groups/informatics_group/shared_record_professional_gui.aspx
3. The BMA's GPC guidance can be accessed via our website <http://www.lmc.org.uk/uploads/files/news/SCR/scrguidancebmmamar10.pdf>
4. For all SCR updates to practices from Londonwide LMCs go to <http://www.lmc.org.uk/guidance/information-for/default.aspx?dsid=7119>

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