

7<sup>th</sup> October

Dear Minister

### **Reviews into the Summary Care Record**

You asked us to conduct two reviews of the Summary Care Record: the first into the content of the Record and the second into the information that patients receive regarding the Record and the process by which they can opt out. This letter summarises the reviews and key recommendations.

A wide range of patient and clinical groups participated in the reviews and it is clear that an overwhelming consensus exists for change.

In an advanced national health care system it is reasonable for citizens to expect that when they arrive in an Accident & Emergency department or require treatment out of hours clinicians have access to the essential medical information they need to support safe treatment and reduce the risk of inadvertent harm.

It is recommended that the core Record should only contain a patient's demographic details, medications, allergies and adverse reactions and this should continue to be copied from the patient's GP record.

We note the coalition government's commitment to ensuring patients have an ownership of their care records. The Summary Care Record is the minimal information required to support safe care in urgent or emergency situations. Both review groups agreed that any further information added to the Summary Care Record should require explicit consent from the patient.

Patients must not only be clear about the information contained in the Record but they must play a key role in deciding the evolution of the Record. This means that new arrangements should be introduced to define responsibility for decisions about the introduction of any new content to the Record. As a principle, any change to the scope of the Record must be driven by citizens and patients, with appropriate advice from professional bodies and tempered by knowledge of the Information Technology capability. This is important for building trust in the system.

You also asked us to look at the information sent to patients about the Summary Care Record and the process by which they opt out. There was wide agreement that the content of the letter and information leaflet should be simplified in future and an opt out form should be included. This would provide reassurance that if someone does not want a Summary Care Record, we will follow their wishes.

In order to reinforce this message for those patients that have already received information and those about to be mailed, it is important that PCTs and individual GP practices are supported to further raise awareness.

Finally, we need to work with key professional groups including the BMA and Royal Colleges to balance ease of use of the Summary Care Record with maintaining a level of data security, which protects patient confidentiality.

We are personally grateful to all the people who participated in this review for their willingness to openly discuss and challenge assumptions. The full set of recommendations and those organisations who contributed to the review are contained in Annexes to this letter.

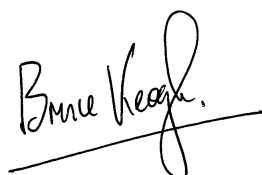
To summarise the changes that the review groups have recommended:

It is important that when patients require urgent or emergency treatment the attending clinicians have access to the minimal essential medical information they need to support safe treatment. We have defined the minimal, essential scope of the Summary Care Record. Additional information should only be with explicit consent of the patient.

By ensuring that opting out is made easier and that patients are actively involved in deciding to add additional information we also ensure that patients remain in control of these records and that their civil liberties have been protected.

Yours sincerely


**Professor Sir Bruce Keogh KBE**



Medical Director of the National Health Service in England

Chair, SCR Content Review

**Joan Saddler OBE**



National Director Patient and Public Affairs, Department of Health

Chair, SCR Patient Information and Preference Review

## **Annex A – Recommendations from the SCR Content Review**

1. It is recommended that the Summary Care Record should contain only a core set of essential information: a patient's demographic details, medications, allergies and adverse reactions.
2. Where a patient and their doctor wish to add additional information to the patient's Summary Care Record, this should only be added with the explicit consent of the patient.
3. We should only consider expanding the content of the Summary Care Record when we have built trust in the system and when patients request that we do so. We therefore recommend that new governance be established, for the content of the Summary Care Record.
  - a. As a principle, any change to the scope of the Record must be driven by citizens and patients, with appropriate advice from professional bodies and tempered by the Information Technology capability
4. Standards need to be defined to support a patient's wish to add information to their Summary Care Record. An example of the kind of additional information would be the inclusion of a patient's end of life preferences, a care plan for patients with long-term conditions or the inclusion of a patient's significant medical history. As standards are published, we will communicate with the NHS and patient groups to ensure that patients can make informed choices about what they might choose to include in their record.
5. We heard strong opinions that the use of smart cards was not universal within GP Practices and this has implications for accurate updating of the Summary Care Record. The Information Governance policy and controls that mandate smart cards are wider than the Summary Care Record Programme and as such, this issue is outside the remit of this review. However, we understand that this issue is important and we recommend that further potential options are investigated to mitigate this risk.
6. Whilst not considered as part of the content of the Summary Care Record, it is recommended that standards and systems continue to be developed to allow direct transfer of discharge letters electronically to GP systems.

## **Annex B – Recommendations from the Patient Information and Preference Review**

- 1 The core information of patient demographics, medications, allergies and adverse reactions should continue to be added to the Summary Care Record under informed implied consent. Where a patient and their doctor wish to add additional information to the patient's Summary Care Record, this should only be added with the explicit consent of the patient.
- 2 There should be no requirement to re-mail those patients that have already received information on the Summary Care Record. However:
  - a. The patient letter should be simplified and reference the accompanying leaflet for clarity and detail. A template letter should be provided to include core-standardised text with the ability to tailor elements locally.
  - b. The leaflet that accompanies the patient letter should be simplified with key points emphasised and more prominence placed on the patient telephone information line to support those patients requiring additional information or help/advice (for example language translation, uniphone, text phone).
  - c. The outer envelope that patients receive should have clear emphasis that the information contained in the envelope is about "Your health records, you need to make a choice".
  - d. To make opting out as easy as possible the information pack that is sent to patients should include an opt out form.
- 3 For those patients that have already received information and those about to be mailed, it is important that PCTs and individual GP practices are supported to further raise awareness
  - a. We propose to work with patient and other voluntary organisations to raise awareness amongst their members.
  - b. We will target the consumer media nationally
  - c. We will work with SHAs on local and regional awareness raising initiatives.
- 4 Greater emphasis should be placed on raising awareness and training front line NHS staff to enable them to support patients and the public with their questions.
- 5 To support patient ownership of their health information, services such as Health Space should continue to provide patient access to and control of their Summary Care Record.
- 6 To ensure that there is a consistent approach to making new patients aware of the SCR when they register at a GP practice, the GMS1 form should be modified to include a paragraph on the Summary Care Record and the ability to record patient preference.

- 7 For clarity, the branding of Summary Care Record should focus and a strap line developed that describes the purpose of the Summary Care Record, for example “Your Emergency Care Summary”.

## **Annex C – List of organisations contributing the Reviews**

### **Content Review**

- Association for the Directors of Adult Social Services
- British Medical Association
- Bury Primary Care Trust
- College of Emergency Medicine
- College of Occupational Therapy
- Department of Health (National Clinical Director for Primary Care and representative for National Clinical Director for Children, Young People and Maternity Services)
- East Midlands Ambulance Service NHS Trust
- Heart of England Hospital and Birmingham East PCT
- Macmillan Cancer Support
- Medway On Call Care (Primary Care Out of Hours provider)
- NHS East Midlands
- Royal Bolton Hospital
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Physicians
- Royal College of Psychiatrists
- South East Coast Strategic Health Authority

### **Patient Information and Preference Review**

- Age UK
- British Medical Association
- Cambridge PCT (PALS)
- East of England SHA
- Essex and Southend LINK
- Haringey PCT (PALS)
- Help the Hospices
- The Information Commissioner's Office
- Liberty
- National Association of Patient Participation Groups
- National Children's Bureau
- National Voices
- NHS Bradford and Airedale (Communications)
- NHS London (Communications)
- NHS Patient
- The Patients Association
- Royal College of Nursing
- Royal National Institute for the Blind

- Salford PCT (Communications)
- Scottish Consumer Council
- South Birmingham PCT (GP Practice Manager)
- South Birmingham LINK
- South East Essex PCT (PALS)
- Thames Valley University
- West Berkshire LINK