



Royal College of
General Practitioners



Connecting for Health

Informing shared clinical care

**Shared Record Professional
Guidance project –
Quick Reference Guide**

June 2009

The RCGP Health Informatics Group

1. Introduction

- 1.1 The purpose of the Shared Record Professional Guidance (SRPG) project was to develop a set of professionally led guidelines that would consider the governance, medico-legal and patient safety consequences of shared electronic patient record (SEPR) systems in the primary care domain.

The purposes of clinical records can be summarised as:

- **Clinical purposes** (to facilitate the care of individual patients)
- **Assist in the clinical care of populations** (e.g. health needs assessment, screening programmes)
- **Non-clinical purposes** (e.g. audit, commissioning, medico-legal and research)

The literature review found that the main health benefits of **shared records** are probably improvements in the quality and safety of care, in access to care or in cost effectiveness. However, these anticipated improvements in efficiency, safety, equity and cost-effectiveness of care have not been realised in the few rigorous studies on a large scale anywhere in the world.

- 1.2 The objective for the NHS Care Record Service (NHS CRS) is a single record for an individual patient that is accessible by the GP and by community and local hospital care settings. The vision for the NHS CRS therefore is of a patient-centred secure electronic patient record, linked and accessible across (health) organisational boundaries, with patients able to make choices about sharing some or all of the content of their detailed (care) records with health professionals involved in their care.

1.3 The key questions for this project to address were:

- ***What are the purposes of shared detailed care records?***
- ***How can these requirements be delivered safely?***
- ***What are the principles and practice that ensure clarity, safety and continuity?***
- ***At what level does responsibility for shared detailed care record governance lie?***

- 1.4 This report provides evidence and principles to inform generic guidance for consideration and implementation by primary care and community professional groups who use existing and future shared, multi-contributory electronic record systems.

The SRPG final report, reference report and this quick reference guide are available online at:

http://www.rcgp.org.uk/get_involved/informatics_group/shared_record_professional_guidance.aspx

Semantics and Definitions

The descriptions and definitions below are limited to the context of the NHS Care Record Service (NHS CRS). However, the scope of NHS CRS does not cover everything that the NHS might regard as detailed record functionality. These guidelines will have important implications for all models of shared electronic patient records.

For the purposes of this project we are concerned with records of *prime entry* that were *shared* by two or more (probably many more) legal entities. It is important to differentiate this from shared records (usually summary records) created by an act of publication from the records of prime entry of one or more individual organisations.

Throughout the report the term *Shared Electronic Patient Record* (SEPR) has been used as a generic term to encompass all forms of shared electronic patient records. An organisational (or local) *Detailed Care Record* (DCR) is a record of everything that is relevant to the care of that patient known to the organisation maintaining the patient health record. A *shared DCR* (sDCR) is a subset of information derived from contributing DCRs that can be usefully shared. This, whilst appearing vague, has the advantage of defining the purpose of a shared detailed care record without imposing any technical or architectural constraints on such records.

Information sharing” and “shared electronic patient record” are not synonymous. The distinction between the two also comes out of the findings: the focus of this work is the shared electronic patient record

2. Principles for record sharing

Principle 1.

The success of SEPR/sDCR programmes should be measured alongside the operational characteristics of these programmes allowing evaluation of such systems in a wider context.

Principle 2.

Joint guidance on record sharing should be produced and maintained collaboratively by professional regulatory bodies and representative organisations to ensure a multi-professional approach to record quality, consistency and clarity.

Principle 3.

A community using a SEPR/sDCR system should establish governance rules and processes that ensure the clear allocation of responsibility and define the rules and mechanisms for its transfer. The rules need to be clear on who has responsibility for content and for action based on the record content within and between organisations.

Principle 4.

SEPR/sDCR systems should be designed to support the governance principles outlined in Principle 3 (above).

Principle 5.

Health professionals should have a shared responsibility for maintaining and assuring data quality in SEPR/sDCR systems.

Principle 6.

Health professionals should be properly educated and trained to meet their legal, ethical and professional responsibilities for using and managing SEPR/sDCR systems. This should form part of their ongoing professional development.

Principle 7.

Semantic issues should be considered in the design and implementation of SEPR/sDCR systems so that meaning is preserved and must be sensitive to issues of language, interpretation and context.

Principle 8.

Governance arrangements should be in place to deal with errors and differences of opinion in SEPR/sDCR systems.

Principle 9.

Organisations should have the facility to update/correct erroneous information added to their DCRs from other sources, (with the original information retained in the audit trail).

Principle 10.

Content and provenance data should identify unambiguously the originator or editor of each entry in the SEPR/sDCR.

Principle 11.

SEPR/sDCR should be able to store and present information in styles that meet the particular user's needs.

Principle 12.

SEPR/sDCR systems should improve the quality and safety of care by facilitating communication and coordination between health professionals and informing best clinical practice.

Principle 13.

SEPR/sDCR systems should support structured communications between users (e.g. referrals).

Principle 14.

Health organisations should be able to explain to patients who will have access to their SEPR/sDCR and must make information available to patients about such disclosures.

Principle 15.

Health professionals should respect the wishes of those patients who object to particular information being shared with others providing care through a SEPR/sDCR system, except where disclosure is in the public interest or a legal requirement.

Principle 16.

There should be an organisational (or team) guardian with clinical and information governance responsibilities for that organisation's shared and organisational DCRs, in order to assure best practice is followed.

4.1. What are the purposes of shared detailed care records?

The objective for the NHS CRS is a single record for an individual patient that is accessible by the GP and by community and local hospital care settings. So the vision for the NHS CRS is of a patient-centred secure electronic patient record, linked and accessible across (health) organisational boundaries, with patients able to make choices about sharing some or all of the content of their detailed (care) records with health professionals involved in their care.

See Principle 1.

4.2. How can these requirements be delivered safely?

Good clinical and information governance practice is essential for the safe use of SEPR/sDCR systems. Health organisations and health professionals need to be familiar with relevant legislation, common law, acceptable ethical practice and relevant DH policy and standards. Professional regulatory bodies and representative organisations produce useful guidance for their members but there are areas where guidance is unclear or incomplete and will require interpretation.

See Principles 2, 3, 4, 5, 6.

4.3. What are the principles and practice that ensure clarity, safety and continuity?

It is desirable for errors to be corrected by the originator but where they are unable to do so it should be possible for others to make corrections. Systems need to be able to clearly mark errors as such, point to corrected information and ensure future processing is based solely on the corrected data. The audit trail should be easily accessible so that users can understand how others may have acted on erroneous data they believed to be correct at that time.

See Principles 7, 8, 9, 10, 11, 12, 13

4.4. At what level does responsibility for shared electronic patient record/detailed care record governance lie?

See Principles 14, 15 and 16

It is essential to engage patients as full partners in these sharing decisions, to inform professional practice and maintain patient confidence in both health professionals and the information systems used to support the care process.

The very nature of a “shared” record complicates the issues of responsibility. However it is clear from the contents of the report so far, that responsibility for safe and effective governance of sDCR systems exists at many levels and includes:

- Government
 - To understand the business requirements of the service and commission systems that are fit for purpose.

- To provide an appropriate legal framework within which good clinical practice can be established.
- Clinical professions
 - To ensure that professional guidance is developed and delivered to health professionals working with shared record systems and that this is reflected in professional requirements for registration, training and Continued Professional Development.
- Health organisations
 - To ensure that high quality clinical and information governance practices are followed.
 - To provide an appropriate education and training framework for staff
- Health professionals
 - To ensure they understand and follow best practice in relation to clinical record keeping and are aware of the particular issues and challenges presented by shared health records.
- Patients
 - Patients are key stakeholders and should participate as full partners in these matters.

The Data Protection Act requires that patients are informed about how and why information about them is used and who will have access to their information. It does not prevent information being used for healthcare purposes providing the principles are satisfied but may prevent health information being used for non-healthcare purposes without a patient's explicit consent. The key points are that the processing (use) of sensitive personal information has to be:

- For a legitimate purpose
- No more than is necessary for the purpose, and
- In the case of use for a medical purpose, processed by health professionals or other people under the same duty of confidence

The proper use (and sharing) of sensitive personal information for medical purposes depends:

- First on using it to the extent necessary for the purpose, and
- Second on limiting the use to people who will keep it confidential

Suggested wording for health professionals to open a discussion with patients regarding the sharing of decisions:

Everyone looking at your record, whether on paper or computer, must keep the information confidential. We will aim to share only as much information as people need to know to play their part in your healthcare. When we provide healthcare, we will share your record with the people providing care or checking its quality (unless you have asked that we limit how we share your record).

We will not share health information that identifies you for any reason other than providing your care, unless:

- ***You ask us to do so;***
- ***We ask and you give us specific permission;***
- ***We have to do this by law;***
- ***We have special permission for health or research purposes;***
or
- ***We have special permission because the public good is thought to be of greater importance than your confidentiality.***

The NHS CRS that is being implemented by NHS CFH will change the pattern of data controllers across the service. The concept of locally held data will probably gradually disappear and there will be a number of data controllers sharing responsibility in common for each data subject.

Unfortunately it is not clear who the data controller is for shared electronic health records. It would seem that the data controller of each participating organisation has a role and the idea of a “data controller in common” has been proposed, where the data controllers of each participating organisation have a shared responsibility for the total contents of the shared electronic health record. It is not clear how current legislation supports this concept or how it could be organised in practice.

Requirement 1.

The Information Commissioner should be asked to clarify how the requirements for a Data Controller and other obligations under data protection legislation should be met in the context of SEPR/sDCR systems and provide policy advice on implementation in practice.

Requirement 2.

Government should be asked to clarify issues of data and record preservation and deletion in shared patient record systems.