Informing shared clinical care

Final (reference) report of the Shared Record Professional Guidance project

June 2009

The RCGP Health Informatics Group
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The SRPG final report, this reference report and the quick reference guide report are available online at:

http://www.rcgp.org.uk/get_involved/informatics_group/shared_record_professional_guidance.aspx
Chapter 1 – Introduction

1.1 Background and context

The governance and guidance of primary care clinical record systems has historically rested with general practice, which has assumed supervisory roles for the pragmatic purpose of allowing wider clinical teams access to an effective locally shared electronic record.

Over the past few years NHS Connecting for Health (NHS CFH) system suppliers have implemented primary/community IT systems with explicit sharing of a single electronic record by health professionals from different teams and NHS bodies. This has led to rising levels of uncertainty from all sides about the governance, medico-legal and patient-safety consequences of shared electronic patient record systems.

Professional anxieties have been expressed about shared electronic clinical record systems by the British Medical Association (BMA), the Joint GP IT Committee (JGPITC) of the General Practitioners Committee (GPC) and Royal College of General Practitioners (RCGP) and the Primary Health Care Specialist Group (PHCSG) of the British Computer Society. These concerns can be summarised under the following headings:

- Describing and defining shared electronic patient records
- Uncertainty about the best models for data sharing
- Issues about data ownership and control
- Uncertainty about information governance issues in shared records
- Helping patients make informed choices about sharing their health information
- Maintaining patient privacy and trust in shared record systems
- Clarifying responsibility for action on data in shared records
- How to maintain record quality and ensure the contents of individual records
- How to handle errors and different opinions and their resolution, or manage the resulting dissonance when resolution is not possible
- How to ensure that the provenance of data is clear and that changes to data are apparent
- How to handle the needs of record users for different styles or granularity of information relating to the same event, episode or aspect of care
- How to manage workflows and structured communication within a shared electronic health record
- Understanding data controller issues related to shared records
- Health professional education and training issues
- Four nations issues

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

The SRPG project was awarded to the RCGP after a competitive tendering process. Members of the RCGP Informatics Group, co-opted domain specialists and academic departments at the universities of Dundee and Aberdeen undertook this project on behalf of the RCGP.
1.2 Project aim and scope

1.2.1 Aim
The principal aim of this project was to develop a professionally led set of guidelines for the governance of shared electronic patient records in the primary care domain that should carry the endorsement of the full range of relevant health professional representative bodies and be promoted by NHS CFH to their clinical system suppliers and all system users.

The key questions for this project to address were:

- What are the purposes of shared electronic patient 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 electronic patient record governance lie?

1.2.2 Scope
The project brief was to focus on shared electronic patient record systems used in Primary Care including those provided through the National Programme for IT (NPfIT) by their Local Service Providers (LSPs) and those supplied by other Existing Service Providers (ESP) and provide guidance that covered:

- The implementation of patient decisions on consent to share electronic detailed care records
- Governance of clinical records relating to clinical staff that currently have the ability, or potential, to add records (including):
  - General practitioners
  - Practice employed clinical staff
  - Community clinical staff
  - Clerical staff
- The work will be expected to cover ownership, responsibility and governance of record elements, together with medico-legal record integrity and liability.
- Furthermore, all routine functions from the above groups that need to be recorded in the shared record would be considered. Record maintenance and the ability to filter, edit and amend records between different legal entities was also included, as were issues relating to ‘lapsed’ legitimate relationships, search and audit implications, and business issues such as Quality and Outcomes Framework (QOF) score.

Defining and limiting the purpose and scope of the project was the first key stage in developing the SRPG project plan. The project scope did not include the areas listed below:

- Role-based access control definitions
- The Summary Care Records and consent model issues
- Secondary care clinical systems
- ‘Outreach’ secondary care health professionals
- Pharmacy
- UK ‘wide’ considerations
- Prison service
- Genito-Urinary medicine services
- Mental health systems
- Child health systems
- Maternity systems
- Social services
- Care pathways
Constraining the scope of the project would be a challenge given the open approach the project team had adopted. While we were determined to deliver the project within the agreed financial and time constraints, we were equally determined to keep track of potential stakeholders deemed out-of-scope who may still have important contributions to make in this field.

This report represents the first steps in developing professional guidance about the use of Shared Electronic Patient Record (SEPR)/ Shared Detailed Care Record (sDCR) systems to support shared clinical care. The scope of this project was constrained and several important areas were excluded from our remit. It is important that these principles and guidance are tested in other shared care clinical scenarios, particularly relating to child health and protection, care of vulnerable people, mental and sexual health services and by a wider spectrum of professional users.

We also noted that there was confusion between issues of information governance and clinical governance. Shared electronic records bring to the surface issues of clinical governance, which are sometimes misunderstood as being issues of information governance (e.g. The question of who has duty of care for a patient at a point of time is a clinical and not information issue, and yet it is sometimes considered to be an information governance issue)\(^1\).

We recognised from the beginning that “information sharing” and the “shared electronic health record” are not synonymous and the focus of this work is the shared electronic health record.

### 1.3 Project approach

This project is different from other projects undertaken by the RCGP Informatics Group, in that its key aim was to develop guidance that is endorsed by all key stakeholder groups in the primary care setting. This would require multi-professional stakeholder engagement and consultation throughout the project.

From the outset, this project was seen as an iterative process requiring review of the defined scope, exclusions and dependencies throughout the project lifespan. The RCGP Informatics Group and NHS CFH established the Shared Record Professional Guidance project steering group (SRPG SG) as the formal owner of the project with a senior officer from each organisation to act as project sponsor/Senior Responsible Owner within their respective organisations (Prof. Michael Thick for NHS CFH and Prof. Steve Field for RCGP). Dr Peter Short and Dr Manpreet Pujara (NHS CFH GP National Clinical Leads) would co-chair the steering group and membership would include NHS CFH programme management, health professionals and RCGP project team members to provide regular updates. The steering group would have authority to make and alter decisions on project scope, direction and timescales.

Our first task would be to describe and define the various models of shared electronic patient records that were being proposed or implemented by NHS CFH systems.

\(^1\) CLICSIG meeting report, PHCSG January 2009.
1.4 Shared electronic patient records – descriptions and definitions

One of the difficult areas we faced at the start of this project was lack of clarity and agreement about 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. We anticipate that these guidelines will have important implications for all models of shared electronic patient records.

For the purposes of this project, we decided that we were 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 this report we have used the phrase Shared Electronic Patient Record (SEPR) 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. The terms Detailed Care Record and Detailed Record seem to be used interchangeably by NHS CFH and clinical system suppliers.

The Summary(72,599),(994,906)(72,599),(994,906) Care Records (SCR) is a nationally defined record subset of information meant for first point of contact care. The SCR is a centrally stored health summary derived (currently) from a patient’s GP record and contains a minimum dataset of medications, allergies and adverse reactions.

A shared DCR (sDCR) is a subset of information derived from contributing DCRs that can be usefully shared between two or more organisations (legal entities). This may seem rather vague, but has the advantage of defining the purpose of a shared detailed care record without imposing any technical or architectural constraints on such records. So the definition will include systems where some or all of the organisational detailed care records may be linked and also single patient centred electronic detailed care records that span several organisational domains. The PHCSG have suggested the alternative definition of a multi-organisational EHR (MOEHR) also called a Single Shared Electronic Patient Record (SSERP).2

1.5 Key stakeholders and interested parties

The RCGP and its senior officers, including the College Chairman would assist in direct approaches to key stakeholder organisations to ensure their involvement at the highest level. The RCGP would play a key role as an authoritative neutral host and sponsor for the project. The project steering group would identify and agree with NHS CFH a list of key stakeholders and interested parties to be consulted as part of the guidelines development process, to include:

- Professional regulatory bodies
- Medical professional representative groups
- Nursing professional representative groups
- Allied Health Professional representative bodies
- Medical Defence organisations
- Clinical system suppliers and users

2 CLICSIG meeting report, PHCSG January 2009.
The Office of the Information Commissioner
Institute of Healthcare Management
The Primary Health Care Specialist Group of the British Computer Society
Patient representative groups

The project steering group would assist in identifying and making contact with key individuals within the stakeholder organisations. The role of the steering group would be to provide strategic advice to the project team and facilitate access and communications with government agencies, other organisations and NHS CFH itself. The terms of reference of the steering group were agreed at its first meeting in September 2008.
Chapter 2 - Project plan

2.1 Deliverables

The project was undertaken by the RCGP Informatics Group on behalf of the RCGP, co-opted domain specialists and teams from the University of Dundee led by Prof Jeremy Wyatt and the University of Aberdeen led by Dr Bob Milne. The project plan would be delivered in several stages linked to a formal timeline and agreed project milestones. Achieving each milestone would trigger project payments. The project deliverables would consist of:

- An agreed Project Initiation Document (PID)
- Ongoing documented review of project purpose, scope, content and decision milestones (supervised by the project steering group)
- A literature review to inform the draft records guidance, the consultation process and the design of the stakeholder survey
- A description of the current state of play of shared electronic records in the UK
- A description and analysis of the stakeholder consultation process
- SRPG project interim report and draft guidelines
- Final report and recommendations covering the aims of the project based on the outcome of the stakeholder consultations and literature review
- Close down meeting and lessons learnt discussion

2.2 Project stages, key dates and milestones

The project would run in several overlapping stages to include the key milestones and project deliverables within an agreed timeframe. This is summarised in table 2.2 below.

Table 2.2 - Project stages, key dates and milestones

<table>
<thead>
<tr>
<th>Stage</th>
<th>Date</th>
<th>Milestone</th>
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<tbody>
<tr>
<td>Stage 1</td>
<td>a) Develop PID</td>
<td>August 2008 – September 2008 PID development and agreement</td>
</tr>
<tr>
<td></td>
<td>b) Assign project team tasks</td>
<td></td>
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<td></td>
<td>c) Identify key stakeholders</td>
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<td></td>
<td>d) Begin literature review</td>
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<td>Stage 2</td>
<td>a) Develop and deliver stakeholder briefing pack and survey</td>
<td>November 2008 - January 2009 Stakeholder engagement process document</td>
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<td></td>
<td>b) Develop and test clinical records sharing scenarios</td>
<td></td>
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<tr>
<td></td>
<td>c) Complete literature review</td>
<td></td>
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<tr>
<td>Stage 3</td>
<td>a) Analysis of literature review</td>
<td>January – February 2009</td>
</tr>
<tr>
<td></td>
<td>b) Analysis of clinical records sharing scenarios</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c) Analysis of stakeholder survey responses</td>
<td></td>
</tr>
<tr>
<td></td>
<td>d) To inform draft report and guidelines</td>
<td></td>
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<tr>
<td>Stage 4</td>
<td>a) Production of draft report and guidelines</td>
<td>January - February 2009 SRPG draft report and guidelines</td>
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<tr>
<td>Stage 5</td>
<td>a) Quality assurance with</td>
<td>March – April 2009</td>
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### 2.3 Assumptions, dependencies and mitigation

There are a number of assumptions that underpin this project. Perhaps the most important was that the key stakeholders would recognise and accept the importance of this project and would be willing to engage with us. For this reason we felt it was vital that the RCGP take the lead in establishing initial relations with key stakeholders. We are also reliant on stakeholders giving this project a high priority within their organisations to give us the feedback we need within the tight timescales of the project.

We set out by assuming that there would be some robust evidence in the international literature to help inform the project report and production of guidelines. Our relationship with University of Dundee would be crucial to the eventual success of the project. However, we understood that we may have to develop guidance iteratively, getting input and feedback from stakeholder organisations to assist in guidelines development.

We also assumed that a consensus would emerge around the governance of shared electronic health records. We anticipated that stakeholder experience of electronic record systems would differ across the country and we were uncertain whether some stakeholders would have much experience of such systems and may therefore be unwilling or unable to engage actively in the process. Should no consensus emerge we would develop guidance on the basis of “best practice” and continue to engage with stakeholders, to gain their approval for the guidelines development process and reports.

Perhaps the biggest assumption of all was that we could deliver meaningful outcomes within the agreed constraints. For this reason, we adopted an iterative approach to the project from the outset and recognised that the steering group would play a crucial role in managing and prioritising the project, but also crucially constraining the scope of the project given the limited resources and timescales agreed between NHS CFH and the RCGP.

### 2.4 The stakeholder engagement process

Key stakeholders in the primary care domain were identified with the help of the RCGP, NHS CFH and the project steering group. Stakeholder organisations contacted by the project are categorised and listed below:

- **Professional regulatory bodies**
  - The General Medical Council
  - Nursing and Midwifery Council
  - Health Professions Council
- **Medical professional representative groups**
  - The British Medical Association (General Practitioners Committee)
• Joint GP IT Committee, Royal College of GPs, Royal College of Physicians (London)

• Nursing professional representative groups
  o The Royal College of Nursing
  o The Royal College of Midwives
  o Community Practitioners and Health Visitors’ Association
  o Community and District Nursing Association

• Allied Health Professions representative bodies
  o The Chartered Society of Physiotherapists
  o British Association of Occupational Therapists and College of Occupational Therapists
  o British Dietetic Association
  o Royal College of Speech and Language Therapists
  o Society of Chiropodists and Podiatrists

• Medical Defence Organisations
  o The Medical Protection Society
  o Medical Defence Union
  o Medical and Dental Defence Union of Scotland

• Clinical system suppliers (LSP and ESP)

• Clinical system supplier National User Groups
  o iSoft
  o EMIS
  o INPS
  o GPASS
  o Ascribe
  o Healthy Software
  o TPP user representatives

• The Office of the Information Commissioner
• The British Computer Society (Primary Health Care Specialist Group)
• Patient representative groups
  o Patients Association
  o RCGP Patient Partnership Group
  o P3 Group, RCGP Scotland

The project would run in several overlapping stages to include the key milestones and project deliverables within an agreed timeframe. This is summarised in table 2.2 below.

The first stage of the stakeholder engagement process was a formal invitation to participate in the project sent by the RCGP and NHS CFH to the Chief Executives of the organisations shown and signed by Prof Steve Field and Prof Michael Thick for RCGP and NHS CFH respectively, in September 2008. Those organisations failing to respond within four weeks were contacted again by the relevant NHS CFH National Clinical Lead (NCL) to encourage participation. By the end of November 2008 all the stakeholder organisations had expressed an interest in the project and willingness to participate in the consultation phases of the project with the exception of the Institute of Healthcare Management and UNISON – who did not respond.

While we were busy identifying and contacting the stakeholder groups, three other strands of the project were underway:

• The first of these was a review of current and planned shared electronic record systems in the UK (see chapter 3)
• The second was a review of professional guidance produced by the health professional regulatory bodies and representative groups that was relevant to record keeping – part of our larger information governance review (see chapter 4)
The third was to develop and test a set of clinical records sharing scenarios (see chapter 6).

We used the results from the systems and professional guidance review to develop a briefing pack for the stakeholder groups, to help them understand the issues and address the four key questions that the SRPG project had set out to address (see chapter 1.2.1 and below).

However, before we could enter into formal dialogue with our stakeholders, we had to address the issue of definitions. Once these were agreed (Chapter 1.4) we modified the key questions to focus on shared Detailed Care Records:

- 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?

The main aim of the second phase of the stakeholder consultation process was to develop a set of professionally endorsed principles that would help define the clinical and information governance requirements for shared DCRs. We would not try to define technical solutions, but begin to set out clearly the information governance requirements for shared DCR systems from a professional and patient perspective within current legal and ethical frameworks. (See chapter 7 - The stakeholder survey).

The project team then contacted the nominated representatives from the stakeholder groups to introduce and explain the survey and agree a process that suited each organisation to give feedback within the project timescales. Dr Bob Milne’s team at the University of Aberdeen led the stakeholder survey analysis process.

Our aim was to build a stakeholder consensus around the principles where there are high levels of agreement between the different organisations. The responses would be analysed using a mixture of quantitative and qualitative methodologies. Quantitative analysis was by simple tabulation, setting out the responses from each organisation. Comments were also collated and analysed using a qualitative (thematic) analysis of questionnaire comments and other feedback.

The project team contacted stakeholders during the feedback period to discuss any issues that emerged from the questionnaire, to provide advice for any membership surveys stakeholders might wish to perform and to meet stakeholders where personal interview or focus group would be the preferred method of feedback to the project team.

The results from the principles questionnaire were used to help develop the professional guidelines development process, informed by the main literature review, reporting in January 2009.

The literature review and stakeholder survey would be central to the guidelines development process, providing a structure for the draft report and operationalising the draft recommendations into principles and guidelines for clinical professional practice in our final report. The draft report and guidelines were sent out for consultation in March 2009. Stakeholder organisations were offered the opportunity to endorse the SRPG report and we sought advice on the process for gaining stakeholder endorsement from each organisation.

The project’s final report and recommendations were completed in May 2009, following stakeholder responses to the draft report and after they have been asked to consider endorsing the final report.
Table 2.4 – The stakeholder engagement process

<table>
<thead>
<tr>
<th>Date</th>
<th>Engagement phase</th>
<th>Project description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sept 08</td>
<td>Phase 1</td>
<td>Identify and contact key stakeholder organisations</td>
</tr>
<tr>
<td>Nov 08</td>
<td>Phase 2</td>
<td>Stakeholder briefing pack and “Principles” questionnaire</td>
</tr>
<tr>
<td>Mar 09</td>
<td>Phase 3</td>
<td>Consultation on draft report and guidelines</td>
</tr>
<tr>
<td>May 09</td>
<td>Phase 4</td>
<td>Consultation on draft final report and guidelines</td>
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</tbody>
</table>
Chapter 3 – The national context

3.1 The NHS Care Records Service

This description of the NHS CRS has largely been taken from the NHS CFH website\textsuperscript{3} and as such, represents the current public position of the NHS CFH on shared electronic records.

The NHS Care Records Service\textsuperscript{4} (NHS CRS) will be a secure service that links patient information from different parts of the NHS electronically, so that authorised NHS staff and patients have the information they need to make care decisions. There will be two elements to the NHS Care Records Service: Detailed Records (held locally) and the Summary Care Record (held nationally). The NHS Care Records Service will enable each person's detailed records to be securely shared between different parts of the local NHS, such as the GP surgery and hospital.

Over the next few years, as the NHS CRS develops, instead of having separate records in all the different places where a patient receives care, NHS organisations which normally work together in a local area - such as hospitals, clinics and GPs - will develop and begin to link and access detailed electronic records for each patient.

At present patients have many detailed (care) records. These include a GP record, usually held electronically but often supplemented by paper records. Where patients have visited a hospital or clinic, there will usually be the following:

- An electronic patient administration record
- A separate written clinical record in their local hospital
- A separate paper record if they have been pregnant
- A further separate paper record if they have received mental health treatment
- Another separate paper record if they have been treated in the sexual health clinic
- A separate record if they have attended Accident and Emergency (A+E)

Each of these records will be repeated for each hospital or clinic the patient has attended. In addition the patient may have a community record if receiving long-term care in the community (e.g. physiotherapy).

NPfIT has a clear objective to reduce this duplication of diverse records by providing a patient centred electronic detailed record that spans these areas. As a minimum, this would be within a hospital but there are potential benefits when providing a consistent record across a local health community and across the boundaries involved in care pathways for a patient.

The NHS CRS proposes to allow the NHS to move away from its current organisation-centred patient records, to records that are centred on the patient. This should make caring for patients across organisational boundaries safer and more efficient. It will also give patients themselves access to a record that covers care across organisations.

*The overall objective is a single detailed record for an individual patient that is accessible by the GP and by community and local hospital care settings.*

Over the next few years, as the NHS CRS develops, instead of having separate records in all the different places where a patient receives care, NHS organisations which normally

\textsuperscript{3} http://www.connectingforhealth.nhs.uk/
\textsuperscript{4} http://www.connectingforhealth.nhs.uk/systemsandservices/nhscrs
work together in a local area, such as hospitals, clinics and GPs, will develop and begin to link and access detailed electronic records for each patient. These groupings will be determined locally, by need and technical capability. A patient who has attended NHS organisations in different areas may have more than one set of linked detailed (care) records.

All detailed records will be kept electronically, to be accessed locally. Detailed electronic records will typically contain:

- Name, address, date of birth and NHS Number
- Details of any medicines, allergies, results of tests and X-rays
- Details of any health conditions, such as asthma or a heart problem
- Notes about any treatments, diagnosis or operations that the patient has had; and proposed plans or reminders

They will sometimes include other information the patient has shared (for example, about family or work) but only where this is relevant to the patient’s health care. Linked detailed electronic records will be developed gradually over several years and that process has already started in some places.

Patients will be able to choose how fully they want to participate in linked electronic care records enabled by the NHS CRS. It is therefore essential for them to understand their options for limiting access to all, or parts of, their records. They must also be aware of the potential effects of doing so. Patients can ask for information not to be included and this will be a matter for a health professional’s professional judgement. NHS policy is that the normal basis for sharing confidential information for the direct provision of care and treatment is implied patient consent, and this policy is being applied to information shared through NHS CFH information systems. For implied consent to be valid legally, patients must be informed, and must have some mechanism(s) for expressing their dissent.

The Care Record Guarantee covers people’s access to their own records, controls on others’ access, how access will be monitored and policed, options people have to further limit access, access in an emergency, and what happens when someone cannot make decisions for themselves. The Care Record Guarantee was first published in 2005 and revised in 2006 and 2007. The 2007 version of the Care Record Guarantee has emphasised and strengthened the clear commitment to the confidentiality and security of patient’s information.

So the vision for detailed records within the NHS CRS is of a patient-centred secure electronic record, linked and accessible across organisational boundaries, with patients able to make choices about sharing some or all of the content of their detailed records with health professionals involved in their care.

### 3.2 The purposes of health records

These will be reviewed under the headings of: clinical, non-clinical and other purposes.

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6 [http://www.connectingforhealth.nhs.uk/nigb/crsguarantee](http://www.connectingforhealth.nhs.uk/nigb/crsguarantee)

3.2.1 Clinical purposes
Primary and community care health professionals require patient record systems that have the following functionality:

- Facilitate the clinical care of individual patients by:
  - Assisting the health professional to structure his or her thoughts and make appropriate decisions
  - Acting as an aide memoir for the health professional during subsequent consultations
  - Making information available to others with access to the record system who are involved in the care of the same patient
  - Providing information for inclusion in other documents (e.g. laboratory requests, referrals and medical reports)
  - Storing information received from other parties or organisations (e.g. laboratory results and letters from specialists)
  - Transfer the record to any NHS practice with which the patient subsequently registers (GP record)
  - Providing information to patients about their health and health care

- Assist in the clinical care of the practice population by:
  - Assessing the health needs of the population
  - Identifying target groups and enabling call and recall programmes
  - Monitoring the progress of health promotion initiatives
  - Providing patients with an opportunity to contribute to their records
  - Supporting medical audit

3.2.2 Non-clinical purposes
Health organisations also need a patient record system that can be used to meet administrative, legal and contractual obligations by:

- Providing medico-legal evidence (e.g. to defend against claims of negligence)
- Providing legal evidence in respect of claims by a patient against a third party (e.g. for injuries, occupational diseases and in respect of product liability)
- Meeting the requirements of specific legislation on subject access to personal data and health records
- Recording the preferences of patients in respect of access to and disclosure of information they have provided in confidence
- Providing evidence of workload within a health organisation
- Providing evidence of workload to support claims and bids for resources
- To enable commissioning of community and secondary healthcare services
- Monitoring the use of external resource usage (e.g. prescribing, laboratory requests and referrals)

3.2.3 Additional purposes
Health organisations are increasingly likely to require a patient record system that can be used:

- To interact with a decision support/expert-system
- To support teaching and continuing medical education
- To support clinical governance activities
- To support professional appraisal and revalidation
- To enable:
  - Epidemiological monitoring
  - Surveillance of possible adverse effects of drugs
  - Clinical research
3.3 Shared record implementations in the United Kingdom

This chapter reviews shared record systems currently deployed or planned in the UK, which involve the sharing of records beyond the boundary of a single legal entity, which is either a GP practice or a NHS Trust (providing community and/or mental health services). A more detailed description is provided for three of these approaches; TPP SystmOne, EMIS Web and Graphnet. Systems which involve sharing of data between NHS Acute Trusts and which do not involve GP or community services are out of scope of this project and are not considered. The authors are aware of the following systems within scope:

England

3.3.1 The Summary Care Records (Partially Implemented)

The Summary Care Records is envisaged to be a nationally available information resource (hosted on the National Spine), which will eventually contain information about patients arising from general practice (as a summary updated at each recorded patient contact). In addition, documents arising from secondary care will be uploaded including:

- Discharge reports
- Out-patient reports
- Ambulance reports
- Diagnostic imaging
- Out of Hours (OOH) reports
- A+E reports
- Mental Health reports
- Health and Social Care Integration
- NHS Direct reports
- HealthSpace (patient authored data) reports

Initially, access to this data will be allowed to general practices, OOH centres and A+E departments but other organisations may be allowed access by local agreement/policy.

The content of a GP Summary is mandated to include at least current medications and allergies. However, any item in the record that the custodian health professional’s or patient deems relevant may be included in the summary and it is a requirement that any item deemed worthy of inclusion in a local summary should be sent to the central one.

Access is determined by legitimate relationships i.e. the person/organisation gaining access having a role in the care of the patient concerned. Consent is currently set on the general practice systems concerned but will in future be set as a flag held on the Spine itself. The consent model is of implied consent with the ability to opt out and consent to view at the point of contact. In addition, any patient may state that they wish to share and do not wish to be asked again for their consent. Ultimately, consent to share may be given or withheld at any organisation. If consent to share is denied at any organisation, then sharing will not be possible by any organisation having a legitimate relationship.

Record entities in the Summary Care Records are essentially a series of documents, which cannot be written to after sending. They can only be superseded or nullified. It is not yet clear who will have nullification rights but it is probable that this will turn out to be the authoring organisation only.
HealthSpace\(^8\) is a free, secure online personal health organiser designed to help patients to manage their health, store important health information securely, or find out about NHS services near to them. Crucially, HealthSpace also acts as a portal to the SCR, allowing patients to view the contents of their SCR and make decisions about information sharing. Anyone living in England aged 16 or over, with a valid email address can register for a HealthSpace account, though an advanced account is necessary to access the SCR.

### 3.3.2 Graphnet's Shared Care Record (Implemented)

Graphnet have implemented shared record systems in 10 – 20 health communities across the UK (they are represented in all four home countries) their first and best-known implementation is that in Hampshire and the Isle of Wight.

Each of Graphnet’s implementation is different, but all are based on a common approach and common XML technology which draws together data from existing systems to provide a shared view and can also include additional components to fill the gaps between existing systems.

The scope of Graphnet’s implementations cover primary care, community care, acute services and social care with different mixes of care settings in each community according to local requirements. Graphnet’s solution are able to provide a read-only shared view but can also be configured to write-back to source systems or maintain a shared repository, again according to local requirements.

Graphnet have promoted a consent model based on an implied consent to share (with opt out) and an explicit consent to view (with the option to give enduring or transient consent). Hospital and GP records for 1.5 million patients are available for the NHS to share in the South Central Strategic Health Authority.

The Clinical Data Repository (CDR) has records for 650,000 patients, nearly half a million hospital documents and 2,000 single assessment process (SAP) records already available to view. The CDR is accessible over NHSnet and is designed to be used by health professionals working in out-of-hours, accident and emergency departments, GP practices, hospital pharmacies and in the community. Eight out of ten out-of-hours services within the SHA have agreed to use it. Records are available for any staff treating patients to view, subject to password control and the explicit consent of the patient being treated. An audit trail identifies when patient records have been accessed and by whom and patients can ask for a copy of the audit trail.

### Scotland

### 3.3.3 The Emergency Care Summary (Implemented)

The Emergency Care Summary in Scotland is a nationally available information resource which contains details of a patient’s current medication as known to the GP, and the patient’s allergies. This information is available to OOH centres, NHS 24 and A+E departments. The consent model is implied consent to send with the ability to opt out and consent to view at the point of contact. The resource is about to be extended to include palliative care data collected under the gold standards framework. This information will be collected with a different consent model namely express consent to send and free access at point of legitimate contact.

\(^8\) Healthspace https://www.healthspace.nhs.uk/visitor/default.aspx
3.3.4 Tayside Shared Record
This is a system that allows users in both secondary care and primary care organisations to access a shared record. Access is by agreement and determined by a legitimate relationship. Those accessing the record may not write to it directly. Consent is implied. Individual items in the source record may be deemed sensitive.

Wales

3.3.5 CSW
Wales had awarded a national contract to CSW. CSW were placed into administration in November 2008 leaving the future of the Welsh Individual Health Record looking uncertain.

3.3.6 Graphnet
Graphnet has implemented a summary and out-of-hours record scheme for Gwent PCT.

London

3.3.7 London Programme for IT (Planned)
The London Programme for IT originally planned a shared detailed care record based on the IDX Carecast system which would have provided shared access across all care settings in London – This system was never implemented and IDX left the Programme in the autumn 2006. London plans are now based on the implementation of “Best of Breed” systems in each major care setting with documents created by these systems made available across care settings via a the “London Shared Patient Record”.

3.3.8 Care Setting Applications
The four care-setting systems chosen are:

- **Acute Care - Cerner Millennium.** This is being implemented such that it may allow shared access by more than one acute trust. However, sharing solely between acute trusts is out of scope of this project.
- **General Practice - INPS Vision.** Currently about 70 GP practices covering less than 10% of London GPs use the Local Service Provider (LSP) hosted version of Vision. The current implementation limits access to a practices own data and thus does not involve any direct sharing across organisational boundaries. There are no plans within the London Programme for IT to provide a version of Vision that would change this position. (We understand EMIS may also become involved).
- **Community Care – CSE Servalec RiO.** Currently 21 of London’s 30 community trusts use RiO. RiO is implemented as one database instance per trust and does not therefore directly allow sharing of data across organisational boundaries. However, the RiO record does support sharing of data between different professions and teams within a single trust.
- **Mental Health – CSE Servalec RiO.** Currently seven of London’s ten mental health trusts use RiO. RiO is implemented as one database instance per trust and does not therefore directly allow sharing of data across organisational boundaries. However, the RiP record does support sharing of data between different professions and teams within a single trust.

3.3.9 The London Shared Patient Record
The planed London Shared Patient Record (SPR) provides a store of documents created by care settings applications, which can be retrieved by those with an appropriate role and a legitimate relationship with the patient. Configuration determined by the London Programme
for IT determines which documents are stored in the SPR. This configuration is still being determined but documents stored are likely to include:

- GP summary
- Referrals
- Admissions
- Attendances at outpatients and A+E
- Outpatient reports
- Discharge notifications and reports
- Certain assessments
- Test results

Currently, while a patient can dissent to the viewing of stored documents they cannot dissent to their storage nor can an end user stop an instance of a document being stored on their behalf. However, this is likely to change to align arrangements in London with national agreements.

The SPR provides a stateless record such that a user can only determine the current state of a patient by reviewing all documents for that patient in the SPR. The SPR enables documents to be retrieved according to document metadata which will include information about document types, author and date, but will not allow retrieval by document content.

3.3.10 Other Shared Systems

In addition to these major systems there are two other specialist systems that share information on a Pan-London basis. These are:

- The Child Health Interim Application (CHIA) - which supports limited sharing of childhood vaccination and developmental screening.
- eSAP - this provides for the sharing of information to support the Single Assessment Process between health and social care organisations in London

3.3.11 The North, Midlands and East Programme for IT

The North, Midlands and East (NME) Programme for IT, plan to provide a single shared record based on iSoft's Lorenzo product. To date there is very limited implementation of Lorenzo. However, its declared ambition is that it will provide a single shared record for all users, across the whole of the NME regions. In addition the North, Midlands and East Programme for IT, have implemented The Phoenix Partnership (TPP) SystmOne product on a significant scale.

TPP SystmOne hosts its data on a central server. Access to that data is determined at logon by the organisational boundary supported by password/Smartcard. The records of any one organisation may be shared with another by agreement. Statements of preference by individual patients control sharing. Until that preference is set, the default status of the record is not to share.

If consent to share is given, then the record will be visible to all other organisations using SystmOne with whom the patient is registered. However, if any one such organisation deems its record to be sensitive it can prevent access to that record even if consent to share has been given elsewhere. In addition, individual events in the record can be set to be private and not shared outside the organisation. In either of the latter two cases, an entry is made in the record notifying users in other organisations that information is present that is not available to them. This entry does not specify the organisation that holds the sensitive information.
Any organisation with access to the record may both read and write to it. In addition, each record has a flag, which allows patient preference to be set for a Summary Care Record. If this flag is set to not share, then neither a Summary Care Record will be visible, nor will local sharing be permitted across different SystmOne legal entities/organisations. Furthermore, the new enhanced sharing model currently being rolled out also enables 'units' within those legal organisations to be set up as private—such as CASH (contraception and sexual health) services in a PCT so that a greater level of flexibility is now available.

### 3.3.12 EMIS/VISION/ADAstra Consortium (Implemented)

This a new service offered to their users by this supplier consortium. It effectively consists of a set of views to the source records mediated through EMIS Web. What is seen is determined by local agreement and made available to the end user according to that agreement which may include a locally configured dataset. Access is therefore by pre-agreed legitimate relationship. The consent model may also vary according to local agreement but is typically either implied consent with opt out or implied consent/opt out/consent to view.

Write access is not permitted except where care is truly shared (so that two organisations effectively become one) but individual record items may be shared across platforms by prior agreement (e.g. immunisations between community and general practice). The source for such shared items is preserved using globally unique identifiers to prevent duplication. Reporting across platforms is possible by prior agreement.

Although write access is not permitted, systems using this service will have the ability to use prescribing decision support based on the content of a remote record. Ownership/Authorship of information is retained by the source organisation.

Deployment is currently occurring in Liverpool, Tower Hamlets and York but is expected to spread much more widely over the next 2-3 years. The New Health Service for Liverpool strategy led to service redesign to provide patient services outside of the hospital setting. These services require health professionals delivering the service to have access to a summary of the patient’s medical history, which is held electronically at the GP practice and the ability to record clinical information, which the patient’s own GP can access. In order to deliver this, EMIS Web technology has been implemented into these services. Process mapping exercises are conducted with services as part of the overall service redesign agenda, this includes the assessment of information collected and the identification of what information needs to be shared.

In Gateshead, EMIS practices, community and OOH services have developed a series of access agreements (rather than a true shared record). Practices must sign up to participate and agree to upload of its data to the EMIS servers. When a patient of a participating practice presents to the OOH service there is an EMIS tab visible (not visible if not participating); clicking that tab brings up a prompt to enter that the patient has consented to view of the record (recorded) and the patient matching details then become visible. There is no facility to search for patients; the lookup is done from the demographics captured in the OOH system. The details are a truncated view of the EMIS Web record and no data entry is possible directly into the record.

In Practice Systems (INPS) has announced a new suite of interoperability products, which will be aimed at a wider primary care community and marketed under the ‘Vision 360’ name. The core of Vision 360 is a central data hub that utilises the Vision 4 database. This technology makes it possible to store complete records for an entire local health community such as a PCT or Health Board, and the new solution has been built with appropriate
security to accept data from current GP systems including EMIS and Vision 3, as well as future INPS solutions.

Initially INPS is providing a Patient Summary application that allows access by users such as community staff, A+E departments and OOH staff. The Vision 360 Data Hub is due to be piloted in Scotland in 2009.
Chapter 4 - Information governance

4.1 Legal framework

4.1.1 Introduction
The term Information Governance is used to describe the processes, which ensure the quality, security and appropriate use of information. It is concerned with the accuracy, accessibility, consistency, and completeness of information; mechanisms to manage the recording of information to maintain its provenance and ensure the attribution of authorship and changes; processes to ensure information is collected fairly, with informed consent as appropriate and used in a manner consistent with such consent as far as professional ethics and the law allows and mechanisms to protect access and ensure the security of information.

The National Information Governance Board (NIGB) has prime responsibility for supporting improvements to information governance practice in health and social care in England\(^9\). The NIGB takes the view that no system can have zero risk of loss of data through breakdown of security / confidentiality and that security has to be balanced with the risk of harm to patients due to either the difficulty of accessing records or restrictions in working practices; it is a matter of balancing risks and benefits. They recognise that it is human error, negligence or dishonesty, and not information management systems, which primarily put confidentiality at risk. Good practice supported by training is the foundation of good information governance.

Information Governance provides a framework for handling personal information in a confidential and secure manner to the ethical and quality standards that are appropriate in a modern health service. There are a number of tensions (such as the need to balance the requirement for communication between health professionals against a patient’s right to confidentiality), which render this a complex area, but it is not an area that health professionals can afford to neglect. Public concern about the handling of personal information by public sector bodies remains high and it is essential that robust assurance is provided by all NHS organisations.

4.1.2 Rationale
NHS organisations in general and primary care teams in particular are increasingly expected to work in close collaboration with other organisations both within and without the NHS family. It is expected that NHS organisations will endeavour to ensure that services delivered are appropriate to the needs of patients and of high quality. This implies that NHS organisations and other involved bodies should communicate all relevant information between themselves in order to ensure that services delivered are both consistent and fully compatible with patient needs. However, the delivery of services to patients must remain within the legal, ethical and policy framework. This framework needs to be understood by all those involved in sharing patient information.

4.1.3 Scope
Information governance encompasses the principles that apply to the processing and protection of information in whatever form it is processed or utilised. Inclusion of this topic in these guidelines should not obscure the fact that these principles apply equally to written records, oral communications and other media (e.g. photographs and x-rays).

\(^9\)National Information Governance Board http://www.connectingforhealth.nhs.uk/nigb
4.1.4 Legal aspects
Important elements of information governance for NHS bodies are derived from legislation and common law. Some of these elements are clear-cut but many others need interpretation. NHS service delivery requirements, an understanding of acceptable ethical practice and applicable Department of Health policy and standards will all impact on this interpretation. The relevant areas of law are listed below, with an indication of the implications of each.

4.1.5 Common law duty of confidence
The long established principle that health care professionals have a duty of confidence to their patients is supported by the common law (case law established by the Courts). Confidentiality may however be set aside in the public interest or where statute requires i.e. a range of bodies, including the Care Quality Commission, the Audit Commission and Primary Care Trusts that have statutory powers to require disclosure of confidential information.

Key attributes:
Confidential patient information may only be disclosed:
(i) With a patient’s consent, or
(ii) Where it is required by law (statutory instrument or Court Order), or permitted under S.251 of the NHS Act 2006 or
(iii) Where the public interest served by disclosure outweighs the public interest in protecting the right to confidentiality. Disclosures in the public interest must be considered on a case-by-case basis.

Key guidance:
• Confidentiality: NHS Code of Practice
• GMC Confidentiality: protecting and providing information

4.1.6 Computer Misuse Act 1990
The Computer Misuse Act identifies a range of offences relating to unauthorised access to or unauthorised modification of computer records. It may apply where an unauthorised third party accesses information being transferred.

Key attributes:
Where systems are used other than by authorised staff for approved purposes it is likely to be a criminal offence. It is important that all staff members are aware of and comply with a documented acceptable use policy and the security measures put in place to protect all health records.

Key guidance:
Department of Health guidelines
• Information Security Management: NHS Code of Practice
• NHS Information Governance – guidance on legal and professional obligations

4.1.7 Access to Health Records Act 1990
The Access to Health Records Act provides the personal representatives of the deceased or those who have a claim arising from the patient’s death to have access to the health

10http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550
11GMC | Confidentiality: Protecting and Providing Information
records of the deceased. The Act also allows individuals to add a note to their health record to negate this access right.

**Key attributes:**
Provides the personal representatives of the deceased or those who have a claim arising from the patient’s death to have access with a right of access to the health records of deceased patients.

**Key guidance:**
Department of Health guidelines
- The NHS Confidentiality Code of Practice\(^{15}\)
- Department of Health, patient confidentiality and access to health records\(^{16}\)
- NHS Information Governance – guidance on legal and professional obligations\(^{17}\)

### 4.1.8 Data Protection Act 1998 (DPA)

The DPA\(^8\) sets out eight principles to be followed when processing identifiable information about living individuals. The term ‘processing’ includes recording, storage, manipulation and transmission of information. The Act also identifies both the sensitive nature of health information and the particular needs of health professionals to communicate that information between themselves.

The Act provides patients with a right of access to their health records. The DPA applies to both electronic and paper-based record systems.

The eight principles are listed below.

**Schedule 1, Part I, paragraph 1 - The data protection principles**

1. Personal data shall be processed fairly and lawfully, and in particular shall not be processed unless—
   - (a) at least one of the conditions in Schedule 2 is met, and
   - (b) In the case of sensitive personal data, at least one of the conditions in Schedule 3 is also met.

2. Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.

3. Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.

4. Personal data shall be accurate and, where necessary, kept up to date.

5. Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes.

6. Personal data shall be processed in accordance with the rights of data subjects under this Act.

7. Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.

8. Personal data shall not be transferred to a country or territory outside the European

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\(^{15}\) http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550
\(^{16}\) www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicotGuardians/fs/en
\(^{17}\) www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616
Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

Other relevant sections of the DPA particularly relevant to the processing of health data are:

- Schedule 2, paragraphs 5(c) and (d) and 6 – personal data
- Schedule 3, paragraphs 7(1)(c), 8(1)(a) and (b), 8(2) and 10 – sensitive personal data

**Key attributes:**
The 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. 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.

**N.B. The common law duty of confidentiality must be satisfied in order for confidential information to be processed lawfully under principle one of the DPA.**

**Key guidance:**
- The NHS Confidentiality Code of Practice[^20]
- Department of Health guidance on patient confidentiality and access to health records[^21]
- NHS Information Governance – guidance on legal and professional obligations[^22]

4.1.9 **Human Rights Act 1998**
The Human Rights Act (HRA)[^23] incorporates the European Convention of Human Rights into UK law. The Act identifies 15 human rights in Schedule one and requires ‘public authorities’ to ensure that their activities do not violate these rights. GP Practices working within the NHS are public authorities under the HRA and are therefore required to observe the Convention rights in their decision-making, and demonstrate that they have done so.

**Key attributes:**
The Act provides a right to respect for privacy (article eight) that can only be set aside in accordance with the law when considered necessary in a democratic state. The advice from

[^19]: www.informationcommissioner.gov.uk
government is that this right is respected fully where the requirements of the Data Protection Act 1998 and the common law duty of confidence are complied with.

**Key guidance:**
- NHS Information Governance – guidance on legal and professional obligations

### 4.1.10 Freedom of Information Act 2000 (FOI)
The Freedom of Information Act\(^ \text{25} \) gives a general right of public access to information held by public authorities (including GP Practices). The Act also places a number of obligations on public authorities. There are a number of exemptions within the Act, which must be considered before supplying information requested.

**Key attributes:**
Whilst there are a number of exemptions, the main one that will apply in a primary care setting relates to confidential patient information. Requests have to be dealt with within 20 working days.

**Key guidance:**
- Freedom of Information Act – Freedom of Information Act\(^ \text{26} \)
- NHS Information Governance – guidance on legal and professional obligations\(^ \text{27} \)

### 4.1.11 The National Health Service Act 2006
Section 251 of the National Health Service Act 2006 (formerly known as section 60 of the Health and Social Care Act 2001), provides the power to ensure that patient identifiable information needed to support essential NHS activity can be used without the consent of patients. The power can only be used to support medical purposes that are in the interests of patients or the wider public, where consent is not a practicable alternative and where anonymised information will not suffice. In effect it sets aside the common law duty of confidentiality. The Secretary of State for Health is required to consult with the statutory National Information Governance Board before making any regulations under section 251.

**Key attributes:**
The power provided under s251 of the NHS Act 2006 can be used to provide exemption from the common law duty of confidence requirement for consent. It provides no exemption from the Data Protection Act 1998. To date these powers have not been used in a way that would override patient dissent and if this is implied it would be best to check.

**Key guidance:**
- Department of Health confidentiality website The NHS Confidentiality Code of Practice
- Department of Health, patient confidentiality and access to health records

### 4.1.12 Electronic Communications Act 2000
This Act\(^ \text{28} \) sets in place an approval scheme for businesses providing cryptography services, such as electronic signatures and confidentiality services and the processes under which

\(^ {24} \) www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616  
\(^ {26} \) www.informationcommissioner.gov.uk  
\(^ {27} \) www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616  
\(^ {28} \) http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550  
\(^ {29} \) www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/fs/en
electronic signatures are generated, communicated or verified. An NHS order made under the Act allows for the creation and transmission of prescriptions by electronic means in cases where specified conditions are met.

**Key attributes:**
An NHS order made under the Act allows for the creation and transmission of prescriptions by electronic means in cases where specified conditions are met.

**Key guidance:**
- NHS Information Governance – guidance on legal and professional obligations

### 4.1.13 The NHS (General Medical Services Contracts) Regulations 2004, the NHS (Personal Medical Services Agreements) Regulations 2004 and the APMS Directions

These Regulations, which came into force in support of the GP contract, provide Primary Care Trusts (PCTs) with the power to require patient, and other, information to be provided by practices where this is necessary in order for them to discharge their responsibilities.

**Key attributes:**
The Regulations provide PCTs with a right of access to patient records in an identifiable form for key purposes, without patient consent, where it is impracticable to anonymise the records.

**Key guidance:**
- Confidentiality and Disclosure of Information: General Medical Services (GMS), Personal Medical Services (PMS), and Alternative Provider Medical Services (APMS) Code of Practice 2005

### Other relevant publications

**4.1.14 Caldicott Report 1997**
The Caldicott review was commissioned to examine the ways in which information was used by the NHS. The report lists 6 principles to apply to indicate the appropriateness of a proposed communication. The report also carries 16 recommendations for changes in communication processes and practices employed by the NHS.

The recommendations focus on the adoption of a strict ‘need to know’ approach to the transmission of identifiable information and the establishment of an educational and supervisory framework to ensure its implementation.

Although much of the work recommended by the Caldicott Committee has been superseded by the NHS Information Governance initiative, the underlying Caldicott principles and the

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30 Electronic Communications Act 2000 Electronic Communications Act 2000 (c. 7)
32 S.I. 2004/291
33 S.I. 2004/627
34 The Alternative Provider Medical Services Directions 2004 dated 21st April 2004.
36 The Caldicott Report
requirement for senior clinical involvement in confidentiality management remain highly relevant.

4.1.15 Building the Information Core: A Confidentiality Strategy for the NHS
This document, published in December 2001, set out the Government’s strategic approach to managing the confidentiality of patient information. The key elements of this strategy now underpin the approach adopted by NHS CFH. The strategy called for the adoption of a broad based information governance approach, emphasised the importance now placed upon informed consent, advocated far greater reliance upon technology to secure data and proposed a major public awareness campaign.

4.1.16 Confidentiality: NHS Code of Practice
Published in November 2003 with the endorsement of the Information Commissioner, the BMA and the General Medical Council (GMC), this Department of Health publication established an agreed set of guidelines for the NHS. The Code of Practice sets out individual and organisational responsibilities in a clear and coherent way, covering both confidentiality and aspects of the Data Protection Act 1998. It includes a decision support tool for disclosure of patient information.

4.2 Governance issues particular to shared electronic health records

The PHCSG has identified a number of areas that require detailed examination and guidance that particularly relate to shared electronic health record systems. These are discussed below.

4.2.1 Data ownership and control
GPs act as data controllers with their patients the data subjects. Debates about ‘who owns the data’ occur when a party wants to gain access to information held in patient records and there is uncertainty or disagreement about what category of information should be provided, whether the enquirer has any right of access, whether patient safety and/or privacy is at risk, or whether patient consent is required. It is generally more important to resolve these issues than the question of ownership as such and important to remember that “ownership” does not give rights of access to or control over personal data.

Clinical responsibility for each aspect of current care should be clear in a shared record. This might be done by identifying responsibility against items in a problem list or care plan. Careful consideration also needs to be given to developing mechanisms which enable the transfer of such responsibility (these may differ between transfers within an organisation and transfers between organisations).

A community using a shared electronic health record needs to develop governance rules and processes that ensure the clear allocation of responsibility and define the rules and mechanisms by which responsibility can be transferred.

37 Building the Information Core A Confidentiality Strategy for the NHS
38 Confidentiality: NHS Code of Practice The NHS Confidentiality Code of Practice
4.2.2 Data quality
Maintaining good quality records that are complete, accurate and up-to-date requires significant effort both in their creation and ongoing maintenance. Those using records need education and training to understand the value in making this effort and to equip them with the skills to do so. In General Practice electronic records have been the norm in most practices for 15-20 years and there is a good understanding of the value of maintaining record quality, both in terms of the benefits to patient care and for the health of the practice as a business. There is considerable concern from general practice that a shift to shared electronic health records will result in the quality of the records on which they rely being significantly undermined by users with a poor understanding of the issues and little motivation to maintain record quality. The more people that have write access to a record, the more difficult it becomes to police compliance with good record keeping practice and to identify individuals with a clear responsibility for maintaining the quality of the entire record.

4.2.3 Data protection issues
Data protection legislation restricts the sharing of information between legal entities without the consent of the data subject and requires that a data controller is identified for each organisation who has the duty to ensure compliance with data protection legislation. 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 it or how it could be organised in practice.

When people use the NHS, they expect a confidential relationship with the members of the care team they see. But it may be misleading to discuss this relationship in isolation. Patients expect that a practice or NHS Trust will take corporate responsibility for their care and to collaborate with other organisations around a care pathway that provides a package of complementary elements managed to suit the patient's individual circumstances. This might also reasonably include regulators and others responsible for detecting unsafe or ineffectve practice. This creates a tension between the need to share health data for legitimate corporate reasons and preserving patient confidentiality (see also chapter 3.2).

Patients do not in practice expect everything to come to a stop (until they consent) at each step when a new individual has to take part in organising a package of high quality care. They want the high quality care. There is no contradiction in recognising that they also want an effective mechanism when some particular information is especially sensitive and they have a right to object to uses that could be harmful to them.

The DPA does make the bridge between the health professional's duty of confidentiality and the corporate duty to protect personal information which falls on the organisation. The reconciliation of clinical confidentiality with the corporate duty comes when:

- the uses are within the reasonable expectation of the patient, given what he/she has been told about the purposes necessary for the provision of appropriate care (the "legitimate interests of the data controller" in this case), and when
- the uses do not prejudice the rights and freedoms or legitimate interests of the patient; and when

• the care record can be viewed so that particular people use the parts of it they need for their role, and the staff or others who use the information for these purposes are bound to keep it confidential.

The care team is not an entity recognised by legislation. Anyone who uses sensitive information for medical purposes has to be under a suitable duty of confidence. That is one of the conditions that apply to the corporate responsibility of a data controller using personal information relating to a person's "physical or mental health or condition".

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.

The Care Record Guarantee, published by the NIGB\(^41\) underpins the relationship between patients and those who will have access to their NHS Care Records.

4.3 Records and record keeping – guidance from health professional bodies

4.3.1 Doctors
The General Medical Council’s\(^42\) (GMC) Good Medical Practice guidance for doctors\(^43\) makes it clear that patients have a right to expect that their doctors will hold information about them in confidence. Confidentiality is central to the trust between patients and doctors, without which patients may be reluctant to seek medical care or to disclose information needed to support their care. But appropriate information sharing is essential to the efficient provision of safe, effective care, both for the individual patient and to the wider population of patients\(^44\).

The GMC requires doctors to make information available to patients about disclosures of their personal information for purposes of their own care. In the absence of any objection, patients’ consent to information being shared in this way may be implied. But it is not always clear to patients that others who support the provision of care might also need access to their personal information. Patients may not be aware of disclosures to others for purposes such as health service planning or research and must be informed about disclosures for purposes they would not reasonably expect. Doctors must obtain patients’ express consent to disclosure of identifiable information for purposes other than the provision of care, unless the disclosure is required by law or justified in the public interest.

Doctors must make sure that any personal information about patients that they hold or control is effectively protected against improper disclosure at all times. Where doctors are responsible for the management of patient records or other patient information, they must ensure that it is held securely. Doctors should use their professional expertise in the selection and development of systems to record, access and send electronic data. However, doctors are not generally expected to assess the security standards of large-scale computer systems, provided for their use by the NHS or other health service providers, but

\(^41\) Care Record Guarantee www.connectingforhealth.nhs.uk/news/crdb_guarantee
\(^42\) http://www.gmc-uk.org/
\(^44\) General Medical Council Confidentiality Guidance – draft v5.5 (2008)
are expected to understand and adhere to corporate information governance and confidentiality policies.

Patients may give implied consent to disclosure of personal information when sharing information in the healthcare team or with others providing care. Most people understand and accept that information must be shared within a healthcare team to provide care. Doctors should make information readily available to patients explaining that their personal information will be shared within the healthcare team including administrative and other staff who support the provision of care, unless they object. This information can be provided in leaflets, posters and websites as well as face-to-face. Doctors must respect the wishes of any patient who objects to particular information being shared with others providing care, except where disclosure is in the public interest. Doctors must ensure that anyone to whom they disclose personal information understands that it is provided in confidence, which they must respect.

As a general rule, doctors should seek patients’ express consent for the disclosure of identifiable information for purposes other than the provision of care or local clinical audit.

4.3.2 Nurses

The Nursing and Midwifery Council\textsuperscript{45} (NMC) \textit{Guidelines for records and record keeping}\textsuperscript{46} (advice sheet) supports the principle of shared records in which all members of the healthcare team involved in the care and treatment of an individual, make entries in a single record and in accordance with an agreed local protocol. However, the ability to obtain information whilst respecting patient and client confidentiality is regarded as essential. The NMC also emphasises the professional duty of confidentiality to the patient and states that information from health records should only be released with the consent of the patient.

The NMC gives specific guidance for computerised patient records stating that nurses are professionally accountable for making sure that whatever system is used is fully secure. Clear local protocols should be drawn up to specify which staff have access to computer-held records. Although patients and clients can expect their health records to be accessed by different members of the inter-professional health care team, this should only be done where necessary.

The NMC advises that patients and clients do not have the right to limit the amount of information relevant to their care or condition that is incorporated in their records. However, patients/clients can limit access to certain information about themselves and nursing professionals must respect their right to do so.

The Royal College of Nursing’s\textsuperscript{47} (RCN) e-health programme has produced detailed guidance on consent to access, share and create e-health records\textsuperscript{48}. The RCN emphasise the need to ensure that there is informed patient consent to the creation of an electronic patient record and to the sharing and storage of information in this form. In general, patients and clients should be informed of:

- The kinds of information being recorded and retained
- The purposes for which the information is being recorded and retained

\begin{footnotesize}
\begin{itemize}
\item http://www.nmc-uk.org/
\item http://www.rcn.org.uk/
\item Royal College of Nursing, e-health programme. Policy briefing 09/2008. E-health and nursing practice: Consent to access share and create e-health records.
\end{itemize}
\end{footnotesize}
• What protections are in place to ensure non-disclosure of their information
• What kinds of information sharing will usually occur
• The choices available to them about how their information may be used and disclosed
• Their rights to access and where necessary to correct the information held about them on paper based and paper-less records

The key issues for nurses to consider are:

• Patient consent to inclusion of their data in an electronic record
• Who can have access to a patient’s electronic record
• Sharing a patient’s record with others
• Using aggregated data for management and planning (secondary usage)

The RCN state that access by health professionals to electronic patient records should be very strictly controlled on a “need to know” basis. This means that some people can have access to the full record, others to the part that is relevant to them. However, The RCN also states that sharing information about patients is an integral part of nursing and multi-disciplinary care: no one person can provide all the care required all of the time, and communication of relevant information to other carers is essential for patient safety and continuity of care.

4.3.3 Allied Health Professionals
The Health Professions Council’s\(^49\) (HPC) publication \textit{Standards of conduct, performance and ethics}\(^50\) (2008) states that registrants must treat information about service users as confidential and use it only for the purposes they have provided it for. Registrants must not knowingly release any personal or confidential information to anyone who is not entitled to it, and should check that people who ask for information are entitled to it. The need to keep proper records is a professional requirement and records must be protected from being lost, damaged or accessed by someone without appropriate authority. The HPC reiterate this in their \textit{Standards of Proficiency for Physiotherapists}\(^51\), which states that physiotherapists must be able to understand the importance of and be able to maintain confidentiality (1a.3) and informed consent (1a.4).

These standards are echoed in the more specific standards and guidance produced by the various Allied Health Professional (AHP) organisations. Examples are given below.

The Chartered Society of Physiotherapists\(^52\) (CSP) \textit{Core Standards of Physiotherapy Practice} (2005)\(^53\). Standard three states that information that the patient gives to the physiotherapist should be treated in strictest confidence. Information from the physiotherapy record may be shared with other healthcare workers when it is for the benefit of the patient and after discussion with the patient. Physiotherapists have a duty to ensure that steps are taken to protect the confidentiality of identifiable patient information stored or transmitted in electronic formats. Standard 13 requires physiotherapists to contribute to multi-professional records where they are used and that any electronic communication is secure and confidential.

The College of Occupational Therapists\(^54\) (COT) \textit{Record Keeping Guidance}\(^55\) uses the

\(^{49}\) http://www.hpc-uk.org/
\(^{50}\) http://www.hpc-uk.org/publications/standards/index.asp?id=38
\(^{51}\) HPC Standards of Proficiency for Physiotherapists
\(^{52}\) http://www.csp.org.uk/
\(^{53}\) The Chartered Society of Physiotherapists – Core Standards of Physiotherapy Practice (2005)
\(^{54}\) http://www.cot.co.uk/
specific term "care records" and describes their purpose, scope and content for occupational therapists. The COT guidance supports the sharing of care records in multidisciplinary health care settings to support collaborative working. The guidance has a detailed section on the handling and management of care records with due respect for their service users' confidentiality, consent, right to access and overall best interests, highlighting the common law duty of non-disclosure without consent except in certain specified circumstances. There is very detailed guidance on transferring patient information to another professional or agency which states that it is good practice to always inform the service user of the purpose of the data being collected or held and the people who may have access to the information. Only those involved directly in a person’s care should have access to the data. If information is to be shared, the service user’s informed consent should be sought. The information shared should only be the minimum that is needed for appropriate care to be given or continued.

The British Psychological Society (BPS)\textsuperscript{56} in their publication \textit{Record Keeping: Guidance on Good Practice}\textsuperscript{57} has begun to consider and address the issues of shared electronic records. The BPS guidance contains useful advice on discussing confidentiality with clients, particularly in the context of effective care and communications. “\textit{Ensure from the first contact that clients are aware of the limitations of maintaining confidentiality, with specific reference to: (a) potentially conflicting or supervening legal and ethical obligations; (b) the likelihood that consultation with colleagues may occur in order to enhance the effectiveness of service provision; and (c) the possibility that third parties, such as translators or family members, may assist in ensuring that the activity concerned is not compromised by a lack of communication.}”

\textbf{4.3.4 Summary of guidance}

Trust is central to the delivery of healthcare. Patients expect information about their health to be treated as confidential and only shared as far as is necessary for the administration and delivery of their care and for such other purposes for which they have specifically consented. Healthcare professionals need to be able to explain to patients how their data will be used, shared and protected and need to be confident that promises they make will be respected by the systems they use and the governance arrangements that control them. If this trust breaks down, the result is likely to be an increasing reluctance by patients to share sensitive data and by healthcare professionals to record it, with consequent clinical risk.

The emphasis throughout the guidance is on appropriate sharing of health information between health professionals with specific consideration given to the requirements for children and vulnerable adults.

\textbf{Overall, the guidance from professional regulatory and representative bodies clearly supports the sharing of appropriate health information between health professionals for the process of clinical care and audit. However, there is also a consistent emphasis on obtaining appropriate consent and informing patients how their health data may be used.}

\textsuperscript{56}http://www.bps.org.uk/
\textsuperscript{57}The British Psychological Society (Division of Clinical Psychology). Record Keeping: Guidance on Good Practice. Dr Sarah Newton (2008)
4.4 Consent

4.4.1 Consent and confidentiality
Informed consent transactions are typically used to waive important ethical, legal and other requirements in limited ways in particular contexts and for specific purposes. The duty of confidentiality seeks to regulate types of action (e.g. communication or disclosure) rather than the processing of types of data and is a way of protecting the content of many types of communications that can only be waived by seeking consent from the patient.

4.4.2 Consent and the NCRS
The issue of consent has proved controversial for the NHS CRS particularly in relation to patient Summary Care Records (SCRs) being uploaded to the Spine (PSIS) on an implied consent basis and the possible implications for the confidential relationship between patient and health professional. The SCR consent model has now been modified to include a “consent to view” option, following the recommendations of the SCR evaluation report and NHS CFH may in future apply this model to detailed care records, providing NHS CFH are able to identify a model that can respond well across care settings and timescales without having the potential to disrupt or put up barriers to current workflows.

4.4.3 Consent and the sDCR
SEPR/sDCR records are derived from the detailed care records of those patients attending particular healthcare organisations and requiring some form of healthcare. These patients are likely to be actively receiving services from one or more healthcare organisations and it may be that such patient’s could benefit from having a sDCR to facilitate communication between those organisations providing care and the patient.

Patients will generally expect to have a health record kept by each organisation they attend and it is a professional requirement that such records are made. Accessing local (organisational) health records is generally on an implied consent basis. Patents may understand that personal health information will be shared (communicated) between different healthcare professional groups and organisations to facilitate that patient’s care. Accessing communicated information such as referral letters, reports and laboratory tests is also usually done on an implied consent basis. Most of the “rules” governing such professional behaviours have developed through custom and practice within a national legal, ethical and moral framework.

4.4.4 Consent, confidentiality and trust
Trust underpins the confidential relationship between patients and health professionals and cannot be replaced by other systems of accountability, including electronic systems. Deciding what information might and might not be disclosed in a sDCR depends fundamentally on the human relationships between patients and their health professionals.

*We do not believe that the content of the sDCR can be decided by computer algorithm, such decisions depend on context, content and consent given or refused.*

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60 UCL SCR Independent Evaluation http://www.ucl.ac.uk/openlearning/research.htm
Chapter 5 - Shared patient records - the literature review

5.1. Introduction to the literature review and its context within the report

Aim, objectives and scope of review:
The literature review was carried out to inform the draft records guidance, the consultation process and the design of the stakeholder survey. The aim of the review was to identify, classify and synthesise as much of the relevant evidence, guidance and other material as possible within the time period. The scope of the review encompasses issues arising from the management and governance of shared patient records. Specifically, the following criteria were applied:

- **Type of sharing**: sharing of records across more than one professional group or outside the boundaries of a single organisation such as a general practice.
- **Type of clinical staff**: those who currently have the ability, or potential, to read or add data to patient records.
- **Type of records**: Any clinical record used as prime data entry. We have also included some studies on record summaries. Most of the documents reviewed relate to electronic health records. However, these aspects of paper records were included – Benefits of sharing, preserving privacy, semantics across professions and data quality. Patient held records and patient access to records were excluded.
- **Type of data**: Any general practice patient record data, hospital patient data, laboratory data etc.
- **Activities using patient data**: General practice and hospital based clinical care including referrals, investigations and treatment. We have excluded from this review issues relating to sharing patient records for social care and most issues around their use for research.
- **Types of documents reviewed**: We discuss the above issues informed by empirical studies carried out in any country and documents describing UK legislation and published professional guidelines. Some opinion pieces were also included. All material was critically appraised on its own merits so both published and “grey” materials are included.

We therefore focused on identifying and reviewing material from a wide variety of published and unpublished sources relevant to the key topics that arise in the context of changing from records held within a single primary care organisation to records held and shared across professional and organisational boundaries. These topics were initially identified after a preliminary screen of the literature on shared records and later revised. The final list of topics identified and reviewed is shown in Table 5.1:

<table>
<thead>
<tr>
<th>Table 5.1 - Topics covered in the literature review</th>
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<tbody>
<tr>
<td>1. The benefits of data and record sharing</td>
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<td>2. The rationale for and methods for preserving privacy</td>
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<td>3. Getting and managing permission to access data in the shared electronic patient record</td>
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<td>4. The organisation and labelling of data items in the record</td>
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<td>5. The meaning, interpretation and semantics of data across professions and organisations: data entry, coding, import and translation</td>
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<td>6. Responding to significant data in the shared electronic patient record</td>
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</table>
This approach to scoping the review means that material on more generic health records matters that are not affected by the introduction of shared records (such as how to enter data, how to structure and code it for computer processing or ensuring its availability when and where needed e.g. data security and backup) has been excluded.

Most of the topics we have reviewed are based on electronic health records. However, some topics related to issues, which were common to both paper and electronic records. We have included paper records in these topics to support the evidence gathered from electronic records. These topics include: benefits of sharing, preserving privacy, semantics across professions and data quality.

5.2. Description of literature review method and analysis

We adopted the meta-narrative review approach of Greenhalgh et al, modified\textsuperscript{62} for the limited time and resources available and the large volume of the literature, as shown in Figure 5.2

Figure 5.2 - Outline of the process used to carry out the literature review

In summary, the review stages were:

1. Clarify the types of document needed and scope of the review with RCGP group
2. Solicit relevant material from contacts including members of the project team

3. Search relevant databases using a variety of relevant text strings (Appendix 6.1)
4. Carry out a preliminary assessment of relevance all documents from the abstract
5. Enter relevant document details into the database
6. Gain an overview of the topics that arise in shifting from single to cross organisational shared records
7. Carry out further literature searches as necessary
8. Order full copy of document
9. Carry out detailed assessment of eligibility and simple critical appraisal using a checklist (Appendix 6.2)
10. Identify further documents likely to be relevant from references of eligible documents, go back to stage 7
11. Classify the documents under the topic headings, synthesise the insights under these headings: evidence, guidance, legal, other
12. Circulate working papers for each topic to relevant project team members
13. Revise working papers
14. Summarise the main issues arising under each topic in this chapter

### Table 5.2 - Databases searched

<table>
<thead>
<tr>
<th>Database (time period and host publisher/version)</th>
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</thead>
<tbody>
<tr>
<td>HMIC (1983 to August 2008) (hosted via NLH 2.0)</td>
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<tr>
<td>Health Business Elite (hosted via NLH 2.0)</td>
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<tr>
<td>Medline (1950 to August 2008) (hosted via NLH 2.0)</td>
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<tr>
<td>CINAHL (1981 to August 2008) (hosted via NLH 2.0)</td>
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<tr>
<td>BNI (1985 to August 2008) (hosted via NLH 2.0)</td>
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<tr>
<td>AMED (1985 to August 2008) (hosted via NLH 2.0)</td>
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<tr>
<td>Embase (1980 to August 2008) (hosted via NLH 2.0)</td>
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<tr>
<td>PsycInfo (1806 to August 2008) (hosted via NLH 2.0)</td>
<td></td>
</tr>
<tr>
<td>The Cochrane Library (via <a href="http://www.library.nhs.uk">www.library.nhs.uk</a>) (1800-2005)</td>
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</table>

The review process was iterative to some extent, with search strategies evolving during the review process to capture new interpretations of the topics as they became apparent. Citation searches were also carried out when we became aware of certain classic articles or articles by well known authors. In addition, one topic that did not arise during the initial overview was added (The knowledge and training needs of professionals with respect to shared records) and two topics (data security and secondary data uses) that appeared relevant during the initial overview were later deleted as they were not related to the shift to shared records.

### 5.3. Literature review results

#### 5.3.1 Summary of the results of searching and critical appraisal

The literature searches yielded 5369 documents from a wide variety of sources of which 936 were selected after removal of duplicates and review of Medical Subject Heading (MeSH) terms. After initial screening of abstract for relevance, we entered 587 (63%) onto the master database. After excluding documents describing patient access to records we obtained copies of 450 of these during the project timeframe. Following critical appraisal by either SS or MP, 256 documents (43.6% of the initial 587) were considered relevant and of sufficient quality to enter the synthesis process. The documents were then mapped according to the topics listed below by MP and SS.
In terms of the document type and origin, 116 (45% of the appraised documents) were journal articles, 50 (20%) were publications from government or professional bodies (e.g. policy documents, guidelines or codes of practice) and 90 (35%) were other kinds of documents (book chapter, conference papers etc.). The topics were summarised with more weight given to evidence and to government/other professional publications than, for example, to technical documents.

5.4 The benefits of data and record sharing

5.4.1 Definition and scope of the issue and main findings
It is important to weigh up the benefits of shared records versus the risks and extra issues that arise when such records are implemented. Thus, the first part of our review focused on identifying the potential and actual benefits to patients, professionals and health care organisations of any kind of electronic patient record (EPR), aiming to concentrate on benefits due to the exchange of information between different health care professionals or organisations such as would occur in shared records.

We conclude that documented improvements due to implementation of SEPR systems in clinical performance are not impressive and unintended adverse consequences have been reported. When they do occur, 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.

Greenhalgh has suggested that, if a NHS CFH programme were to be evaluated in terms of the numbers of lives saved, adverse reactions averted, duplicate tests avoided or patients empowered per pound invested it might risk being tagged a failure. Measures of success need to be developed organically alongside the operational characteristics of each programme, allowing evaluation in a wider context. In the case of shared records, such measures probably need to include:

- The amount of data sharing between professionals / organisations for treatment of patients
- Patient opinion about the benefits of data sharing
- The benefits of sharing data with patients or patient consent about sharing

5.4.2 Synthesis, key disagreements, gaps in knowledge
Health policy has embraced the concept of “shared care” and sharing information with colleagues is an important aspect of general practice. The potential benefits of sharing information electronically are enormous but, without adequate safeguards, so is the potential

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for misuse and errors\textsuperscript{67,68}. It has been argued that information security is greater with electronic than with paper records because tighter control can be implemented than for paper records and audit trails make it possible to know exactly who has accessed the record, when\textsuperscript{69,70}.

While it is usually accepted that electronic clinical information systems are needed, documented improvements in performance are not impressive and unintended adverse consequences have been reported\textsuperscript{67}. Up to 2000, the literature had not demonstrated that positive effects in the quality of care can be explained by electronic communication\textsuperscript{71}. By 2006 there was evidence to support the contribution of computerised patient records to the quality of care and patient safety, facilitating work flow, decreasing medical errors and reducing costs, and improving communication among physicians. There was evidence of positive impacts of EPRs on preventive care, but improvements in medical practice and better adherence to guidelines are less certain. EPRs could decrease prescription errors, although many of these studies have produced inconclusive results. So, while health professionals acknowledge the value of EPRs in improving the quality of care, the results on clinical performance or patient outcomes are not always conclusive\textsuperscript{72}. Key factors in realising the benefits are: commitment and involvement of all stakeholders, strong leadership, looking at benefits from a range of perspectives, organisational change and a long-term perspective\textsuperscript{63}.

Quality improvement and error reduction are two of the justifications for healthcare IT. Paradoxically, evaluations also show situations where they have caused errors. If practice workflow does not adapt to reflect information system constraints and vice versa, new cognitive and communication errors can occur (e.g. entering orders for the wrong patient when interrupted, picking the wrong item from a list when similar items are close together, losing track of the overview of the patient because of data fragmentation and excessive detail, not recognising when data entry does not result in effective communication)\textsuperscript{67}.

People are in general positive about the use of electronic health records, with 99.5% of patients in one study seeing it as a positive element of practice\textsuperscript{73}.

According to Berger (2002) the benefits of sharing electronic records are patient-focused care, quality improvement, cost-effective care and system development\textsuperscript{69}. Improving safety was one of the early justifications for healthcare IT. It is argued that by supplying information when and where needed, by eliminating communication and process errors, and by reducing the cognitive burden on the medical team, fewer errors in treatment will be made\textsuperscript{67}.

The benefits identified in the literature are listed below under the headings: more patient focused care, care quality improvement, organisational ability to carry out quality improvement, cost effectiveness, patient safety and accessibility to health care.

\textsuperscript{67} Stead WW. Rethinking electronic health records to better achieve quality and safety goals. Annu Rev Med 2007;58:35-47.
5.4.3 More patient-focused, integrated care

Documented benefits include:

- Improved physician familiarity with the patient\(^{72}\) (and conversely, greater appreciation of physicians\(^{71}\))
- Consultations judged more satisfactory and effective\(^{72}\)
- Improved discharge planning\(^{70}\). Evaluation with GPs and domiciliary agents showed highly positive attitudes to faxed discharge summaries\(^{74}\)
- Increased openness and involvement in children’s care\(^{75}\)
- Patients do not need to keep answering the same questions to different health professionals\(^{68 76 77}\)
- Continuity of care after a disaster e.g. Hurricane Katrina\(^{78}\)
- Dispassionate information, even when the patient is unable to give a credible account of themselves\(^{76}\)

Integrated care pathways are used to support a multidisciplinary activity such as managing a patient admitted for hip replacement. They consist of a problem specific checklist on which data are recorded directly and other material, such as a scoring scale (eg. Barthel index), reminders to carry out relevant actions (eg. prescribe prophylactic antibiotics) and space to record reasons why actions were not done. Integrated care pathways obviously include more than just a shared record, but experts suggest that the lack of a shared electronic patient record could be a significant barrier to more integrated care\(^{79 80}\). A systematic review on the effects of integrated care pathways found a decrease in hospital cost for patients and a decrease in their length of stay\(^{81}\). However another systematic review on in-hospital care pathways for stroke found lower quality of life scores and patient satisfaction\(^{82}\). The authors concluded that there was evidence of advantages of a care pathway over standard medical care in terms of major clinical outcomes.

5.4.4 Care quality improvement

The use of electronic patient records in all settings and good communication will form the vehicle for quality assurance across all sectors of the health service\(^{83}\).


\(^{78}\) Layman EJ. Ethical issues and the electronic health record. Health Care Manag (Frederick) 2008;27(2):165-76.


\(^{82}\) Kwan J, Sandercock P. In-Hospital Care Pathways for Stroke - An updated systematic review. Stroke 2004;36:1348-1349

Although there are few rigorous impact studies such as randomised trials, documented increases in the quality of care associated with EPR\textsuperscript{71, 72, 76, 84, 85} include:

- Improvements to the integration of services, and medical care\textsuperscript{86}
- Physicians reported improved knowledge of patient’s medical history, better medical examination and improvement in quality of care\textsuperscript{87}
- 12 studies on the impact of EPR on medical practice and on guideline compliance showed that positive experiences were as frequent as experiences showing no benefit\textsuperscript{87}
- Nurses reported increased access to care protocols\textsuperscript{87}
- EPR enabled instant referral to other health professionals\textsuperscript{88}
- Patient follow-up was more systematic\textsuperscript{88}
- Quality should improve following introduction of EPR by reducing the cognitive and communication burden on the medical team\textsuperscript{87}
- In three studies there was a positive impact of electronic records on preventive care\textsuperscript{63, 72, 87}
- In two studies there was a benefit in terms of clinical performance\textsuperscript{72, 89}

Studies in which the EPR has been associated with increased record accuracy / better decisions include:

- Increased accessibility of patient data\textsuperscript{63, 72, 74, 78, 90, 91}
- Better legibility of patient data\textsuperscript{74, 78}
- Increased accuracy of patient records\textsuperscript{91}
- Better information\textsuperscript{68}
- Improved documentation\textsuperscript{85}
- Comprehensiveness of the decisions made by physicians\textsuperscript{72}
- Improved data quality, data variability and thus improved decision making\textsuperscript{92}
- Better informed doctors making better decisions\textsuperscript{63, 67}
- Audits of the quality of information in the discharge summary demonstrated that 95% of summaries in 2001 and 90% in 2002 were adequate with respect to the required clinical parameters (diagnosis, ancillary problems, procedures/investigations, inpatient management, post-discharge instructions and discharge medication)\textsuperscript{74}
- Helping physicians make better decisions more quickly\textsuperscript{93}


\textsuperscript{86} Smit M, McAllister M, Slonim J. Building Public Trust for Electronic Health Records: Dalhousie University, 2005.


\textsuperscript{88} Salford Royal Hospitals NHS Trust’s Electronic Patient Record (EPR) Project, 2005.

\textsuperscript{89} Dodds SR. Shared Community-Hospital Care of Leg Ulcers Using an Electronic Record and Telemedicine The International Journal of Lower Extremity Wounds 2002;1(4):260-270


\textsuperscript{92} Byrne E, Kalra, D., Stramer, K., Greenhalgh, T. Data Quality Evaluation for the Summary Care Record
• Quality is paradoxically worsened when patients fail to provide full information, for example if they doubt the privacy and security of their electronic health records.
• Improved content of the records; better patient records, easier access to test results and nursing documentation.
• Timeliness, effectiveness, efficiency of treatments offered.
• Supporting the diagnostic and therapeutic processes.
• Allows the use of decision support systems which analyse information about the patient in combination with biomedical knowledge to make patient-specific recommendations.

EPR has also been associated with improved communication on medical issues— but less than expected. For example:
• Community and hospital components of team worked more effectively.
• More rapid speed of communication.
• Allowed change of processes e.g. direct communication between GP and hospital.
• However, just making information available doesn’t necessarily improve communication.

The impact of EPRs on patient outcomes has rarely been rigorously studied. The following studies are relevant:

• Healing rates of leg ulcers at 12 and 24 weeks were 100%; in this study, follow up visits to hospital also decreased.
• In one systematic review, none of the six studies (2000-2003) analysing the impact of EPR on patient outcomes reported any useful benefits. The only measurable improvement was a reduction of 2.3-mmHg diastolic blood pressure in one study, which is of questionable clinical significance.

Other probable benefits of EPR include:

• Better informed patients and carers.
• Facilitates research into new care processes and treatment.
• Makes life easier for the professional.
• Improves workflow.

5.4.5 Enhancing the organisation’s ability to implement continuous quality improvement
EPR can improve an organisation’s capacity to improve quality by:

• Highlighting problems with data quality and variability.
• Supporting continuous audit of outcomes.
• Allowing re-use of information, e.g. a system used to check the insurance status of the patient. However, data can only be re-used if it is accurate and complete.

5.4.6 Cost-effectiveness of care
EPR can be associated with improved efficiency in the following ways:

• Reduced duplication of tests, visits, procedures.

• Increased efficiency of care\textsuperscript{63 76 78 94}
• More efficient administration\textsuperscript{63}
• Time saved for health professionals\textsuperscript{63}. However, there is good systematic review evidence that nurses are more likely to gain time efficiencies, while there is usually a time penalty for physicians\textsuperscript{72 87}. This is discussed later in section 5.12.5.1
• Divisions using bedside data input decreased the length of time for the end of shift report or abolished the report, and decreased the end of shift meeting duration\textsuperscript{95}
• Reduced waiting times for patient registration and retrieval of health records at the point of care\textsuperscript{96}
• In a paediatric intensive care unit, a computerised documentation system resulted in more legible, complete and accessible patient records without affecting the time spent in direct patient care. In an urban paediatric primary care setting an electronic health record improved the documentation of an interim health history, risk assessment, developmental screening, and physical examination and guidance topics\textsuperscript{78}
• EPR improves efficiency by connecting information across health care transitions and eliminating unnecessary care steps and reworking\textsuperscript{67}

EPR can also reduce the costs of health care activity\textsuperscript{63 71 72 78 86}. For example, in an informal analysis, all 10 case studies examined by consultants employed on an EU wide project showed a positive economic impact, however the range of benefits is very wide. Annual benefits exceeded annual costs on average by year four. Citizens and Health Provider Organisations were the two main beneficiaries. Neither ICT applications nor information by itself brought these benefits as the gains came from changes in processes or working practices associated with the introduction of electronic shared records. The change can also be in the form of faster or otherwise improved execution of familiar procedures\textsuperscript{63}.

A somewhat cynical view of the role of cost containment in the implementation of EPR is expressed by Terry 2004: “The idealist might conclude that the world’s health care delivery systems’ commitment to technology has been driven by a shift in health care policy designed to improve and increase patient access to services. Particularly in the US, however, the adoption of IT has been driven by business concerns, including the imperatives of reducing transaction costs and minimising expensive medical errors.”\textsuperscript{65w}

5.4.7 Patient safety
In theory, safety should improve by reducing the cognitive and communication burden on the medical team\textsuperscript{67}. EPRs could improve safety by supplying information when and where it is needed to help people make better decisions, by eliminating communication and process errors, and by analysing information about the patient in combination with biomedical knowledge to make patient-specific recommendations\textsuperscript{67}. They can also give health professionals an improved overview of the state of the patient\textsuperscript{84}. EPR allows systems to check on contra-indications and drug allergies or intolerance\textsuperscript{84}. ICT in general (EPRs, decision support, computerised physician order entry, adverse event systems, incident reporting) can help prevent medical errors and adverse events, initiate rapid responses to any event and can track events if they occur and provide feedback. Hospital/community information exchange has been advocated as a strategic priority to reduce adverse outcomes on discharge\textsuperscript{74}.

\textsuperscript{95} Kurihara Y, Asai N, Ishimoto R, Kawamata S, Nakamura S. A Survey of the Effects of the full Computerized Nursing Records System on Sharing Nursing Records among Health Professionals. The 12th World Congress on Health (Medical) Informatics Brisbane, Australia, August 2007.
These predictions are borne out in practice, in terms of reduction in error rates\textsuperscript{63 68 70 72 85 86}. Multiple studies support the conclusions that ICT systems can lead to considerable benefits in patient safety\textsuperscript{84}.

However, not all EPR and decision support systems are safe and, worryingly, GPs have a poor knowledge of the safety features of computer aided prescribing systems. This sometimes leads them to assume that their system will pick up safety issues even when it is not programmed to do so\textsuperscript{97}.

5.4.8 Accessibility of health care to patients and the public
A powerful illustration of the impact of access to health information occurred after Hurricane Katrina in the US when data on thousands of patients was available within a few days of the disaster. This connectivity supported continuity of care and access to care\textsuperscript{76}. In general, it appears that electronic records enable the delivery of care to remote locations\textsuperscript{94}. Other documented benefits in terms of access include:

- Convenience / flexibility in the delivery of services to citizens\textsuperscript{63}
- Increased availability of advice\textsuperscript{63}
- Easier for ethnic minorities to access GP services\textsuperscript{76}
- EPR helps close the gap between geographically dispersed providers, physicians and patients\textsuperscript{83}

Hence, there are numerous benefits of sharing patient data electronically across health organisations and professionals, with varying levels of evidence supporting these. But there are also possible concerns and harms which could arise while sharing patient records. Some of the main concerns are discussed in the following sections.

5.5 The rational for and methods for preserving privacy
5.5.1 Definition and scope of the topic
There is a great deal of literature on privacy and electronic patient records. However, for this review we have focused on the main issue that arises when considering shared records: the dilemma of a health professional using a shared record over whom else has access to that record, what data their access rights allow them to see and therefore what data to mention in discussion with another health professional.

The next topic, getting and managing permission to view the record, is closely related to this topic.

5.5.2 Problem scenario
When a single health professional has complete control of a patient record, they know exactly what others know and can confidently discuss a complex problem with them, as they are responsible for either sharing the entire record or preparing an extract of relevant data for the second health professional. However, if two health professionals have access to a shared record, it is hard for one of them to know reliably what data in the record can be seen by another health professional. For example, in a patient with recurrent Urinary Tract Infections (UTI) and a Sexually Transmitted Disease (STD), an STD clinic nurse may not know exactly how much the patient’s General Practitioner (GP) knows about that patient’s STD, as this part of the record will usually not be accessible to the GP. This type of

‘asymmetric sharing’ can lead to confusion and difficulty in multi-disciplinary discussions and decision-making. The diagram below illustrates the problem.

**Figure 5.5.2 - Problem scenario**

![Diagram showing the problem scenario]

5.5.3 Key issues raised in this topic

- Who gets access to which data in the shared record?
- Who knows which other record users can get access to?
- Under what circumstances is it necessary for one health professional to notify a second health professional that there is some data in the record that the second health professional cannot see but which is relevant to managing the patient?
- Who can expand the access rights of other health professionals to data, when it is in the patient’s interest for a full and frank discussion of all relevant data to take place?

5.5.4 Synthesis of the literature

Assuring the privacy of the data that a patient shares with a health professional is vital to maintain their confidence in the health service. The European Court of Human Rights considers respect for confidentiality as a crucial factor for public confidence. In Canada, a survey found that 11 – 13% of Canadians held back medical information from health professionals over fears about privacy. A stakeholder survey in Canada found that unauthorised access by hospital staff to patient data was their top concern about electronic health records. Another study found that 87% of doctors had at least one patient who had asked them to withhold information from their health record as they were worried about sharing of data without their consent. These studies provide evidence that when using a shared record, the patient’s trust is vital to acquire all the information needed for the best possible care.

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102 Harris Interactive, “Many nationwide believe in the potential benefits of electronic medical records and are interested in online communications with physicians,” Harris Health Care Poll 2005;4(4).
Control of access by other users is important in preserving the privacy of the information. A study conducted in 1995 on patient concern on confidentiality regarding medical notes at the foot of the bed found that only 26% of the patients were concerned about an unauthorised person viewing the notes compared to 83% of doctors and nurses. A study on the views of elderly people found that almost 90% were confident that only the correct person would have access to all parts of their health record. Some participants in the study regarded their General Practitioner as a secondary controller of data after they had given consent. Studies found that the public was willing for their data to be shared on the condition that their physician also gave consent for sharing. However studies in other countries, patient groups and in different eras found different results. For example, in America, a public opinion survey in 2000 showed that 71% of patients were against doctors - other than those given direct permission - accessing their medical data [survey quoted in review].

A system successfully implemented in Geneva University Hospitals granted the patient’s physician the right to act as a mediator for the patient. The physician in this system had control over user access to parts of the record based on the potential benefits and confidentiality risks. A series of focus group studies conducted in 2000 by Northumberland Health Authority found that the participants believed that GPs should first discuss with patients what information they needed to share with other health professionals before doing so. The study found that there is not the same level of trust with OOH GPs and consultant surgeons as with GPs from the patient’s own practice. Only 16% of the respondents agreed to share their entire health record with a consultant surgeon to whom they were referred by their GP for a minor surgery, while the rest were willing to share only the relevant part of the record. The responses varied according to whether the situation was trivial or emergency, with up to 58% willing to share their complete data with OOH GP and practice nurses in emergency. Some participants in this study felt that GPs could decide who else can access their data, whereas others felt that GPs are required to discuss with the patient before granting access or disclosing information.

This difference in willingness to share medical information with different health professionals raises our next key issue in this topic: the circumstances in which a health professional has to notify another health professional regarding some further data in the record relevant to managing the patient. The UK Department of Health states that the duty of confidence is held by all health professionals in the NHS. Information related to individuals is protected legally by the Data Protection Act 1998 and professionally by the General Medical Council. The Good practice guidelines for general practice electronic patient records state

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103 Luke, Gallagher, Lloyd. Staff and family attitudes to keeping joint medical and nursing notes at the foot of the bed: questionnaire survey.
105 Wanless D. Securing our Future Health: Taking a Long-Term View, April 2002.
that doctors working within the NHS are covered by the Human Rights Act and are required to observe such rights in their decisions.

The Department of Health guidelines on sharing medical information state that the information may only be shared with health professionals currently involved in the patient’s care in strict confidence\textsuperscript{112}. However, it is not clearly stated if this can be done without the patient’s permission. The guidelines also state that any such discussion should only contain the ‘minimum’ information required to execute the duties. The European Directive for the protection of personal data adds to this by stating that the information disclosed should be relevant to the purpose\textsuperscript{113}. The directive also adds that there is no implied right to see the information for any other purpose without the informed consent of the patient. With regard to the scenario above, if a health professional who has access to all parts of the records feels the necessity to share information about the patient’s STD with another health professional, they can do so in strict confidence, provided the patient has not explicitly denied such knowledge to the second health professional. However, matters of sexual health, pregnancy and mental health are considered sensitive data and patient groups show less willingness to share these data\textsuperscript{114}. The GMC guidelines state that personal information can be disclosed when the patient consents implicitly for the sake of their own care\textsuperscript{115}. These guidelines emphasise the importance of respecting patient wishes on sharing particular information within the healthcare team. A review on nursing record systems found that nurses preferred face-to-face handover of notes as it resolved the confidentiality problem, especially for psychological aspects\textsuperscript{116}. Nurses also kept personal records as ‘scraps’ as they felt ward documentation was inadequate\textsuperscript{117}.

While the Government in UK has the legal power to control the use of anonymised medical information for commercial purposes using the Health and Social Care Act 2001\textsuperscript{118}, it is not clear who has the power to override any specific patient access control and share information between health professionals. The Good Practice guidelines state that the Department of Health will act as a data controller in contact with NHS bodies as the responsible body for medical data. These access controls are particularly important in maintaining confidentiality if the health record is to be shared. The NHS Care Record Service guidance to patients states that widening the range of professionals having access to their records is a possibility, but such a step would only be taken after discussion and informing the patient\textsuperscript{119}. The issue of data security is also key in maintaining the privacy of medical information in a shared record. A 2006 questionnaire study regarding patient data confidentiality practices among UK surgical trainees found that only 21% of PCs used by the trainees were password protected. There was use of similar passwords and 96.5% of trainees had never encrypted any sensitive data\textsuperscript{120}. The Caldicott committee report

\textsuperscript{115} Confidentiality - a draft for consultation: RCGP?, 2008.
\textsuperscript{119} GUIDANCE FOR THE NHS ABOUT ACCESSING PATIENT INFORMATION IN NEW AND DIFFERENT WAYS AND WHAT THIS MEANS FOR PATIENT CONFIDENTIALITY. Version 1.0. NHS Connecting for Health, NHS Care Records Service 2006.
recommends various privacy enhancing technologies to be used to minimise the risk of unlawful disclosure of personal medical information\textsuperscript{121}. These include physical access controls, logical access controls, audit trails, pseudonymisation, separated and layered databases and encryption. Medico-legal guidelines recommend nominating a person as responsible for handling confidential data in each practice and that disclosure of such data is only to be done for the minimum relevant information\textsuperscript{122}. International Privacy Laws for data sharing are discussed in detail in the recent data sharing review report by Thomas and Walport\textsuperscript{123}.

Privacy is a key concern in establishing patient confidence in the health care system and thus establishing a complete shared health record. Adherence to the law and privacy enhancing mechanisms are considered important measures for achieving this. According to the power granted by the patient, the health professional can disclose only relevant medical information to another health professional if they are directly involved in that patient's care and only in strict confidence. But with a wider range of health professionals having access to a shared record and with patient's fears about loss of confidentiality with such access, guidelines need to address specific scenarios where the patient has denied access to other health professionals.

5.6 Getting and managing permission to access data in the shared patient record

5.6.1 Definition and scope of the issue
This topic reviews the issue of how to obtain and manage patient decisions on consent to share their data in electronic health records with health and other professionals. Since more than one category of health professional access shared records, there is a specific focus on the topic of role based access control and on the role of the patient in determining this access. Also in scope are patient or health professional rights to restrict access to parts of data in the shared record from professionals or others who might otherwise have access to the record. Legal regulations and guidelines on accessing the shared record for clinical and non-clinical purpose are reviewed and discussed.

We have identified in this review the existing guidelines on this topic and through evidence, evaluated the need for implementation of more specific guidelines on access control of shared medical records. Technical details on how the design of a shared record can be delivered safely are also briefly reviewed in this section. Details of access to records for secondary uses of data such as research are not discussed except where specific issues arise relating to shared records.

5.6.2 Key findings
The evidence about patient views regarding sharing of their health data suggests that the public are more willing to share their information with health professionals directly caring for them than with others who require access for more distant care or for secondary uses. Many people believe that their health records are shared more widely than was the case. Most studies revealed that patients were more willing to share information with doctors over other health professionals. Use of medical data for research was considered favourably among a larger proportion of the public, however with the requirement that the data are anonymised.


A variety of access control mechanisms exist to help enforce these general rules. Audit trails of access are essential when investigating suspect or unauthorised access, but how to analyse audit trails to deter such use remains a challenging problem.

### 5.6.3 Synthesis, key disagreements and gaps in knowledge

Medical data is clearly listed as sensitive data in the European Parliament Directive for the Protection of Personal Data\(^\text{124}\). In the United Kingdom, the patient should be made fully aware that health professionals working for the NHS have strict controlled access to their health records\(^\text{125} \ 126 \ 127 \ 128\) and responsible health professionals should protect against the improper disclosure of information concerning the patient to those not authorised to receive it\(^\text{127} \ 128 \ 129 \ 130\).

However, when electronic health records are shared across different professions, access protection and rights become more complicated as the appropriateness of access rights for a given health professional is multi-dimensional, as shown in the figure below.

#### Figure 5.6.3 - Access protection and rights

The figure above gives an overview of the issues influencing access to patient data stored in a shared electronic patient record. The areas of concern are derived from the factors influencing each stage represented in the figure. The numbers correspond to the relevant document number referenced to that factor. The main areas of concern are:

1. Obtaining patient consent for health professionals to access the record. This is largely influenced by:

\(^\text{125}\) Quality guidelines No. 9. The protection and use of patient information. Institute of Health Record Information and Management.
\(^\text{126}\) Record on the Review of Patient-Identifiable Information.
Individual patient attitudes and beliefs towards sharing of their record, including perception of benefits from sharing their medical data

- The type of data to be shared, and its sensitivity
- The purpose of data use – for patient management or for secondary uses

2. Providing access to health or other professionals to the record based on explicit or implicit consent, according to:
   - The professional’s individual or organisational role during a specific time and place
   - Their relationship with the patient, length of access rights and the content of the data requested
   - Legal or professional recommendations on access to patient data

3. Access rights are further technically distinguished by an ‘Access Control System’ into:
   - Access to view, add, edit or delete data in the record, part of the record or extract of the record
   - Access to identifiable or anonymised data

4. Grouping parts of health record based on role based access:
   - Distinguishing data into demographic or clinical elements
   - Defining the data which patients consider ‘highly sensitive’ and restricting the viewing and editing of this subset to a more selected group of health professionals

5. Developing policies, models and methods based on guidelines and evidence for secure access control and auditing technology

5.6.4 Relevant evidence

The proximity of the relationship of the health professional with the patient is a crucial factor in gaining access to the record. Some types of consent (for example, general consent with specific denial for certain data items in the record) might be given to a more trusted health professional rather than to non-clinical staff. Evidence from empirical research shows that patients were more comfortable to share their medical information with their GP, emergency services and other health professionals rather than with non-clinical staff. However, a few studies contradict the statement. For example, patients...
in one study were not concerned if their records were seen by others in the hospital\textsuperscript{143} and in another study, the results varied when benefits of using the information in health records for secondary purposes were added\textsuperscript{133}. Parents of hospitalised children in another study were less concerned about privacy than staff\textsuperscript{144}. There is also evidence that patients do not always expect to be asked for consent each time their information is used\textsuperscript{137,145}.

Evidence has also suggested that patients did not want their records to be seen by other family members, paramedics, researchers, government agencies, their employer and police\textsuperscript{133,134,136,139,140}. Research across the European Union has also shown that doctors and medical services are highly trusted with regard to their use of individuals’ personal information, much more so than tax authorities, banks, employers, and insurance and credit card companies\textsuperscript{146}. Patients are poorly informed about the use of their records\textsuperscript{134,136,147} and, in one study, many people believed that their health records were shared more widely than was the case\textsuperscript{146}.

Interestingly, people with stigmatising illnesses were more positive about sharing their records than advocates for the same groups of patient\textsuperscript{134}. This argues for making direct contact with patients rather than the more usual approach of relying on advocates who often appoint themselves to speak for the majority, but do not appear to have representative views.

While people are generally positive about the use of electronic patient records, with 99.5% of patients in one study seeing it as a positive element of practice\textsuperscript{148}, 16% of primary care patients identified some information in their EPR that they would not want to share\textsuperscript{149}.

A brief summary of studies on patient views on sharing their data is given in Table 5.6.4.
### Table 5.6.4: Patient Views on access to their health records

<table>
<thead>
<tr>
<th>Description of Study</th>
<th>Patient willingness to share their health data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Series of surveys in Canada regarding patient attitudes to privacy(^{133}).</td>
<td>% willing to share with: Doctor (90%) Public Health Nurse (46%)</td>
</tr>
<tr>
<td>Survey of adult primary-care patients in New Zealand(^{136}).</td>
<td>% willing to share with: Practice Doctor/Nurse (78%) Emergency Doctor/Nurse (84%) Hospital Doctor/Nurse (52%)</td>
</tr>
<tr>
<td>Interview and focus group study to determine public views of the SCR in England(^{134}).</td>
<td>Patient expressing willingness to share record with 'anybody' working at their practice.</td>
</tr>
<tr>
<td>Questionnaire and interview study of Seniors’ views on EHR in Canada(^{137}).</td>
<td>88.9% of participants were confident that the only the concerned health professional would access their medical data.</td>
</tr>
<tr>
<td>Interviews of patients and health staff in UK(^{139}).</td>
<td>Patients willing to share within medical care, e.g. Referrals.</td>
</tr>
<tr>
<td>Views of British public in use of medical data by the National Cancer Registry(^{150}).</td>
<td>87% of the respondents did not consider a letter for participation in research, via their doctor as a privacy violation.</td>
</tr>
<tr>
<td>Series of surveys by National Health and Medical Research Council Australia(^{151}).</td>
<td>Larger proportion of general public agreed that automatic access should be given to health providers.</td>
</tr>
</tbody>
</table>

\(^{150}\) Barrett, Cassell, Peacock, Coleman. National survey of British public's views on use of identifiable medical data by the National Cancer Registry.  
\(^{151}\) Ridsdale, Hudd. What do patients want and not want to see about themselves on the computer screen: a qualitative study.
### Public views on access to at least some part of Health record, England

| 64% willing for paramedic/ambulance crew to access. 43% for dentists, 29% for pharmacists, 17% for NHS Managers and 14% for alternative therapists. *- varied according to whether or not received treatment from the staff. |

### Patients’ opinions on use of their health records for research, Canada

| 26% were satisfied with being notified passively. 74% wanted the opportunity to provide consent first. 31% needed no time limit for consent, 49% felt consent should be valid for the duration of the study, 20% preferred an annual review. |

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Another factor that influences the patient’s decision to consent to allowing record access is the type of data concerned\(^{138}\). Data about pregnancy, contraception, sexual and mental health are commonly regarded as ‘sensitive’ information by patients\(^{149}\). If the patient desires, these data should be hidden from the view of individuals to whom the patient does not want to disclose the data\(^{154}\). But there is a dearth of research evidence on which to base specific policies\(^{149}\).

Many guidelines recommend fully informing the patient regarding the use of their medical data\(^{125} 126 127 128\). However, this is often not practical, as most health professionals do not know who will use patient data nor over which channels it will travel during a complex care episode. Patients therefore have not been always been fully informed (or are not always aware of) for which purposes their data is being used, and by whom\(^{135} 136 137\). However, when there are reported cases of inappropriate access to health records\(^{133} 155\), there is a need to ensure patient confidence in the success of data protection measures.

Studies on the views of health professionals on sharing health records have shown varying results. One study found that 94% of health professionals stated that patient records should be accessible by all who provide care for the patient\(^{156}\), while in another, widening the range of users who can access data was considered ‘unattractive’ by health professionals\(^{157}\). However, most health professionals acknowledged the harm of disclosure of patient information\(^{158}\).

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\(^{152}\) Public Opinion Poll: Health Information: Health Information and Quality Authority, Ireland, October 2008.


\(^{154}\) Kurihara, Asai, Ishimoto, Kawamata, Nakamura. A Survey of the Effects of the full Computerized Nursing Records System on Sharing Nursing Records among Health Professionals.


\(^{156}\) Glasper, Holmes, Brown, Newton. Shared records: towards collaborative working with families.


5.6.5 Legislation
The Data Protection Act 1998 defines the conditions under which processing (including recording, storage, manipulation and transmission) of personal data is legally acceptable or otherwise. Legislation however is unclear about how the health professional's involved in the treatment of a single patient can share the clinical information. The Computer Misuse Act of 1990 identifies a range of offences regarding unauthorised access to or modification of computer records and provides criminal sanctions against unauthorised access or damage.

5.6.6 Guidelines
Guidelines provided to GPs in the United Kingdom state the need to make information available to others who are involved in the care of the same patient. However, there appear to be no specific guidelines on who gets access to what data in the record and principles for deciding which information can be accessed according to the role of the health professional.

Access rights are given to health professionals on a ‘need to know’ basis. There is a need to define the ‘role’ and ‘relationship’ of the health professional based on the time and place. This is complicated by the fact that some users can have several roles active at the same time, e.g. they may be a physician to the patient and a clinical researcher at the same time.

5.6.7 Access during emergency situation
Usually patients can control access to their records by expressing their desires to a health professional for complete access to all data, no access to all data, or restricted access to specific data. But there are no specific guidelines or codes of practice regarding access to confidential data in an emergency situation. There is a suggestion that there should be an emergency override in such situations, safeguarding the subsequent availability of the information after the emergency episode. Theories state that there should be well-defined, routinely monitored override mechanisms built into each system, accompanied by relevant codes of professional practice. This ‘breaking the glass’ action must be reviewed to prevent misuse and could be monitored by various system designs. There have

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161 Good practice guidelines for general practice electronic patient records: guidance for GPs (version 3.1).
162 Confidentiality - a draft for consultation.
163 Medical Law: Medical records as protected commercial interest: Downloaded from Lexisnexis.com 17/09/2008.
165 Harmonized Use Case for Electronic Health Records (Laboratory Result Reporting): Department of Health and Human services, USA, 2006.
167 Bakker AR. The need to know the history of the use of digital patient data, in particular the EHR. Int J Med Inform 2007;76(5-6):438-41.
been questions raised regarding emergency access by healthcare workers without complete medical training\textsuperscript{171}. This issue is not addressed adequately in existing guidelines and codes of practice, so there is a need to cover this area.

The areas of most concern are:

- What happens if the health professionals normally authorised to access information are not available during an emergency?
- Is it necessary to have explicit consent for each access and what is the maximum amount of information, which can be shared without consent?
- What are the implications of restrictions to prevent access to vital information which could be beneficial in emergency situations? This is important as guidelines allow ambulance staff to have access only to demographic data. However, if the staff are well trained, access to certain clinical information (e.g. previous MI/epilepsy), would be beneficial.
- What are the risk implications for health professionals not given access to view sensitive data? E.g. if a patient prevents health professional access to infectious disease data, this could potentially put the professional at risk of contracting the disease as they might not take adequate safeguards. This would not apply in the case of statutory notifiable diseases, where the law over rules patient wishes on confidentiality.

5.6.8 Secondary uses and consent

Regarding the secondary uses of data, patients have the right to refuse to allow their data to be used for research or other purposes if it is not anonymised\textsuperscript{160}. There are guidelines which specifically state that patient information should not be disclosed to third parties like insurance companies, employers etc. without consent\textsuperscript{124, 172}. Information, which is collected for one purpose, cannot legally be used for another purpose without the express or implied authorisation of the provider of the information\textsuperscript{160}. NPfIT provides the patient with the option to dissent to their identifiable information being made available for secondary, non-clinical users.

The access rights of non-health professionals such as managers, researchers and other legitimate users of health information need to be defined specifically. The Caldicott Committee Report on the Review of Patient-Identifiable Information states its concern regarding the legitimate processes involved in the access or handling of the information by non-clinical staff in the NHS\textsuperscript{156}. It is important to define when using data for secondary purposes or across organisational boundaries whether the professional concerned has access to the actual record (e.g. in the case of a subpoena by a court) or only to certain data extracted from the record. The law on health records as protected commercial interest\textsuperscript{163}, the Data Protection Act 1998 and the Computer Misuse Act of 1990 should be used to define regulations for the use of data extracted from the shared record.

5.6.9 Technical Aspects

Access to sensitive data can be limited by the class of user (e.g. nursing vs. therapy professional), the proximity of their relationship to the patient, the time of day (e.g. during STD clinic hours only), type of data (e.g. HIV test results) and machine identity, which is linked to place (e.g. from machines located in the STD clinic). Case studies of systems using the platform of OCHIS (Osaka Community Healthcare Information System). Int J Med Inform 2004;73(3):311-6.


shared patient records have found that the design of the access control system is complex\textsuperscript{143} and not easy to implement or maintain in a real life environment, where some parts of the NHS do not maintain up to date staff lists. Ferreira et al recommend developing structured access control policies by involving all the users and patient representatives: health professionals, patients and non-clinical staff\textsuperscript{175}. Access-rights procedures in other European countries insist on restrictions on access in time and space. In Greece, these rights are established according to the speciality, function, job domain, hierarchical position and intent of each category of user, linked with the type of data to be accessed\textsuperscript{124}. In Germany, legislation requires the adoption of a “treatment connection”, stating that the physician involved in treatment of the patient is allowed access to the patients record, and this specifically relates to ‘current’ treatment only\textsuperscript{176}. In the United Kingdom, the use of data in the health records is governed by the Data Protection Acts 1984 (c. 35) and 1998 (c. 29). Legislative technical requirements include the safeguarding of medical information stored on computers by authorised passwords and access levels\textsuperscript{160}.

5.6.10 Monitoring access
Monitoring access to health records by establishing a permanent record of system use is considered an essential part of all computer held records\textsuperscript{156} \textsuperscript{161}. It is recommended that these audit trials contain the date and time, the identity of the user, the systems accessed, details of the functions performed and the parts of the records accessed\textsuperscript{156}. Caldicott guardians can determine access to shared records by clinical professionals; control the duration of their role and review data sharing procedures\textsuperscript{161}. For non-clinical i.e. secondary users, the recommendation given by the Caldicott Committee in establishing secure access is by use of a coded reference identifier instead of the patient identifier and removing other identifying items such as postcode or key dates such as date of birth or hospital admission within information flows\textsuperscript{156}. The committee also insists on the use of logical access control, where only certain users with access rights are permitted to use specific terminals and perform specific functions. The system to be implemented must incorporate the comprehensive security requirements issued by the ISO17799:2000 and BS7799-2:2002 Information Security Standards. However, a key concern with audit trials is their size and how often to analyse them to detect and prevent unauthorised use. Guidance is needed in this area.

5.7 The organisation and labelling of data items in the record

5.7.1 Definition and scope
This topic is about labelling and organising data items in a shared record unambiguously so that all record users can find them fast and interpret them without error\textsuperscript{177}. In a single record, this will not usually be a problem, as record organisation and labelling can be optimised for the local user or users. However, in a shared record serving several organisations and/or professional groups, there may be a significant mismatch between the ways that data items are grouped and labelled and individual user’s understanding or expectation about these.

\begin{thebibliography}{99}
\bibitem{Greenhalgh_2007} Greenhalgh, Stramer, Bratan, Emma Byrne, Mohammad, Russell. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory.
\end{thebibliography}
Examples of some alternative labels that can be used in some records for four similar root concepts are shown in the table.

<table>
<thead>
<tr>
<th>Root concept</th>
<th>Alternative label 1</th>
<th>Alternative label 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>Problem</td>
<td>Issue</td>
</tr>
<tr>
<td>Drugs</td>
<td>Medications</td>
<td>Prescription</td>
</tr>
<tr>
<td>Test results</td>
<td>Investigations</td>
<td>Lab reports</td>
</tr>
<tr>
<td>Advance directive</td>
<td>DNR status</td>
<td>Patient preferences</td>
</tr>
</tbody>
</table>

The main related topic is data entry, import and translation.

### 5.7.2 Key issues

The diagram shows the issues that might arise if, for example, one health professional (a bacteriologist, for example) expects data about a patient’s UTI to appear under the heading “Current Infections” while another user (for example a GP) expects any information about a UTI to appear under the heading “Current Problems”. In this example, perhaps because the shared record design was led by hospital based specialists, the data about the patients current infections do not yet appear in the Current Problems section, so causing it to be neglected by the GP.

**Figure 5.7.2 - Data labelling issues**

The key issues are:

- Risk of a health professional missing one or more data items in the record if the organisation of the record is unfamiliar, or is designed for the convenience of a different professional group
- Risk of a health professional misinterpreting a data item in a shared record because it is labelled differently from how it would be labelled in a profession-specific record, as suggested in the diagram above
- There is also a significant issue about the transfer of “meaning” between different clinical settings. This is why context (narrative) is so important in clinical communications and why the transfer of coded data alone is neither sufficient nor safe

### 5.7.3 Summary of Evidence

The literature search yielded four reasonable quality publications regarding the structure and labelling of data in an electronic patient record. Two studies were reviews of the structure of
electronic patient records\textsuperscript{176 179} and the other two analysed the views of healthcare professionals on the structure of the record\textsuperscript{180 181}.

Mann and Williams (2003) reviewed the development of a structure of electronic patient records in the UK\textsuperscript{179}. They found a decrease in data entry time, a decrease in errors, improvement of patient outcomes and reduction in healthcare costs when the record structure was designed to aid entry and had significant advantages over the paper record. The labelling of data in a shared record could actually improve communication as the healthcare professionals would focus only on the displayed data relevant to their use and not focus on other items.

A review by Hayrinen et al 2007 on electronic patient records found that the structure of the EPR has varied and evolved over time\textsuperscript{178}. They described the structure of EPRs from 15 papers, in three perspectives; \textit{time-oriented}, \textit{problem-oriented} and \textit{source-oriented}. In the \textit{time oriented} structure data appears in chronological order, the \textit{problem-oriented} structure organises data according to subjective information, objective information, assessment and plan (SOAP) and in the \textit{source-oriented} structure, data is organised according to the place where the information was obtained e.g. from a laboratory or from nursing notes. Mizani and Baykal\textsuperscript{182} suggest labelling of the different parts of the EPR according to their sensitivity, e.g. demographic details as “personal identifiable”, data accessible to healthcare team involved in treatment as “private to health professional” and data with restricted access as “highly confidential”; access to these data would depend on the rights granted by the patient.

An electronic Delphi study on the safety features of GP systems found that health professionals have preferences on how the data structure should respond to their needs\textsuperscript{180}. For example, when the health professional is selecting a drug from a drop-down menu there should be mechanism in place to make it difficult to erroneously issue a drug with similar name if it could cause serious harm to the patient e.g. penicillin and penicillamine. An interview study of stakeholders regarding GP computer systems found that users of electronic patient records were concerned that the systems were not structured specifically to their needs\textsuperscript{181}. Factors such as the shapes and positioning of alert messages were not satisfactory to the users need and experience. Some participants felt that clinical systems do not take into account these factors in the design of alert messages. Several participants found the need to take more account of human ergonomics in the design of systems, but found the lack of resources as a significant barrier.

Ten years ago, the need for a structured multi professional record was proposed as a means for ensuring high standards of data quality and standard record headings were developed as an aid to help all health professionals in quickly identifying and using information within clinical documents. The Headings for Communicating Clinical Information Evaluation Projects\textsuperscript{183 184 185 186 187} were commissioned to investigate different approaches taken by


\textsuperscript{182} Mizani, Baykal. A software platform to analyse the ethical issues of electronic patient privacy policy: the S3P example.

\textsuperscript{183} Headings for Communicating Clinical information, Site Evaluation Final Report: Gloucestershire Royal NHS Trust, 2001
various health care professionals in structuring patient data using the proposed headings. The following concerns regarding the use of the headings were explored empirically in these projects:

**Data quality:** The introduction of structured headings into records in a number of specialties did not result in any diminution of data quality, and brought about significant improvements in certain respects. However, one project\(^{182}\) highlighted that incorrect information was recorded under certain headings. There were also instances when data under one heading was combined with data belonging to another heading.

**Semantics:** Users felt that the definitions of the proposed headings were inadequate for direct use at the point of data entry. They agreed that the headings were not intuitive and that the definition describing the data to be recorded was ambiguous in some cases. Concerns were also expressed at the extent to which headings would be used consistently by different professionals.

**Data entry:** In one project there was difficulty assigning data items to headings according to the contextual perspective of the professional at the time of recording\(^{187}\).

**Knowledge and training:** Practice and repetition appeared to speed the process of consistent use of headings. Results from projects suggest that consideration should be given to a computer based training to aid fluency.

Recommendations from the headings evaluation projects included that:

- Many of the issues raised in the projects related to the need for greater clarity or more in-depth definitions of the proposed headings.
- Definitions need to be phrased in less ‘academic’ language and to include on-screen examples.
- The majority of health professionals taking part in the project requested that the headings should be adaptable and flexible enough to support health professional-specific demands for information retrieval.
- Guidance is required for classifying some actions which can be both diagnostic and therapeutic at the same time (such as endoscopy), as it can be difficult to differentiate between assessment and treatment. The guidance was vague on this issue.
- The introduction of a common set of headings would require all stakeholders in the process to engage in further discussion, especially relating to training issues.

### 5.7.4 Guidelines

The draft ISO EHR standards ISO 18308 (summarised on pages 30-31 of Byrne 2008\(^{188}\)) state that the EHR should preserve the original headings in the record, the original data, codes and measurement units at time of data capture, the ordering of data items,

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\(^{184}\) Headings for Communicating Clinical Information, Report of in-use evaluation by the Gastroenterology Team: Neath General Hospital, 2001

\(^{185}\) Headings for Communicating Clinical information, Therapy Department In-Use Evaluation Site: Royal Cornwall Hospital, 2000

\(^{186}\) Headings for Communicating Clinical information: Salford Royal Hospitals NHS Trust, University of Salford, 2001

\(^{187}\) Headings for Communicating Clinical information, Report of in-use evaluation by the SCIPiCT Project Team: NHS Wales, 2001

\(^{188}\) Byrne. Data Quality Evaluation for the Summary Care Record, An independent evaluation by University College, London.
qualification of items (e.g. requested or absent), any label information, and be able to
represent the time of data points imprecisely.

The content of the GP summary in the Summary Care Records is described in detail in the
report by the RCGP Health Informatics Group\textsuperscript{189}. They found that limitation in the production
of GP summaries due to the variance in the record structure from GP2GP transfer of
records. This could be a major challenge in implementing a shared record, so GPs and other
healthcare professionals need to be trained to use a standard record structure.

The Health Informatics Unit of the Royal College of Physicians describes 12 generic record
keeping standards applicable to any electronic patient record\textsuperscript{190}. These standards define the
terms used in the headings in the health record. It is important for all health professionals to
understand and master these standards to promote a uniform structure for computerised
patient record. For example, the standards define the use of the term –religions needs in the
‘personal circumstances’ part of the patient’s social history. However, if one health
professional records this data under ‘lifestyle’ it could disrupt the uniform structure of the
record. This could result in wrongly coded data and show erroneous results when the data
are used by other professionals or for other purposes. The standards at present are intended
for paper records only and need to be extended to shared electronic patient records.

Guidelines for record keeping and structure exist for other healthcare staff\textsuperscript{191,192}. These need
to state the requirements for maintaining the structure of the record according to the type of
information recorded. The European Committee for standardisation has published rather
abstract pre-standards (ENV 13606) for the structure of the health record\textsuperscript{193}. It proposes to
categorise the components of a record (Original Component Complex) into:

1. Folder
2. Composition
3. Headed section
4. Cluster

Each category is clearly described, with the ‘folder’ category having a broader aspect, e.g. a
particular disease and the ‘cluster’ being a narrow category e.g. a particular blood
investigation required for the disease addressed in the ‘folder’. Such a concept needs to be
tested and then adopted across health professional groups. This approach is being used in
GP2GP message programme and in the HL7 Clinical Document Architecture Standard used
in England.

However, in the implementation of a shared record, it is important to go beyond descriptions
of the content of the record. For example, it has been found that some personal notes by
nurses can be very useful in handing over patients, planning patient care\textsuperscript{194,195} and also in

\textsuperscript{189} GP Summary Component of the NHS Summary Care Record. In: Group RHIS, editor.
\textsuperscript{190} A Clinician’s Guide to Record Standards – Part 2: Standards for the structure and content of
medical records and communications when patients are admitted to hospital: Royal College of
\textsuperscript{191} Record Keeping: Guidance 2.
\textsuperscript{192} Guidelines for records and record keeping; Nursing and Midwifery Council, 2002.
\textsuperscript{193} Electronic healthcare record communication - Part 2: Domain term list. European PreStandard
\textsuperscript{194} Hardey, Payne, Coleman. ‘Scraps’: hidden nursing information and its influence on the delivery of
care.
\textsuperscript{195} Allen D. Record-keeping and routine nursing practice: the view from the wards. Journal of
medico-legal cases\textsuperscript{196}. These notes could be useful for nurses, but are perceived to be of lesser importance to other health professionals. Hence, ways to incorporate such notes into the records while retaining clarity in the overall structure needs to be addressed. Our review did not find documents specific to this subject.

It is clear that the design of shared records needs to take account of this problem. Some potential recommendations, which might reduce the chance of this kind of problem occurring, are to ensure that:

1. Representatives of all health professionals using the shared record are involved in defining the headings under which data items are listed
2. Data items can appear under multiple headings as necessary
3. The names of the headings are as explicit as possible to as many professional groups as possible, to reduce ambiguity
4. Patient involvement in deciding headings could be considered as an option if no agreement can be reached between professionals. This would also help patients to navigate their own record, an important goal but one which is outside the scope of this review.

5.8 The meaning, interpretation and semantics of data across professions and organisations: data entry, coding, import and translation

5.8.1 Definition and scope of the topic
This topic concerns agencies adding data to records used by health professionals or health professionals trying to interpret data added to a shared record by another agency, whether this agency is another health professional, an import from another information system (e.g. a lab or pharmacy\textsuperscript{197}) or data originating from the patient themselves (e.g. a peak flow or blood sugar measuring device).

Understanding the risks of data import and translation is crucial before we can safely import data from external sources, merge records or integrate data originating from outside an organisation. We have searched the literature to try and identify the sources and document the frequency, severity and consequences of this risk. We have also identified potential solutions to ameliorate these risks, to allow safe data import and merging of records for clinical purposes.

This topic concerns issues that impact on the interpretation of patient data by health professionals and thus on patient safety. These issues are already recognised and usually managed adequately in single organisational records but they are much less understood and recognised amongst the users of shared records. For this reason, they pose a much greater threat to patient safety.

The three main issues are:

1. Differences in the meaning of data items across clinical settings and professions and how they can be overcome
2. The choice and use of clinical coding systems and terminologies, and problems that can arise from them

\textsuperscript{196} Sexual assault: nursing notes help to convict perpetrator. Legal Eagle Eye Newsletter for the Nursing Profession: COURT OF APPEALS OF GEORGIA 2007

3. The development and use of an ontology (a model of the concepts in a domain and their relationships – in this case the domain is patient data items) to support safe mapping of data items from one coding system and record to another.

The specific issue of how to support health professionals in responding to clinical significant new data items being added to a shared record is addressed in the next topic, responding to significant data in the record. Different record structures and different labels for data items are covered in the preceding topic. The issues around data import and use for research or other secondary purposes are not included under this heading – see topic 2.

**5.8.2 Summary of findings**

It is clear that the definitions of clinical data items, and even of the headings under which these items appear in the record, vary considerably from one professional group to another and from primary to secondary care. Such differences can usually be overcome over time by discussion in the context of a well circumscribed organisation such as a single general practice. However, when records are shared across multiple professions and organisations, it will become increasingly hard to interpret and rely on the data entered by others unless radical steps are taken to develop shared definitions of clinical concepts across all relevant professionals groups. A precedent for this is with the national Headings project promoted by the Conference of Colleges and led by Martin Severs in the mid 1990s.

A linked activity should be the development and dissemination of definitions of data items as part of the activity of national guidelines producing bodies. However, the evidence suggests that simple dissemination of shared definitions of data items to general practices may not be effective, and more complex implementation approaches are necessary, such as training of staff.

**5.8.3 A model for data import and translation**

When several health professionals in a tightly knit organisation such as a single general practice use a single record system, issues over different understanding of the meaning of data items do arise, but are usually resolved rapidly in practice meetings. Most GP systems are designed to reject direct data transfer from other systems, so require the GP to actively confirm data for transfer into the system after taking necessary steps to translate the data and / or act on any significant items (see next section). As the first section of this literature review showed, careful data sharing has a large number of potential benefits so is to be encouraged. However, the picture with a shared record system crossing organisational boundaries is much more complex.

To take an example, the figure shows a typical flow of information when a community psychiatric nurse (CPN) wishes to access and use an item of data in a shared record to support her decision about a patient, Mrs Smith.

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200 Wilson. Special issue: Infrastructures to support integrated care: connecting across institutional and professional boundaries - ‘Trying to do a jigsaw without the picture on the box’: understanding the challenges of care integration in the context of single assessment for older people in England
201 Avery. Improving general practice computer systems for patient safety: qualitative study of key stakeholders
The original data item, “Problem = anxiety”, was entered and coded by a GP using their GP record system (bottom left of the diagram), and is the result of the following processes:

- The GP’s construction of the meaning of the concepts “problem” and “anxiety”, which result from their training and clinical environment, with the entire context this entails (peers, organisational pressures, financial incentives etc.). National guidance may have some role in this by proposing a single standard definition of anxiety, but such guidance is known to penetrate poorly into primary care settings\(^2\).
- The GP’s understanding of the purpose of recording data in their GP record system, and who will have access to it.
- The GP’s ability to find the right concept on their practice computer screen that adequately expresses the concept “symptoms probably due to anxiety”
- The accuracy of the GP’s clinical data capture tool in translating user actions to the correct internal code, probably a Read code, and storing this in the problem field in Mrs Smith’s record.

This data item in the GP’s area of a shared record system then needs to be transferred in a usable format to the part of the shared record system used by the CPN. This requires the following processes:

- The contents of Mrs Smith’s GP problem field need to be identified and sent to the CPN’s part of the record system
- The coding system used in the CPNs interface needs to recognise the data item as a Read code
- A translator from Read to the coding system used in the CPN’s interface, DSM4, needs to correctly translate the code
- The CPN’s interface needs to place the code into the nearest equivalent of the problem field in Mrs Smith’s CPN record

Finally, the CPN needs to use the data item to inform their decision about Mrs Smith. This requires:

• Finding Mrs Smith’s record and the problem section within it, if it exists under that name (see previous section)
• Understanding the nature of a “problem” in GP terms and how it might differ from the CPN’s conception of a problem
• Inferring what a GP might mean by “anxiety”, and possible reasons why they might have recorded it under the problem heading
• Using this additional information about Mrs Smith in their decision making

This process is highly dependent on the context in which the CPN works, their training and experience.

The key points of concern around data interpretation in shared electronic records are thus:

1. The differing education, training and other factors that lead to health professionals from different professional backgrounds to disagree about, or be unaware of differences in their understanding of, the meaning of a clinical finding, patient problem, diagnosis, plan, prognosis, conclusion, hypothesis, or anything else captured in the record
2. The similarities and differences in health professionals' understanding of, and responses to, specific data items in the record (e.g. “problem = anxiety”) when making their decisions
3. The need for all patient findings to be recorded in the record in their original format and ordering
4. The ability of the GP interface to a shared record system to accurately capture and code clinical findings (e.g. problems) in Read codes and store these on the database of a shared record system
5. The ability of other user’s interfaces to the shared record to recognize the data item, identify and translate the Read code accurately into the relevant coding system (e.g. DSM4), and then use this to populate that user's view of the patient record
6. The ability of external NHS bodies such as National Institute for Health and Clinical Excellence (NICE) or Scottish Intercollegiate Guidelines Network (SIGN) or professional bodies such as RCGP to influence and standardise any of these processes

5.8.4 Summary of studies identified
Wilson et al carried out a case study in four sites of the single shared assessment process. They concluded that it is essential to avoid silos in public service delivery, as stated in various government policies e.g. Our health, Our care, Our say 2006. The aim of the process should be inter-organisational and cross sectoral sharing of data about a person, to improve communication and coordination amongst professionals and agencies via a single assessment process. But they concluded that this is a significant challenge.

Avery et al conducted a Delphi study on the need for safety features for GP prescribing using computers. The issues where there was highest (>90%) agreement included the need for an effective user interface; to highlight drugs with similar names and the use of specific codes for drugs rather than drug classes when activating alerts. These are all relevant to the issue of varying interpretation of data items in the shared record context.

In a case study in one general practice, Darroch described how individuals from various professional groups enter data using Read codes to a single shared record. The practice started to computerise 20 years before, using a free system. The team soon identified the need for close working and open discussion of data definition issues. However, external feedback on data quality and payment for data was an important factor that helped to
improve the quality and completeness of GP data. However, getting data entered after home visits remained a challenge. Darroch concluded that consistency is vital – everyone entering data into the record needs to agree on the data format and exactly which codes will be used in which circumstances, to ensure that data about an individual patient can be safely and reliably interpreted. Consistency is also vital to allow patient data to be analysed for secondary purposes.

Pirnejad 2007 carried out a case study in the Netherlands of the growth and problems of a national shared record, the Dutch medication record, including interviews with 10 senior staff. This system was instituted following a study by WINAP (the Dutch institute of pharmacists) who estimated that 300M Euros pa. are wasted due to 90000 extra hospital admissions due to avoidable medication errors. At least some of these admissions are due to failure to share medication data between the patient’s normal High Street pharmacy and OOH pharmacists. 80% of Dutch GPs now use e-prescribing, with 10-35% of prescriptions sent electronically to the pharmacy, and about 5% of GPs get an electronic summary of the patients medication from pharmacy. However, the primary source of medication data in this shared record is the patient themselves, which Pirnejad commented is not a reliable source as patients often do not remember or understand their medication. The result is that information about changes in medication is often delayed or incomplete.

Gabbay and colleagues carried out a detailed ethnographic study in two general practices that had a high reputation for being evidence based, trying to understand where and how external knowledge such as guidelines was used by the practitioners. They concluded, after over a year of careful observation, that external evidence and guidelines were rarely mentioned and that the practices emphasised locally constructed “mind lines” far more than guidelines. The implication is that simple dissemination of definitions of data items through guidelines may not be effective, and more complex implementation approaches are probably necessary, such as training of staff.

5.8.5 Summary of guidance
The draft ISO EHR standards ISO 18308 (summarised on pages 30-31 of Byrne 2008) state that every EHR should preserve the original headings in the record, the original data, codes and measurement units at time of data capture, the ordering of data items, any qualification of the items (e.g. item requested, item absent), any label information provided by a third party, institution or medical device, and be able to represent the time of data points imprecisely. All of these are necessary to support more reliable interpretation of data when it moves across organisational and professional boundaries.

The Requirements for Accreditation of GP computer systems, RFA 99, used to include tests that GP record systems complied with most of the ISO requirements for EPR and also a test of data extraction and upload methods. Byrne et al have recently stated that this test of compliance with ISO requirements should be retained.

5.8.6 Summary of legal material
No relevant legal material was identified.

5.8.7 Summary of technical articles
In a decentralised model, there is a need for syntactic interoperability as well as a reference information model to support unambiguous data transfer i.e. semantic interoperability. Edifact, as used in the Netherlands pharmacy system, provides only part of this, and means that local systems must be able to translate data items reliably to the codes used in local systems. However, in the Dutch case study and interviews it was found that this is not enough – laborious manual work must be employed routinely to review incoming data. The
authors commented that centralised system design and standards such as HL7 should help avoid this.

However, as always, technical solutions will not be sufficient to resolve the problem, and will only support reliable transfer of data if agreed national data definitions are available and adhered to, by all concerned.

5.9 Responding to significant data in the shared electronic patient record

5.9.1 Definition and scope of the issue
Responding to significant data in the shared electronic record is concerned with how to ensure that the professionals concerned take the appropriate actions when clinically significant data arrives and needs to be added to a shared record. ‘Significant data’ in this context refers to any clinically significant data which appears – or fails to appear - in the shared record, including new laboratory data with clinical relevance for a patient. It is assumed that the data are genuinely clinically significant, rather than an artefact arising from system malfunction; this is discussed under the topic Data quality and validity (5.10).

The key area for discussion is how to develop and support professional responsibility for responding to abnormal data and take appropriate action when new data with clinical importance for a patient is added to the shared electronic health record.

This issue is linked with the access and availability of specific patient data to a healthcare professional. This is based on factors such as the patient – health professional relationship, patient privacy, data sensitivity, policies and regulations, discussed in other topics.

5.9.2 Synthesis, key disagreements and gaps in knowledge
In the United Kingdom, permission to share information with individuals involved in the patient’s care is on a ‘need-to-know’ basis and patients can choose to withhold sensitive information from disclosure without their expressed consent\textsuperscript{203}. The ‘responsible health professional’ could be defined as the health professional that has the primary responsibility for acting on that patient’s data, normal or abnormal. According to the Joint GP IT Committee (of the GPC and RCGP) this will typically, but not always, be the person who requested the data\textsuperscript{204}. However, this review has found that there are no specific guidelines defining the role of the health professional as the primary responsible person and the actions that should be taken to respond to such data in a shared electronic health record. The Good Practice Guidelines for GP electronic patient records\textsuperscript{205} (Section 5.3.2.2, Receiving external data) state that GP systems should always allow the review of external clinical data before incorporation into the patient health record, and this is what currently happens in standard (non shared) records. Regarding the issue of clinically significant abnormal data, whether technically incorrect or correct, the guidelines specify that GPs should judge the validity of the test results, check for data corruption and reject any clinical result if it appears technically incorrect. This issue is not discussed in detail, and there are no detailed indications on how

\textsuperscript{203} Paterson. HealthConnect and privacy: A policy conundrum.
\textsuperscript{205} Good practice guidelines for general practice electronic patient records: guidance for GPs (version 3.1).
GPs are to judge the technical validity of data or further actions to be taken if the results appeared incorrect due to a system fault.

One study illustrating this problem is an audit of delayed access to clinically significant abnormal test results following the introduction of computer access to laboratory data in the emergency room via a ward terminal instead of telephone calls to the lab. This showed that the results of 45% of urgent requests from accident and emergency and 29% from the admissions ward were never accessed. In 3% of the tests, the results were never looked at and are likely to have led to an immediate change in patient management. The study concluded that when electronic methods are used as the sole mode of communicating test results, this can seriously worsen rather than promote communication. However, our literature review found that there is a dearth of other empirical evidence in this topic.

The main areas of concern arising from this topic are:

- When accessing the shared health record, who has the responsibility to act on a clinically relevant data and then add it to the patient record?
- In the absence of a designated ‘responsible’ health professional, who is then authorised to view and take action on a clinically significant data item?
- What are the extra requirements for a shared record system to safely address these issues? For example, is there a need for an automatic system to filter data before it arrives at the shared record, to classify the clinical significance of every incoming data item according to an agreed level of clinical significance and if necessary notify the responsible health professional for further action?

5.9.3 Responsibility for responding to new clinically significant data items

The GP is traditionally viewed as the primary caregiver to the patient, with consent from the patient to manage their care and to create and access the confidential information required to carry out that task. The role of the specialist while the patient is an outpatient can be seen as a source of advice to help the GP manage the patient. When the patient is an inpatient, the specialist takes over primary responsibility for the patient. Abnormal clinical data is usually managed in shared record systems by sending an alert to the ‘ordering’ health professional. However with more than one health professional having access to a shared electronic health record, there needs to be a system which can analyse the results and send alerts to the ‘responsible’ health professional, who may differ from the person ordering the test (e.g. in patients recently admitted to or discharged from hospital). Another challenge arises where a health professional has ordered a test and the patient later denies that health professional access to the result. In this scenario, the ‘ordering’ health professional can no longer be responsible for taking action when the test results arrive. A further challenging scenario is when the ‘ordering’ health professional is not immediately available and the data item requires urgent clinical action (e.g. severe hypoglycaemia).

There needs to be guidance about exactly who is responsible for taking the necessary action covering all of these scenarios. However, there are gaps in the current guidelines which need to be filled to establish standard and uniform regulations that apply in the context of

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208 Bakker. Digest of the discussion group sessions. Realising Security of the Electronic Record.
209 Bakker. The need to know the history of the use of digital patient data, in particular the EHR.
record sharing. The issue of patient rights to deny other health professional’s access is discussed in the second and third topics.

5.9.4 Alerting responsible health professionals to significant data according to the severity of the consequences

Various system designs have been identified describing proposed and implemented models for electronic health records. Drawing on the models suggested, we suggest a ‘Shared records consequence’ system, which could analyse each new data item and classify them according to their likely clinical consequences.

The role of the system would be to determine the main implications of a new data item added to the shared record and to decide whether to notify the health professional or not (represented in the diagram below). The three possible consequences are:

1. The consequence of the data item is classified as ‘Trivial’; hence, the item is simply added to the shared record automatically
2. The consequence of the data item is classified as ‘Unknown’ or ‘Significant, but routine’: the data item is held until the responsible health professional enters the patient records system, when it is displayed to them with a request to act on it or add it to record
3. The consequence of the data item is classified as ‘Significant and Urgent’: the responsible health professional is identified and immediately alerted by appropriate means (SMS, email etc.). The health professional is then requested to take any appropriate actions on the patient and record these actions in the record; the data item is then added to the shared record

Figure 5.9.4 – Responding to new data in a shared record

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210 Harmonized Use Case for Electronic Health Records (Laboratory Result Reporting).
211 Mizani, Baykal. A software platform to analyse the ethical issues of electronic patient privacy policy: the S3P example.
Formalising the requirements for such a system and drafting guidelines to define the levels of clinical significance and the identity of the ‘responsible’ health professional under various circumstances will be a challenging task. However, there are currently few guidelines in this topic area and this is considered essential before setting up shared electronic health records. Scenario development and testing is one method likely to be useful to advance our understanding of this area.

5.10 Data or record quality and validity

5.10.1 Definition and scope of the topic
This topic concerns the quality of the data in a shared record and ensuring the integrity and correctness of data by defining data quality standards that apply across professions and organisations. The topic is also related to the last topic on the knowledge and training of health professionals to maintain high quality of patient data.

5.10.2 Problem scenario
With a wide range of health professionals accessing and adding data into the shared record, it is important to maintain high data quality standards to ensure the usefulness of the record. The scenario outlined in the figure below is an example taken from the Good Practice Guidance and Business Procedures for the Use of Pathology Reports EDI for General Practice End Users\(^{213}\). In a traditional record system, a health professional requests the laboratory test such as a fasting blood sugar and on receiving the results checks their validity before input. However, in a shared record, other professionals might input the data, unaware of the importance of that data to e.g. patient’s diabetic status or whether the blood sugar was random or fasting. Therefore, if the blood sugar was not measured during fasting or if a fasting blood sugar is entered into the random blood sugar field in the record, the quality of the data in the record is compromised.

**Figure 5.10.2 - Problem scenario**

Another problem is excessive data. The Good Practice Guidelines identify meaningless data in terms of data quality as a cause of poor clinical practice\(^ {214}\). As various professionals can access the shared record, it is important to define the terms and extent of data input for each profession, to ensure that the amount of data in the record is manageable.

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\(^{213}\) Good Practice Guidance and Business Procedures for General Practices Version 1.005.

\(^{214}\) Good practice guidelines for general practice electronic patient records: guidance for GPs (version 3.1).
5.10.3 Key issues raised in this topic

The key issues include:

- Deciding on access rights for data entry by different health professionals without compromising the quality of data
- Defining an acceptable standard of data quality within and across professions and organisations
- The role of audit trails to help ensure the quality of data in shared records
- The shared responsibility of the different organisations concerned to ensure the quality of data in a shared record
- Minimising system level errors in electronic shared record e.g. prevention of data loss during transmission from one organisation to another, ensuring that different systems are able to match and maintain the patient’s identity

Errors in health records often occur. Examples include erroneous codes added by a doctor or secretary; flawed data transfer, missing data and software misinterpretation. Audits of the quality of information in the hospital discharge summary demonstrated that 5% of summaries in 2001 and 10% in 2002 were inadequate with respect to required clinical parameters (diagnosis, ancillary problems, procedures/investigations, inpatient management, post-discharge instructions and discharge medication). Such errors affect the quality and validity of the health record. The correctness and completeness of the data in a health record are key elements in determining the validity and usefulness of the record.

The term “data quality” refers to the data being timely, comprehensive, relevant, accessible and accurate in whatever form it is recorded (text or codes). High standards of data recording are necessary for the data to be useful for all involved in clinical care. Good quality data is also needed for audit, research, health care planning and commissioning. In a shared record, it is also necessary to keep the data up to date and complete to ensure the proper function of role-based access controls. An evaluation of the Summary Care Records in England indicated that the risks associated with poor quality data included not only clinical errors but also limited end user uptake and failure to deliver sufficient benefits to users.

Guidelines based on the existing framework of technical and legal directives on medical data in the EU, USA and Canada recommend that personal health data should be accurate and where necessary kept up to date and that every step should be taken to ensure that

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217 Stead. Rethinking electronic health records to better achieve quality and safety goals.
218 Hayrinen, Saranto, Nykanen. Definition, structure, content, use and impacts of electronic health records: A review of the research literature.
219 Ilioudis, Pangalos. A framework for an institutional high level security policy for the processing of medical data and their transmission through the Internet.
220 Byrne. Data Quality Evaluation for the Summary Care Record An independent evaluation by University College, London.
inaccurate data are erased or corrected. In the UK, guidelines for the quality of data recording exist for various professions. The Good Practice Guidelines for General Practice electronic patient records Section 4.6 lists guidelines for retrospective and prospective data recording to ensure data quality.

However, comparing the results of studies reveals no standard definition of data quality, with the terms ‘accuracy’ and ‘completeness’ used in a variety of ways. Defining standards for data quality is even more important in shared records, as these will be accessed by a range of professionals in a variety of organisations, and the meaning of ‘data quality’ is likely to vary according to the profession, access rights, each person’s knowledge, training and the type of data.

The diagram below illustrates a scenario where a patient’s health record has missing or irrelevant data due to access restriction or incorrect entry by some health professionals treating the patient. This is likely to lead to misinterpretation of data by other health professionals directly involved in treating the same patient.

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**Figure 5.10.3 - Issue scenario**

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**5.10.4 Completeness of data**

Research on the validity of electronic records suggests that validity depends on the degree of completeness of the record and the degree of control exercised over its creation. Completeness implies that all the required data is present and authenticated, consistent with...
standards and guidelines. A literature review on the completeness of medical data showed high variability, from 27% to 100% and correctness of 44% to 100%. A systematic review on data completeness of computerised health records found that this varied greatly between practices. The review also found that correctness and completeness of data varied according to patient condition, with conditions having clear diagnostic features being more correct and completely recorded than those with more subtle clinical findings.

A retrospective analysis of primary care records of five general practices in the UK in 2008 found that one in five of all primary care patients with cancer could not be identified in a search for cancer patients using standard electronic codes for malignancy. The electronic codes for cancer in these records were found to have low levels of completeness (29.4%) and correctness (65.6%). This was attributed to a delay in transfer of paper summaries to electronic records as well as incorrectly coding benign neoplasms as malignancy.

The completeness of a shared record system is a key issue if a range of health professionals add or edit data in the record. An audit of the type of data collected by nurses in Australia showed that data, which are considered important for the patient condition, were usually kept in an unstructured area of the record. A similar study on the quality of physiotherapy entries found that only 4.3% of physiotherapy records were 100% complete. However the documentation was considered a reasonable overall standard, based on important patient characteristics only e.g. Diagnosis. Hence, a minimum standard of data quality needs to be defined for each profession. The completeness of the data in the record will also depend on the access rights provided to professionals by the patient.

5.10.5 Incorrect data
A systematic review on data quality in UK primary care found validity to vary according to the type of data, with prescribing data of better quality than lifestyle data. Quality of data entry by health professionals varies according to the perceived importance of the data e.g. there is a deficit in recording health promotion advice by GPs. However, such health promotion advice given to patient would be more important to a public health nurse involved in patient care. Some data inaccuracy can be attributed to gaps in information about care by providers who are not using the electronic patient records.

An audit of electronic patient data in England showed that primary care electronic health records contain errors of various types. The incorrect information in this audit however was based on a small number of patients from one general practice and further investigation

235 Wilson A, McDonald P. Comparison of patient questionnaire, medical record, and audio tape in assessment of health promotion in general practice consultations BMJ 1994;309:1483-1485
revealed that some data was correct. A study on the accuracy of GP produced summaries in
the NHS core clinical record based on patients' views found 24% of the summaries had one
or more inaccuracies, with 47% of the inaccuracies of obvious clinical importance including
wrong diagnosis and missing major morbidity. A systematic review on the accuracy of
hospital discharge coding identified that coding accuracies were high in the UK (median of
90%) but varied from 53% to 100% in different studies\textsuperscript{237}. However, research has also
revealed that in the patient's view, electronic records contain high quality information\textsuperscript{238}.

The EC Directive on Data Protection, 1995 states that personal health data should be
adequate, relevant and not excessive in relation to the purposes for which they are collected
or processed\textsuperscript{223}. Excessive or meaningless data in the health record would invalidate
investments in IT infrastructure\textsuperscript{214}. In the UK, a 1998 study on the unification of inter-
professional case notes adopted by one hospital found that 19% of the doctors had
complaints against the nurse's notes\textsuperscript{239}. Their complaint was addition of irrelevant
information to the record by the nurses. A review of collaborative record keeping in North
America adds to this, stating that cluttering of the patient record with poor quality nursing
notes is a disadvantage in sharing records\textsuperscript{240}. However some of this incomplete
documentation has also been found to be prevalent among doctors and nurses\textsuperscript{241}. Further
research is needed to compare the documentation standards of different health care
professionals with the core information in the shared record\textsuperscript{218}.

5.10.6 System level errors
The quality of data in the record now relies more on the skills and professionalism of the
people producing the data than on the system in which it is recorded\textsuperscript{220}. A study of the errors
in the SCR in England found that errors detected through clinical audit were given to GPs to
correct, while system level errors were strangely ignored\textsuperscript{242}. A model health care network
including GPs, specialists and patients found that structured electronic information exchange
is difficult due to organisational frameworks, heterogeneity of software and legal
constraints\textsuperscript{243}. Problems can arise in transferring information between different types of
clinical computer systems with different approaches to the coding of clinical concepts\textsuperscript{244} (See
Topic 5).

5.10.7 Auditing clinical data to improve data quality
Regular audit of and feedback about the quality of clinical data is required to improve
credibility and quality\textsuperscript{214}. Audit can help to identify the source of any systematic mistakes in
data production and can be used to promote organisational change and good quality data\textsuperscript{220}. A study of policies on the processing of medical data across the globe recommends regular
quality evaluation of data, as well as evaluation of the software used by health care
systems\textsuperscript{219}.

\textsuperscript{237} Campbell SE, Campbell MK, Grimshaw JM, Walker AE. A systematic review of discharge coding
\textsuperscript{238} Morin, Tourigny, Pelletier, Robichaud, Mathieu, Vezina, et al. Seniors' views on the use of
electronic health records.
\textsuperscript{240} Gallinagh R, et, al. Collaborative record keeping: a review. International Journal of Therapy and
\textsuperscript{241} Peter S, Fazakerley M. Clinical effectiveness of an integrated care pathway for infants with
bronchiolitis. Paediatric Nursing 2004;16(1).
\textsuperscript{242} Greenhalgh, Wood, Bratan, Stramer, Hinder. Patients' attitudes to the summary care record and
HealthSpace: qualitative study.
\textsuperscript{243} Muller, Uckert, Burkle, Prokosch. Cross-institutional data exchange using the clinical document
architecture (CDA).
\textsuperscript{244} Avery. Improving general practice computer systems for patient safety: qualitative study of key
stakeholders
Auditing of health records can help in monitoring the standards of data quality and identify areas for improvement and staff development. Methods to check that the shared information is of sufficient quality and that any problems have been rectified should be put in place by the organisations receiving data from elsewhere.

5.10.8 Measures recommended in literature to ensure high quality data in shared records

The BCS Health Informatics panel suggests that a nationally facilitated effort is necessary across all care sectors, focussed on patient data quality. But improving the quality of data collected for patient care is challenging because of a lack of clinical time, interruptions and inconsistent definitions and practices. Most data quality standards were designed for supporting individual health professionals treating individual patients in the context of a single organisational record. Studies have not yet addressed the problems arising from erroneous or missing data in a cross-professional or multi organisational context.

However, the implementation of shared records across professions and regular audit has been shown to prompt data quality measures in practices. Though audit can provide quantitative measures of the internal consistency of the patient record, it only captures data at one moment in time and is applicable only to a minority of data, mainly that for which an independent gold standard source can be defined. The Good Practice Guidelines for General Practice electronic patient records lists quality measures to reduce or eliminate the impact of externally received erroneous data. Practices are recommended to follow section A2.7.2 of the guidelines on receipt of the external record. These include checking the accuracy of the incoming record, minimal modification and no deletion unless there is inaccuracy. The first consultation with a new patient requires reviewing and verifying patient data in the electronic health record against other documents and the patient themselves. Practices are also advised to consider asking patients to judge the accuracy of their health record.

A review on electronic health records suggests that structured data entry improves data accuracy and completeness and also that completeness improves with time. A further challenge is the use of standard terminologies in order to achieve semantic interoperability. To achieve this, all health professionals must agree on clinical terminology and definitions and on the structure of the shared health record.

It is important to recognise the need for training to ensure the quality of the data in the shared health record (See the last topic in this review). A review of long-term trends affecting the health service in the UK suggests the need for increased training in the value of high quality information, to ensure better use of health information technology. Jaspers et al state the importance of enhancing health professional awareness in of improving the quality of data multi-purpose i.e. shared documentation.

The data sharing review by Thomas and Walport recommend that the quality of information should be checked before it is shared for any purposes. To check data accuracy, a

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247 Byrne. Data Quality Evaluation for the Summary Care Record
249 Wanless. Securing our Future Health: Taking a Long-Term View.
250 Jaspers, Knaup, Schmidt. The computerized patient record: where do we stand?
sample of records should be checked as it is rarely possible to check every data in every record. The report also states that guidelines should be in place to resolve disagreements regarding the quality of data. External validation with a disease registry e.g. a regional Cancer Registry is likely to improve completeness and correctness of practice records\textsuperscript{231}.

A review found that record systems that failed to allow for clinically relevant answers or for the recording of data regarding patient compliance lead to data inaccuracies\textsuperscript{217}. However, excessive data can also lead to inaccuracies. Hence, guidelines need to specifically define what data is required in what format (coded or free text) for a health professional to input into the shared record, according to their role to ensure the quality of the record. Other standards such as standards for content, authentication and completion also need to be addressed\textsuperscript{228}.

5.11 Data and record preservation and deletion

5.11.1 Definition and scope of the issue
Record preservation and deletion looks at the issues surrounding the long-term management of electronic records, including storage without loss of integrity and deletion at an appropriate time. Data preservation is not just a matter of archiving; it involves safeguarding the information content of any digital resource from the ravages of time, technological change, and decaying media\textsuperscript{251}. A record preservation system is thus a set of internally consistent rules that govern the intellectual and physical maintenance by the creator of semi-active and inactive records over time, and the tools and mechanisms necessary to implement them\textsuperscript{252}.

The added dimension with shared records is that there may potentially be misunderstanding or disagreement over the preservation of different parts of the record. For example, one health professional may apply standard rules for destroying their part of the record following a patient’s demise, unaware of the fact that the patient had a condition that requires that the entire record is preserved for considerably longer – see diagram.

Figure 5.11.1 - Data and record preservation and deletion

\textsuperscript{252}Duranti. The Protection of the Integrity of Electronic Records: An Overview of the UBC-MAS Research Project.
5.11.2 Synthesis, key disagreements, gaps in knowledge

There is no good evidence available to guide policy decisions on the optimal strategy for record preservation, even for a single organisation’s records. There is one published review\(^\text{251}\) that also highlights the paucity of evidence, and includes some policy recommendations as a framework for reaching consensus on issues. The authors comment that there seems to be a lack of awareness of the issue in the healthcare sector and no clear strategies or guidelines. There is, however, a greater awareness of the problems than when USA guidelines\(^\text{253}\) in 1992 commented that retention would be less complicated when there is a completely computerised patient record, because data capture is automatic and storage space not a problem. One author highlights that electronic health records should be managed as business documents\(^\text{254}\). The UNESCO recommendation\(^\text{255}\) that society at large should be involved in the decision making process about broad policies in relation to human genetic and proteomic data could equally apply to all health data. Policy documents from the UK mention the issue, but do not give any detailed recommendations\(^\text{256} 257 258 259 260\). The Information Commissioner’s Office Framework Code of Practice for sharing personal information includes a section on retention of shared records, but only in general terms. There are already statutory retention periods for some data, and policies on disposal of records that have lost their value. Several authors give more details of the technical and management/procedural problems and describe possible solutions both generally\(^\text{261} 262\) and within the proposed EHR systems in Australia\(^\text{264}\) and Germany\(^\text{265}\). There is some dispute as to how much data will need to be retained. The discussion from the International Medical Informatics Association (IMIA) conference in 2003 suggested that some clinical data lose their relevance rapidly, and it may be sufficient to be able to look back several years\(^\text{266}\). This contrasts with the view that it should be possible to recreate any moment in time, for audit, self assessment and handling of complaints\(^\text{267}\). A history would have to be kept for each data item, and deactivation of patient data would not be possible with all the implications for storage of data, audit trails, logistic data and previous versions of software. The draft EHR requirement standard (ISO 18308 cited in\(^\text{268}\)) includes clinical information


\(^\text{253}\) [The UNESCO international declaration about human genetic data ].

\(^\text{254}\) Good practice guidelines for general practice electronic patient records: guidance for GPs (version 3.1).


\(^\text{257}\) Record Keeping: Guidance 2.


\(^\text{262}\) Iacovino. Trustworthy shared electronic health records: recordkeeping requirements and HealthConnect.


\(^\text{264}\) Bakker. Digest of the discussion group sessions. Realising Security of the Electronic Record.

\(^\text{265}\) Bakker. The need to know the history of the use of digital patient data, in particular the EHR.

\(^\text{266}\) Byrne. Data Quality Evaluation for the Summary Care Record
An independent evaluation by University College, London.
context requirement that include preservation of original headings and data values, but does not indicate for how long.

The main current recommendations for paper records in primary care are listed in the table below. However, under the agreement between the Information Commissioner and GPC, no electronic records or audit trials of electronic patient records should be deleted for the foreseeable future.\(^{256}\)

**Figure 5.11.2 – Current recommendations for records in primary care**

<table>
<thead>
<tr>
<th>Type of record</th>
<th>Recommended retention period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper maternity records</td>
<td>25 years</td>
</tr>
<tr>
<td>Paper records relating to children and young people (including paediatric, vaccination and community child health records)</td>
<td>Until the patient’s 25th birthday, or 26th if an entry was made when the young person was 17; or 10 years after death of a patient, if sooner</td>
</tr>
<tr>
<td>Paper records relating to persons receiving treatment for a mental disorder within the meaning of the Mental Health Act 1983</td>
<td>20 years after no further treatment is considered necessary, or 10 years after patient’s death if sooner</td>
</tr>
<tr>
<td>Paper records relating to those serving HM Armed Forces</td>
<td>Not to be destroyed</td>
</tr>
<tr>
<td>Paper records relating to those serving a prison sentence</td>
<td>Not to be destroyed</td>
</tr>
<tr>
<td>All other paper personal health records</td>
<td>10 years after conclusion of treatment, the patient’s death or after the patient has permanently left the country</td>
</tr>
<tr>
<td>All electronic records and audit trails of access to these records</td>
<td>Not to be destroyed (RCGP / Information Commissioner advice)</td>
</tr>
</tbody>
</table>

Source: summary of HSC 1998/217: Preservation, Retention and Destruction of GP General Medical Services records relating to patients

5.12 The knowledge and training needs of professionals with respect to shared records

5.12.1 Definition and scope of the topic
This topic concerns the knowledge of the healthcare professionals regarding the use of electronic health records and their training requirements for maintaining quality standards in a shared record. This topic is related to the quality of data in a shared record, reviewed earlier.

5.12.2 Problem scenario
To maintain the quality of data in a shared electronic patient record it is important to ensure that all users of that record have sufficient knowledge and training in the use of the system. Patient data can then be interpreted and used by other healthcare professionals. In a single organisational record, the issues of terminology, coding and data organisation are less complicated than with a multi-organisation record, and training needs can often be met locally.

Various factors influence the ability of a healthcare professional to input, edit and interpret the data in a shared electronic record. These are illustrated in the diagram below.

This review aims to identify and summarise the evidence on healthcare professional knowledge of the use of electronic health records and training requirements for maintaining data quality. Knowledge barriers to the implementation of shared patient records are identified from the literature and recommendations for overcoming these barriers are summarised.

**Figure 5.12.2 - Scenario**

The topic is summarised under the following issues:

- Evidence about the knowledge of health professionals regarding the use of electronic patient records (6.12.3)
- Healthcare professional views on their knowledge and training requirements
- Possible knowledge barriers reducing the use of shared electronic records
- Recommendations to maintain and improve training in the use of shared records

**5.12.3 Evidence about the knowledge of health professionals regarding the use of electronic patient records**

The introduction of a shared electronic patient record requires healthcare professionals to be equipped with knowledge regarding the underlying concepts on which the system is based as well as the basic skills to use the specific technology. The table below summarises the evidence obtained from the literature regarding the knowledge of healthcare professionals about information systems.

<table>
<thead>
<tr>
<th>Description of study</th>
<th>Study findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literature review[^270] on access control and barriers in integration of electronic health record, 2007</td>
<td>Lack of proficiency in IT and extra time required in acquiring skills among healthcare professionals.</td>
</tr>
<tr>
<td>Data quality evaluation of the Summary Care Records in England[^270]</td>
<td>Varying degrees of competence and IT skills&lt;br&gt;Need for developing awareness in</td>
</tr>
<tr>
<td>Year</td>
<td>Study Title</td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
</tr>
<tr>
<td>2003</td>
<td>Qualitative study of key stakeholders in improving GP computer systems in UK</td>
</tr>
<tr>
<td>2005</td>
<td>Survey of UK GPs on safety features of computer clinical systems</td>
</tr>
<tr>
<td>2003</td>
<td>Survey of GPs in England on computer alerts</td>
</tr>
<tr>
<td>2004</td>
<td>Qualitative study regarding sharing of patient data</td>
</tr>
<tr>
<td>2007</td>
<td>Evaluation of the Summary Care Records in England</td>
</tr>
<tr>
<td>2005</td>
<td>Quantitative study of surgical trainees regarding data confidentiality practices</td>
</tr>
<tr>
<td>2002</td>
<td>UK Department of Health - Surveys by National Strategic Programme</td>
</tr>
<tr>
<td>2006</td>
<td>Survey of UK nurses on NHS IT developments</td>
</tr>
</tbody>
</table>

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272 Avery. Improving general practice computer systems for patient safety: qualitative study of key stakeholders.
274 Avery A, Savelyich, BS, Teasdale, S. Improving the safety features of general practice computer systems. Informatics in Primary Care 2003;11(4):203-206.
275 Stone. Sharing patient data: competing demands of privacy, trust and research in primary care.
276 Greenhalgh, Stramer, Bratan, Emma Byrne, Mohammad, Russell. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory.
279 Results of an online survey by Nursix.com on behalf of the Royal College of Nursing. Nurses and NHS IT developments: Royal College of Nursing, June 2006.
Six studies found a lack of IT skills regarding the use of electronic patient records among healthcare professionals. Surprisingly, some of this included a lack of knowledge about existing systems used in their own practices for some time. This demonstrates the challenge when a new system is introduced to health professionals. Lack of training regarding the use of electronic patient health record was found in four studies. This emphasises the need for proper training programmes for healthcare professionals about the utilisation of NHS information systems. However, for successful implementation of training programmes, the views of the healthcare professionals about such training need to be understood.

5.12.4 Healthcare professional views on their training needs
A systematic review of primary care computing articles published between 1980 to 1997 found that health professionals viewed the then existing training programmes in computer use as being poor. In 2006, a survey of 4,451 nurses working in the UK found that 83% viewed the provision of training for nurses as an important factor to the success of the electronic patient record. However, the survey showed that 57% of them had not received any IT training in the last 6 months. Disappointingly, this figure has risen compared to previous years. Similar surveys in 2004 and 2005 found that 51% and 54% of them had not received any IT training, respectively.

However, the issue goes beyond implementation of training programmes. Evaluation of the Scottish Emergency Care Summary found that, though a facilitator had visited practices after installation of the electronic care summary, health professionals still felt that training was inadequate. It is important to understand the needs of the end users before setting up a training session. This is complicated due to the fact that a variety of health professionals will have access to the shared record. A study on the use of computerised clinical systems in England founds that GPs were concerned about the patient safety features in their information systems. Specific functions were perceived as important training areas by GPs, such as identifying patient referrals, patient recall and searching to identify prescriptions for contraindicated or hazardous drugs.

An example of a successful implementation of this protocol is described in the Summary Care Records evaluation project in England. The healthcare professionals in a particular practice viewed the training to be successful because the trainer was ‘flexible’ and covered all staff using individual personalised sessions. In another study, GPs found that training done following errors identified using audit trials raised awareness of system processes and the contribution of individual roles, rather than just making individual corrections.

5.12.5 Possible barriers to the use of shared electronic records
A lack of knowledge about information technology can clearly be a significant barrier to healthcare professionals’ willingness to use shared electronic health records. This can be addressed by implementing user-specific training programmes. But training sessions, even those implemented according to needs of specific users, can be successful only if there is active involvement and motivation of the participants themselves. It is therefore important for all those implementing health records systems and training health professionals to be aware of the following perceived barriers to the implementation of shared electronic patient records.

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5.12.5.1 Disruption of workflow
A literature review on the use of electronic health records found disruption to workflow as an important barrier in various healthcare professionals including doctors, nurses, pharmacist and IT staff. Lack of relevant education was also seen to hinder the proper use of the record and the extra time taken to learn and use the system was seen as a disruption to workflow and professional performance. Education and a lack of confidence in use of IT systems were also found to be barriers in other studies. However, the actual disruption of workflow caused by EPR differs according to the professional role and situation. A systematic review of studies on the impact of electronic health record on the time taken to complete patient documentation (largely in US inpatient or ambulatory care) found that bedside computers saved nurses 25% of documentation time but increased physician documentation time by from 98% to 330%. The authors explained this difference between nurses and doctors documentation time on the following basis:

- **Information retrieval:** Doctors used systems to view information, perform data entry, and respond to alerts and reminders. These purposes were significantly less prominent in the nurse’s use of the system. Nurses often documented using more standardised forms than doctors.

- **Degree of exposure:** Nurses tend to work in a single location and are therefore exposed to the same system, unlike doctors who tend to work in several locations, inside and outside the hospital. Nurses are also more likely to attend and receive support from training sessions than doctors. However, once familiar with the system, doctors take significant advantages from it.

- **Autonomy and accountability:** These are different for doctors and nurses, which is likely to influence their performance.

Another literature review by the RCGP Health Informatics Group found that implementation of electronic records can have significant effects on the working practices of health professionals and organisations and these can lead to failure of or at least under-utilisation of such systems. This would be particularly important when a shared record is implemented because failure of one or more healthcare professional to use the system optimally could affect the practice as a whole, leading to abandonment of the information system by those who had adopted it. Lack of time is frequently cited as a problem for nurses using computerised information systems, according to a systematic review on nursing record systems. This included lack of time to familiarise themselves with the new system and increased documentation time. However, the review found that time taken to use the system decreased as the nurses became more familiar with the system – and the objective evidence cited in the paragraph above seems to contradict nurses’ views.

5.12.5.2 Data input and interpretation
The need to enter highly structured data proved to be a great challenge to the implementation of electronic records in some Danish hospitals, as the professionals traditionally recorded data as free text. A qualitative study of key stakeholders in the UK

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285 Urquhart, Currell. Reviewing the evidence on nursing record systems.
286 Nohr, Kristensen, Andersen, Vingtoft, Lippert, Berstein, et al. Shared experience in 13 local Danish EPR projects: the Danish EPR Observatory.
found that healthcare professionals had problems regarding the use of ‘free text’. The study added that many GPs used ‘free text’ for clinical terms for which a specific Read code already exists. The Good Practice Guidelines for general practice electronic patient records state that SNOMED CT has been selected as the standard terminology scheme for the National Programme for IT and will eventually replace the current clinical Read codes. This is a much richer clinical vocabulary specifically designed for recording the detail of clinical encounters, so should prove more acceptable to staff and thus enhance the recording and communication of coded clinical information. The challenge will be in providing training for staff who are using the current system.

5.12.5.3 Lack of resources
A systematic review had previously identified the lack of training as a significant barrier to use of computers by GPs. Lack of resources including people, money and time has also been found to be barriers to training practices. This could certainly be a problem in the most deprived areas as the patients have more problems to discuss (particularly psychological) and GP stress was already higher than affluent practices. The same problem was found for other healthcare professionals. A literature review on the role of electronic health records systems in physiotherapy practice revealed that initial implementation required overtime at nights and weekends for staff to receive training.

5.12.5.4 Willingness to use IT
Lack of motivation has also been found to be a barrier in the use of electronic health records by healthcare professionals. Some US physicians believe that the process of data entry is ‘someone else’s job’. Interviews with GPs in the West Midlands in 2002 found that a large proportion of practices hardly used the computers present in their practices. The fact that a computer was involved in accessing patient records was considered in itself ‘unsuitable’ by some. Reluctance to be seen to be struggling with the computer by their peers was found to be a problem in a study involving classroom training for physicians. When responsibility for information systems is given to one healthcare professional in a practice, the delegated person is assigned as the ‘technical’ general practitioner by the others.

5.12.5.5 IT in the Undergraduate curriculum
The 1998 RCGP review found that training on record reading and writing was unsystematic and treated as low priority, and had only recently been introduced into medical and nursing undergraduate teaching.

5.12.5.6 Recommendations
The NHS Code of Practice on records management state that all staff, whether clinical or administrative, must be appropriately trained so that they are fully aware of their personal responsibilities in respect of record keeping and records management. This should be done through both generic and specific training programmes, complemented by organisational policies, procedures and guidance.

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287 Good practice guidelines for general practice electronic patient records: guidance for GPs (version 3.1).
The training provided to the healthcare professionals should develop health professional understanding across the three main dimensions of clinical informatics:\(^\text{287}\):

- **Use of technology** – Basic computer skills, using the clinical system and getting help
- **Data, information and meaning** – The use of coded and free text, understanding how context affects the interpretation of data, information governance and data quality\(^\text{287} \text{ 293}\)
- **Integrating electronic and interpersonal communication of information** – Using electronic records during consultation and decision making

These are now discussed in turn.

**5.12.5.7 Use of technology**
For use of technology, the Good Practice Guidelines for general practice electronic patient records recommend a general training programme such as the Essential IT Skills service (EITS) combined with on-site system-specific training\(^\text{287}\). The guidelines also recommend that the practices appoint an IT lead health professional who can take responsibility for developing knowledge about diagnosis refinement and amendment, clinical code usage, coding various clinical factors such as signs and symptoms and providing general help\(^\text{287} \text{ 294}\). The role of the clinical IT lead also involves production of a strategy for development of the practice clinical information system, developing audits of information system usage and establishing procedures for indirect, direct and non-routine data entry.

The Royal Society, the national academy of science in the UK, recommends that healthcare professional training should integrate the use of ICTs into everyday practice by focussing beyond the basic IT skills to develop their ability to operate in an “information society” by incorporating information technology into mainstream healthcare activities\(^\text{295}\).

The software used for training should be customised, based on the user needs across professions\(^\text{296}\). Other resources such as feedback of training issues to develop FAQs on intranets would benefit users. In the view of the Royal Society group, information and communication technologies have the potential to transform radically the delivery of healthcare, but whether they actually do so will depend on sufficiently accounting for users’ needs and the provision of adequate support and training\(^\text{295}\).

**5.12.5.8 Data, information and meaning**
Analysis of primary research data from the data quality evaluation of the Summary Care Records in England suggests that, though IT skills training have been provided, it is necessary for the health professional to understand the way in which data are represented and processed within clinical systems\(^\text{271}\). This awareness of how data are recorded and interpreted can only come if health professionals understand the wider context in which the data will be used, in this case, in a shared record. A systematic review on electronic patient records and the quality of care found that knowledge of data processing principles was a

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\(^{294}\) Gaunt, Roger-France. Security of the electronic health care record--professional and ethical implications.

\(^{295}\) The impact of information and communication technologies on health and healthcare. Digital healthcare: The Royal Society, December 2006.

factor demining the satisfaction of health professionals in the implementation of electronic health records²⁹⁷.

Data becomes information only when the context of use is known. Healthcare professionals need to understand the consequences of their actions in using shared electronic records. For example, if a health professional records a high body temperature e.g. 38.5°C, it may represent a higher than normal temperature, but this data is not useful without contextual factors such as the part of body in which it was recorded in, the time of day it was recorded, the pattern of the fever, accompaniments of fever, previous medical history, drug intake etc. The professional adding the data to the record should be trained to consider this act as like leaving a message, adding enough content to the message to help the receiver to decode it. This requires education regarding the following:

- Knowledge that the data will always be used by others
- Minimum standards for data quality
- How to interpret data in the record correctly
- Entering data in a ‘self describing’ format for all health professionals

5.12.5.9 Integrating electronic and interpersonal communication of information

When implementing a shared record, there is a need to address the issue of quick and accurate data entry at the point of care, to ensure a smooth workflow²⁷⁴ ²⁹⁵. Training of healthcare professionals and carers in the use of new information systems should be done when or before they are introduced, as well as ongoing support to address any technical difficulties which may arise²⁹⁵. It is also important to make healthcare professionals aware of patient consent, confidentiality and access control rights. These are discussed in earlier.

5.12.10 Recommendations to improve training in the use of shared records

The specific needs of different health professionals need to be addressed. This could be done by developing curricula and competency frameworks across different professional groups²⁹⁵. ‘Hands on’ training and one-on-one coaching programmes enhance user’s capacity for making good use of systems²⁷⁴ ²⁸⁸ ²⁹⁵. Projects such as the Primary Care Information Service (PRIMIS) run by the NHS can provide training and assistance to PCTs and to local health informatics services staff to use their systems and improve data quality²⁹⁵.

The Royal Society recommends that higher education institutions and professional bodies responsible for the different disciplines (such as the medical Royal Colleges) adapt their curricula to integrate the use and understanding of healthcare information systems into basic professional training and the continuing professional development of healthcare professionals²⁹⁵. Local and national health organisations need to ensure that sufficient resources are allocated to provide initial and ongoing training and support for health care professionals.

Training of multi professional staff requires much co-ordination and planning across various disciplines across healthcare²⁹⁰. The training technique used in some Danish hospitals and primary care centres consisted of designating some healthcare professionals as ‘super users’ by providing them with extra training in the use of the electronic record²⁸⁶. These ‘super users’ were trained in two groups. The first group helped end users resolve daily, uncomplicated technical problems, registering errors and networking end users with

²⁹⁷ Delpierre. A systematic review of computer-based patient record systems and quality of care: more randomized clinical trials or a broader approach?
organisms. The second group dealt with more advanced technical challenges. A project implementing Computerised Physician Order Entry in 10 community hospitals in the US appointed ‘super users’ along with physician peers and nurses as important resources to help physicians master their electronic tasks. The training of users in basic skills is generally easy in hospitals, but transforming some into expert users was still a challenge. In the UK, a Data Quality Facilitator is appointed in general practices to identify gaps in knowledge and provide training in data quality improvement. PRIMIS, the national programme involved in the training and quality improvement of GP practices, could adopt policies to ensure that relevant training is provided across all health professionals accessing the shared electronic record.

The Central Hampshire Electronic Health Record Demonstrator project piloted by the NHS Information Authority found that at least two cycles of abstracting data, analysis, feedback and education of the staff were required before data of usable quality was obtained. However, the times of the training phases vary according to the professions. A literature review of the role of electronic health records in physical therapy practice revealed that after the four-month training phase, ongoing training was still required.

The areas of training which healthcare professionals find useful vary according to profession; so individual training needs to be tailored to those needs. For example, data entry by midwives is very structured and the use of templates or protocols can dramatically facilitate this. The aspects that GPs consider important when learning to use electronic health records are: support for recording data accurately, using reminders effectively and safe and effective use of computer systems. They should also be trained in security measures and about other possible users of the shared record. Regular visiting health professionals can be given training similar to core practice staff. Evaluation of the Summary Care Records in England revealed that some training sessions had been badly timed or were difficult to apply in practice. Careful consideration and planning of training sessions based on practice and user specific needs is needed. For example, over 70% of the nurses in the UK feel that round the clock technical support is necessary to the successful implementation of the electronic health records. Often, the conflicting priorities of health professionals make them miss training sessions.

The Good Practice Guidelines for general practice electronic patient records state that locums also need to be provided with training and national and local guidelines on the use of the record system and coding, as well as practicalities such as how to log on and log off. The information requirements of other clinical staff attached to the practice should be established by interview and monitored by audit.

5.13 Summary of this chapter

This review aimed to identify studies on shared records and the key topics arising when sharing data between healthcare professionals and to summarise the literature according to topics. We did not find a nationally successful shared electronic patient record, although the Emergency Care Summary in Scotland comes close to this. The European Commission has launched initiatives to build interoperable e-health systems across Europe using cross-border EPRs. However, prior to this, details such as the definition of a shared electronic patient need to be addressed satisfactorily. Our review included studies on a wide range of

287 Wright K. The Development of a Multidisciplinary Clinical Record: Changing culture to meet the needs of the EPR: Weston Area Health NHS Trust, January 2002.
electronic patient records including the Summary Care Records, Emergency Care Summary, Care Record Summary etc. to establish the benefits of and barriers to implementing shared records. Some of the studies reviewed were carried out on shared paper records or on EPR in secondary or tertiary care, as this is where clinical systems are commonly used in a shared environment.

The benefits of sharing patient data using an EPR have been explored in the 33 studies that we reviewed. However, the full benefits of a shared electronic record have not yet been realised in any of the studies reviewed. Experts recommend that the attributes of shared records and their impact that are evaluated need to be broadened to quantify the benefits. These attributes could include the amount of patient data shared, patient opinions etc as well as lives saved or adverse reactions averted.

Improvements in the quality of care and a reduction in medical error appear to be the two main benefits that support the implementation of a shared EPR. However, these potential benefits can be achieved only when there are adequate professional guidelines to ensure safe use of the records and improve data quality. We found that preserving the privacy of patient data was the most important factor determining a patient's acceptance of EPRs. We found studies across different patient age groups showing similar concerns about privacy. The issue of privacy also determines the confidence of healthcare professionals in the system. Strict adherence to relevant laws such as the Data Protection Act and professional regulations are an absolute requirement for this.

The granting of rights to healthcare professionals to view a patient's EPR, or part of the EPR, has been found to vary widely according to staff role. We reviewed studies across the UK, USA, Canada, New Zealand and Ireland and found that patients are in general willing to grant access rights to those healthcare staff directly involved in their treatment e.g. GPs, nurses and emergency medical doctors. However, they do not show the same level of comfort in sharing their data with pharmacists, healthcare managers, receptionists and other more distant users of data. Patient lack of awareness could be a contributing factor, as patients feel the need to be informed regarding the use of their data. The record system needs to control this access on a ‘need to know’ basis and to maintain an audit trial of access, to promote patient and staff confidence.

We reviewed 14 studies on the structure of the EPR, its influence on clinical decisions and the delivery of patient care. From the studies reviewed, it is clear that the structure of the shared EPR needs to be designed to make sense from all end user perspectives. We also found the different interpretation of clinical data between healthcare professionals to be a significant challenge in a shared record environment. Willingness by each health professional to input data which can be interpreted by all other professionals with access to a shared record will require a new commitment and associated training across professions, which needs professional leadership. Medical errors arising from delay in responding to significant data have also been found to be a challenge in a shared record, especially in defining who is the ‘responsible health professional’ in different circumstances. Retention periods for paper and computer patient records in the UK have been addressed in the recent 2009 Department of Health Information policy document. However, with a shared records system thought needs to be given to ensuring that all parts of the record are subject to similar retention times.

The definition of data quality varies in the context of a shared record according to role of each healthcare professional. We found evidence of poor data quality in electronic records maintained by doctors, nurses and physiotherapists. Achieving high quality data depends on the data transfer mechanism, the coding system used, the structure of the record and most importantly the IT and informatics skills and awareness of the users. We found varying levels of IT and informatics skills across UK healthcare staff. Training of staff according to their
needs, establishing technical help lines, promoting informatics awareness and willingness to use EPRs are recommended as methods for improving the use of shared records by healthcare professionals, to maximise their benefits and minimise their risks.

**Appendix 5.1 - Examples of search strings used**

<table>
<thead>
<tr>
<th>Sample search strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Search Strategy 1</strong></td>
</tr>
<tr>
<td>Record$ (ti,ab) OR Electronic record$ (ti,ab) OR Care record$ (ti,ab) OR Electronic health record$ (ti,ab) OR EHR (ti,ab)</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Shared (ti,ab) OR Detailed (ti,ab) OR Summary (ti,ab)</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Primary care (ti,ab) OR Primary care (MeSH, exp) OR General practi* (ti,ab) OR General practice (MeSH, exp)</td>
</tr>
<tr>
<td><strong>Search Strategy 2</strong></td>
</tr>
<tr>
<td>Record$ (ti) OR Electronic record$ (ti) OR Care record$ (ti) OR Electronic health record$ (ti) OR EHR (ti)</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Shared (ti) OR Detailed (ti) OR Summary (ti)</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Primary care (ti) OR Primary care (MeSH, exp) OR General practi* (ti) OR Family practice (MeSH, exp)</td>
</tr>
<tr>
<td><strong>Search Strategy 3</strong></td>
</tr>
<tr>
<td>Shared electronic records OR detailed care records OR summary care records OR care records</td>
</tr>
</tbody>
</table>
## Appendix 5.2 - Abbreviated critical appraisal checklists for shared records guideline project

Date: __________  Paper ID: __________________________________  Reviewer: _____  Verdict: Include / Exclude

<table>
<thead>
<tr>
<th>Study type (source of checklist)</th>
<th>Checklist</th>
</tr>
</thead>
</table>
| **Expert reviews, opinion - Editorials, FAQs etc. (JW)** | 1. Does author seem authoritative?  
  2. Is argument is coherent?  
  3. Relevant evidence cited?  
  4. No obvious competing interest? |
| **Survey (JW)** | 1. Relevant, representative population?  
  2. 70%+ response rate?  
  3. Piloted, validated questionnaire?  
  4. Analysis using multivariate statistics if needed? |
| **Audit (JW)** | 1. Outcome defined with reference to evidence?  
  2. Included all the relevant population?  
  3. Measurements objective and defined? |
| **Qualitative studies (BMJ)** | 1. Was the research question clear and context clearly described?  
  2. Did researcher explain theoretical framework and methods used?  
  3. Was sampling strategy described, ensures generalisability?  
  4. Was method for undertaking the fieldwork and analysis described?  
  5. Was analysis repeated by > one researcher to ensure reliability?  
  6. Did investigator seek observations that contradict or modify the analysis?  
  7. Was sufficient data presented (e.g. quotations, sources)? |
| **Case studies (JW)** | 1. Setting relevant to English primary care?  
  2. Description of results adequate to justify conclusions?  
  3. Hazards of confounding in e.g. before-after study low?  
  4. Evaluator has no obvious competing interest? |
| **Guidelines (COGS 2002)** | 1. Focus, Goal, Users / setting, Target population, Definitions  
  2. Developer, Funding source / sponsor  
  3. Evidence collection, method for synthesizing evidence  
  4. Recommendation grading criteria  
  5. Recommendations and rationale, Algorithm  
  6. Potential benefits and harms  
  7. Patient preferences  
  8. Implementation considerations |
| RCT (Consort) | 1. Appropriate population? |
|              | 2. Prior definition of sample size and outcomes? |
|              | 3. True randomisation, allocation concealment? |
|              | 4. Same measurement process in both groups? |
|              | 5. Meaningful, defined outcome measure, blinded measurement where needed? |
|              | 6. >80% follow up in both groups? |
|              | 7. Lack of confounding? |
|              | 8. Analysis by intention to treat? |
| Health economic studies (Drummond) | 1. Was a well-defined question posed in answerable form? |
|                                      | 2. Comprehensive description of competing alternatives? |
|                                      | 3. Was the effectiveness of the programme or services established? |
|                                      | 4. All relevant costs and consequences for alternatives identified? |
|                                      | 5. Were costs etc. measured accurately in appropriate units? |
|                                      | 6. Were costs etc. valued credibly, adjusted for differential timing? |
|                                      | 7. Was an incremental analysis of costs etc. of alternatives performed? |
|                                      | 8. Was allowance made for uncertainty in the estimates of costs etc.? |
| SRs (AMSTAR)                         | 1. Comprehensive literature search performed? |
|                                      | 2. Duplicate study selection and data extraction? |
|                                      | 3. List of studies and their characteristics provided? |
|                                      | 4. Scientific quality of included studies assessed and used in formulating conclusions? |
|                                      | 5. Were methods used to combine findings appropriate? |
|                                      | 6. Was likelihood of publication bias assessed? |
Chapter 6 - The Clinical Scenarios

6.1 Introduction

The idea of analysing scenarios was not in the original project plan. It arose out of a feeling that another part of the project (the enquiry into models of record sharing that are currently in use in clinical systems) was being conducted in something of a vacuum. There is uncertainty about what is meant by record sharing and thus in defining different types of shared record. We thought that looking at a small number of scenarios in detail would help to clarify matters.

6.2 Method

The sub-group consists of three people, ED, MH and PD. Each member of the sub-group prepared one scenario in the first instance, and that has provided us with more than enough material. Each of the scenarios is based on a real-life story (or stories), names and other details being changed to avoid any chance of identifying the subjects. The author of each produced a working document that outlined the narrative of the scenario and the issues thought to arise from it. The scenarios were then discussed, on phone conferences and by email, by the three members. A draft report was prepared and subsequently revised by the overall group.

6.3 The scenarios

6.3.1 Jill

Jill works in a senior role in a mental health trust. She has Hashimoto’s disease (an autoimmune disease of the thyroid) and is under the care of a consultant endocrinologist at a district general hospital. She also suffers from bipolar disorder and is recovering from a severe manic episode that resulted in her detention under the Mental Health Act. She is now discharged from the remote in-patient unit where she was treated and is now at home under the care of the local mental health trust’s home treatment service, subject to section 117 after care.

There is a complex interaction between her two conditions and the drugs used to treat them. This requires close collaboration between her psychiatrist and endocrinologist. As well as her local psychiatrist Jill has a longstanding relationship with another psychiatrist, who does psychotherapy with her. Jill is also still in touch with the psychiatrist who was responsible for her inpatient care. Finally, she has a supportive GP. Thus there are five medical health professionals, each working in a different organisation, involved in her care. In addition Jill has a supportive network of friends, whom she wishes to involve in her care.

6.3.2 Issues flowing from this scenario

Medication: For her Hashimoto’s disease Jill takes thyroxin, prescribed on repeat by the GP on guidance from the endocrinologist. Jill takes various medications in relation to her mental health problems; these are supplied by the mental health home treatment service. The regimen is adjusted in response to her mental state: these changes can affect thyroid function, which requires changes to her thyroxin dose and also affects her mental state. All prescribers need access to details of current medication and results of thyroid function tests and may wish to propose, and possibly make, changes to drugs/doses prescribed by others.

Psychotherapy record: The psychotherapist maintains a detailed narrative record of psychotherapy sessions. She currently keeps records on paper and is unwilling to record these on computer unless she is confident that they will not be accessible by others. She is
willing to provide summary information which she feels is relevant to others providing mental health care to Jill.

**Staff record:** Jill wants to be confident, as a member of staff who hopes to return to work in the Trust that is providing her treatment that details of her record are not available to colleagues other than those directly involved in her care. She is not concerned about colleagues knowing she suffers from a mental health problem but does not wish them to have access to details.

**Informal support network:** Jill has a network of friends who provide her with support and she wishes to allow them to share information about her care. She would like these details with regard to such sharing to be recorded in her record.

### 6.3.3 Sarah
Sarah is in her thirties. She has two children by her long-term partner. They have relationship problems and cramped housing. This scenario focuses on two consultations with her GP, who now works part-time and who has known Sarah and her family for many years.

In the first consultation Sarah tells the GP that her period is late, she thinks she may be pregnant. She is not in favour of abortion, but does not see how she can cope if she is pregnant. Her partner does not yet know the situation. She tells the GP many details of her social and family situation in this consultation.

In the second consultation, Sarah’s urine sample is tested and pregnancy is confirmed. She remains uncertain of whether or not to seek a termination and there is further long discussion about her situation.

### 6.3.4 Issues arising from this scenario
**What to record:** In the two consultations the GP has heard a lot of contextual information about Sarah’s life. He is aware that Sarah may see another GP when she next attends, so he wants to make some of that information available in the notes. Items of social context, e.g. “… not using contraception, sleeping in separate rooms mostly” are recorded in free text, while items of fact e.g. “Urine pregnancy test positive” are Read coded.

The salience of these entries is restricted to the time when Sarah is considering termination and to the people (in the practice and in the local gynaecology unit) who may be involved in that decision.

Even on an existing clinical system that is not centrally hosted it is clear that either elements of those consultation records, or the whole consultation record, may be read at some future time by people outside of the practice through participation in GP2GP transfer or a Summary Care Record for instance. The Read coded pregnancy test result could be considered to be sensitive:

- Should he have recorded only the medical facts and communicated the social information to colleagues by a different medium?
- Should he have discussed his record entry with Sarah?
- Had the GP been using a record system in which a single record is shared by multiple users should he have made these entries in the same way?
- Should the constraint of concern about who may see the record entries in the future outweigh the need to keep immediate colleagues informed of details that may well be relevant to medical decisions they may shortly have to make?
- Should he have made use of mechanisms such as filters to try to restrict readership of these entries?
• If so is it safe to do so if that action potentially prevents an A+E health professional from knowing that she is pregnant?

Social information in the medical record: Sarah’s scenario, like Jill’s, raises questions about the recording of material that is not strictly medical. The question of how this should be handled is picked up later in the report.

6.3.5. Adam
Adam is a 75-year-old widower. He had a myocardial infarction in 2005: type 2 diabetes was diagnosed during the admission for his heart attack.

Discharge diagnosis “MI and newly diagnosed Diabetes Mellitus” and medication “gliclazide, metformin, atenolol, ramipril and atorvastatin” were reported in a discharge letter, but the expected structured discharge summary did not arrive at the practice. On discharge the patient was referred for follow-up to cardiac rehabilitation, medical clinic for the myocardial infarction and the hospital diabetic clinic for the diabetes.

He did not attend the practice (despite frequent reminders) as he thought he was under the hospital, where he was seen once in 2006 for his annual diabetic review: no details sent to the practice apart from “seen for annual review – blood tests requested and will be sent an appointment in one year’s time: referred to Community Diabetic Specialist Nurse for dietary advice” – with a note that his previous HbA1c – a year before – was high: “please add metformin and increase ramipril.”

In 2007 Adam comes to the GP surgery with cellulitis in the right foot. His blood glucose was 23mmol/l and he is unwell: he is sent to hospital as an emergency. The next thing the practice receives is a request for dressings from the district nurses for his amputation stump wound. He has been discharged on insulin, and the district nurses have been asked to administer it twice a day. Clinical discharge letter follows a week later stating above knee right leg amputation and containing a list of discharge medication items and a note that he has been referred to district nurses.

Adam is now housebound and receiving social care. District nurses visit him twice a day for insulin administration and dressings. He has frequency and urgency, probably due to his prostate, but is no longer mobile enough to avoid accidents. The Community Diabetic Specialist Nurse is visiting him regularly and adjusting the insulin dose. The metformin is not on the hospital discharge drug list, but it is not clear whether it has been discontinued, forgotten or he was thought to have some at home.

It is assumed that he has been referred to the regional limb fitting centre and rehabilitation (no information in the clinical discharge letter), but in the meantime he has a wheelchair on loan and is using his remaining leg to propel himself around his house.

6.3.6 Issues arising from this scenario
This scenario is an example of an older patient who has multiple pathologies and multiple providers of care.

Communication: There are communication problems between different services, and also with the patient. Discharge information from the hospital is arriving at the practice late, if at all. In 2005 communication from the hospital was paper-based, while the practice was ‘paperless’. There is ambiguity about the role of the Community Diabetic Specialist Nurse. Meanwhile Adam was not clear about the follow up care that he required following his discharge from hospital in 2005.
**Medication:** The original discharge medication was entered on his records at the GP surgery as repeat prescriptions and updated from letters received from out-patients. Since he was referred to the Community Diabetic Specialist Nurse (an independent prescriber) he has been started on insulin, which has been added to his repeat prescription list:

- Who is responsible for deciding on and initiating medication, and should the same person be able to stop or change previous medication?
- How are any necessary checks e.g. U&E on change of ACE dosage requested and results followed up?
- How does the prescriber know what has been prescribed by prescribers in different organisations?

**Coding and record structure:** The different parties in this scenario are using different clinical coding systems. The GP is using a version of Read, the hospital services apply codes after the episode is complete, and use ICD10 and OPCS-4. Community staff have in the past used another coding system, and may soon move to CTV3. At present these only interact on paper, for instance the discharge letter in this area is a multi-copy form with boxes for diagnosis, investigations, procedures etc. There is space for the ICD 10 codes to be entered: the forms are hand-written and the information is transferred manually to the GP clinical system and represented in Read codes:

- How will coding be managed in a system of shared records that draws information from different discrete clinical systems, which use different coding systems?

**Semantic frameworks:** Different professional groups have different semantic frameworks. In this scenario the main diagnosis of diabetes mellitus is unambiguous. Even so a wide range of professional groups are involved in Adam’s care and there is the possibility of confusion if all contributors to the record (community nurses, chiropodist, GP, social services) do not use the same term to mean the same thing.

**Patient choice and consent:** At some stage, Adam should have had his options explained so that he could make an informed choice and participate in his own care. Equally, he needs to agree to information being shared between the different organisations involved in his care, and to understand that although the Chiropodist and Community Diabetic Specialist Nurse work in the Community Diabetic Service, this does not necessarily mean that everything he tells the DSN will be known to the chiropodist.

- Who has the responsibility to discuss this with him and how will it be ensured that his wishes are observed?

**6.3.7 Summary of the issues from all scenarios**

In the previous section the issues arising from each scenario are presented in the way that they were conceptualised by the author of that scenario. Themes common to the scenarios do emerge though and these will now be discussed.

**Communication between health professionals:** All three scenarios are primarily concerned with communication between different professionals. The purpose of the communication is varied: in Jill’s case it is to allow health professionals dealing with two conditions to collaborate so that they don’t interfere with each other’s care of the patient. For Sarah the communication is largely to do with social factors pertinent to her decision to proceed with, or seek termination of, an unwanted pregnancy. In Adam’s case the communication is between different health professionals in different organisations, all of whom are involved in the care of his diabetes.
The nub of each scenario is that different professional groups in different organisations are involved in the care of each patient and so need to communicate with each other. The question for this project is how a shared electronic record fits with these communication needs.

Firstly, Adam’s scenario illustrates several failures of communication when paper was the medium used by the acute trust. Each scenario illustrates also different problems related to the use of a shared electronic record. These will be dealt with in turn.

**Semantic frameworks:** Adam’s story illustrates very clearly that different professional groups, and the coding systems used by their different organisational records, use different semantic frameworks. Acts of translation are required when data coded in one system is interpreted and then recorded in another coding system.

**Responsibility:** In Adam’s scenario, prescriptions for medication are initiated in hospital and by the community diabetic specialist nurse. Several of these require monitoring, by blood test, in the future. There are questions over how the new prescription is communicated to the GP practice, the providers of continuing care, and also ambiguity about who is responsible for the future monitoring.

**What to record?** Both Jill’s psychotherapist and Sarah’s GP are concerned about recording social and sensitive information in an environment where the writer of the note has no knowledge of who may read it in the future. Sarah’s GP may have made a less detailed note had he been writing to a more explicitly shared record.

**Accessibility:** Jill raises the related issue of accessibility. She is keen for details of her case to be available to her network of friends, but not to colleagues in the trust who are not involved in her care. Meanwhile Adam would have benefited from more information about his condition and its care. Can access controls be sensitive to these different requirements?

### 6.4 Discussion
The focus on communication between health professionals is striking, and somewhat surprising. The three people who made up the sub-group have all been actively involved in health informatics for many years, and all have well-formed opinions about how systems should work. They come from different backgrounds, and each has a different view of the balance between technical and human factors in informatics. They each worked up one scenario, and given their experience this choice of ‘cases’ must be seen as purposive. In spite of the purposive nature of the choice of scenario and the varying interests of the group, the process led them to focus on the human interactions in the scenarios rather than on the clinical computer systems and technical considerations.

Although they were all aware of the technical issues, they did not flow from the narratives in the scenarios. This could be due to the choice of scenario, it may be a consequence of only looking at a small number of scenarios i.e. they did not achieve saturation in terms of the possible range of material, or it may be a consequence of starting from narratives about real people receiving health care.

### 6.4.1 Scope of the medical record and readership
Sarah’s scenario raises questions about the General Practice record. One of the defining features of the General Practice consultation is the way that it integrates features of ‘illness’ (i.e. patient’s experience and how their life is affected) and ‘disease’ (i.e. pathology, prognosis, investigations and treatment). Inevitably large parts of the consultation are concerned with information that is social rather than medical by nature.
Most of the rhetoric that supports the use of shared health records relates to medical information. The examples used to demonstrate the benefits of SCR, for instance, tend to be either factual diagnoses, “this patient is an epileptic”, or relate to medication “this patient is allergic to penicillin”, “this patient is taking warfarin”. Other clinical groups, for instance in Emergency Care or anaesthetics, understandably demand that all information of this type should be readily available to them and therefore should be shared across the electronic record. Does this mean that the entire GP record, which is in part a social record, should be shared in the same way? Should GPs alter their record keeping so that it only reflects medical aspects of their work?

The Division of Clinical Psychology (part of the British Psychological Society) has recently issued guidance on record keeping. This guidance is clear that, in the case of patients seen within the NHS, all of the psychology record is part of the patient’s record. If that line is taken across the NHS it means that access controls need to be both effective, so that Jill’s colleagues in the Trust cannot peek at her record to satisfy their curiosity, and adaptable so that Jill’s network of friends can be informed.

6.4.2 Coordination of care
In Adam’s case there is ambiguity over the role of the specialist nurse in particular, but there is an apparent lack of coordination among all the many services involved in Adam’s care. Arrangements for recording new prescriptions, issued by the hospital or specialist nurse, in the GP record are dependent on manual transcription in the practice. This is only one of several necessary steps though. There is a need for clarity about who is responsible for follow up and monitoring the medication.

This clarity needs to be present in the way that the records are organised, but also in the way that care is organised. Practice and the record cannot be considered in isolation of each other, there need to be clear ways of working and clear ways of using the records system for communicating with colleagues.

6.4.3 Information and communication
A useful perspective on information and communication is provided by a book about re-thinking biomedical ethics. This book, among much else, offers a critique of the mainstream view of information as objects to be passed along a conduit. The metaphorical component of much discussion about information systems supports this conduit/container view, which is represented in Shannon’s telephony model. There is an older (Middle English) meaning of “inform” that has to do with altering the form (shape) of something. Developing this, the purpose of communication is not just to transfer information from one site to another. Different utterances are made with different expectations. Speech acts that are questions are different from those that give instructions, for instance.

The scenarios suggest that it is not enough for health professionals to inform each other in the sense of “tell” or to pass on information. The Middle English usage is more appropriate. In the shared care and shared record environment each practitioner has a responsibility to inform, or shape, the practice of others involved in the care of the patient. As well as recording a new prescription: expectations about who is responsible for follow up and monitoring need to be communicated too. And this includes the patient as in the case of

300 Newton S. Record Keeping: Guidance on Good Practice. Division of Clinical Psychology, the British Psychological Society. Leicester. 2008
Adam, whose behaviour in seeking follow up should have been shaped by his carers. Using this sense of the word “inform” means that the prescriber has not only the duty to record new prescriptions so that others, for example the GP, know what has happened, but also the responsibility to coordinate with others the care requirements that flow from that prescription.

6.5 Conclusion

This chapter, driven by what emerged from the individual scenarios, has focussed on clinical communication somewhat to the expense of consideration of the records themselves and their underlying structures and coding systems.

All of these aspects are necessary for the successful and safe use of shared records, and they can be drawn together under the concept, mentioned above, of the responsibility to inform (shape) the practice of colleagues. This requires an understanding of each other’s roles and ways of working, and a means of communication that accommodates the different semantic frameworks of different professional groups. System architectures and clinical coding systems are as important in this as human behaviours, and all must fit in with considerations of governance as described in chapter four.

In the complex scenarios that were discussed the act of entering the information onto the system is not enough. Initiating a prescription has consequences for future care, in terms of monitoring effects and interaction with other conditions. There needs to be communication about how these consequences will be met to accompany the message “I prescribed x today”. The information systems, human and machine, need to be set up so that this richer communication about expectations can occur.

One view of the electronic record is caricatured by the epithet “data bucket”. The detailed (care) record is seen as a repository, or journal, of what has happened to the individual. While this kind of archive has some uses, its contribution to present care of the individual is limited. If different professionals are collaborating in the care of one patient, they need to know not just what each has done, but with what purpose in mind and how the other professional’s action impinges on their own practice. The other side of this is that each has a responsibility to inform the other (in the Middle English sense of “inform”). It would be as well to include the patient in this richer communication too.

6.6 Key points from this chapter

1. Consideration of scenarios based on individual cases with multiple carers has led to a focus on inter-professional communication.
2. Information transfer on its own is not the same as communication, which is much richer. Acts of communication carry expectations and take account of context and the semantic frameworks of others.
3. Accurate recording of data is not sufficient to support shared care of a patient. There is a responsibility on every health professional to inform the practice of other professionals who may be involved, and to inform the patient too.
4. Both practice, i.e. ways of working, and information systems need to be organised in parallel to facilitate effective shared care.
5. In the complex shared care described in these scenarios contemporary communication between the professionals involved is more pertinent to patient care than historical archives of information.
6. The primary care record, like the psychological record, contains items that are social rather than medical. Their inclusion in a shared health record requires consideration.
Chapter 7 – The stakeholder survey

7.1 Introduction

Key stakeholders in the primary care domain were identified with the help of the RCGP, NHS CFH and the project steering group. Stakeholder organisations contacted by the project are categorised and listed in chapter 3.4. It was decided to approach a range of organisations representative of the main groups of primary health care professional groups and individual primary care health professionals from the various groups who had knowledge and experience of working with shared electronic patient record systems.

The main aim of the second phase of the stakeholder consultation process was to develop a set of professionally endorsed principles that would help define the clinical and information governance requirements for shared DCRs. The aim was to build a consensus around the principles where there are high levels of agreement between the different stakeholder organisations that would inform the guidelines development process.

7.2 Method

The principles were developed from relevant guidance material produced by stakeholder professional regulatory bodies and representative organisations and presented back to the various stakeholder groups and individuals in survey format. The stakeholder survey included a description of the project aims and the stakeholder engagement process together with a set of 28 questions formulated as principles about shared electronic patient records. Respondents were asked to mark their agreement, or disagreement, with each principle statement on a five-point Likert scale from strongly disagree to strongly agree, followed by a space for comments. The survey concluded with a general question on shared electronic patient records and a further space for comments (see appendix A1 and example below).

Figure 7.2 - Example statement from the stakeholder survey

<table>
<thead>
<tr>
<th></th>
<th>-2</th>
<th>-1</th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly agree</td>
<td></td>
</tr>
</tbody>
</table>

25. Comments

The survey was successfully piloted at the Airedale GP VTS following a focus group session with the GP registrars and course organisers.

Surveys were sent by email or post to key contacts identified in the first part of the stakeholder engagement process who were asked to respond within 30 days. Non-respondents were contacted several times (email and telephone) by the project leader and a member of the project steering group representing the non-responding professional group (e.g. nurse, AHP or GP) to ensure a high response rate.

The stakeholder organisations are a heterogenous group who employed a variety of methods of responding to the survey. Some stakeholders nominated a key individual or small group to respond on their behalf while others conducted more formal surveys of their members. In view of these factors it was decided to use simple statistical methods to analyse and present the survey responses to the quantitative arm of the survey and perform
a thematic analysis on the comments after each question and at the end of the survey that represent the qualitative arm of the survey. The comments from the responders were analysed by using the thematic framework approach to identify the themes within the data. This involved the following steps:

- **Extraction of the data:** The data was extracted from the questionnaire to the word document. The comments were arranged according to the principles.
- **Familiarisation:** This involved focusing on raw data by reading and re-reading of the comments for each of the principles to get familiar with the content of the data and identify the similarity and differences between the comments.
- **Generation of the themes/codes:** The data was coded into the broad themes and the individual statement with the same theme was moved together.
- **Splitting the themes/aggregating the themes:** Each broad theme was analysed in more details. Where it was necessary the codes where split into “explicit consent” and “implied consent”) or aggregate as a one code (e.g. “role based sharing” and “relevant information sharing” was aggregated as “role based/relevant information sharing”).
- **Interpretation of the data:** This was undertaken by the project leader.

The survey analysis was performed under the direction of Dr Bob Milne at the University of Aberdeen.

### 7.3 Results

A total of 43 individuals representing the range of stakeholders described earlier (Chapter 2.4) were contacted to participate in the survey. Of these, 40 (93%) responses were received in time to be included in this report. The responding organisations by category are shown in the figure below. The non-responding organisations were; the Community and District Nursing Association, the GPASS National User Group and the Ascribe National User Group.

#### Figure 7.3a - Responding organisation by category

<table>
<thead>
<tr>
<th>Category</th>
<th>Respondents</th>
</tr>
</thead>
</table>
| AHPs (5 respondents) | College of Occupational Therapists  
 Chartered Society of Physiotherapists  
 British Dietetic Association  
 Society of Chiropodists and Podiatrists  
 Royal College of Speech and Language Therapy |
| Doctors (5 respondents) | Royal College of Physicians  
 (Informatics Group)  
 JGPITC of GPC and RCGP  
 RCGP Health Informatics Group  
 RCGP Ethics (Chair)  
 British Medical Association |
| Medical Indemnity Organisations (3 respondents) | The Medical Defence Union  
 The Medical Protection Society  
 The Medical and Dental Defence Union of Scotland |
| Multiprofessional (1 respondent) | Primary Health Care Specialist Group (of BCS) |
| Nurses/NMAHP (11 respondents) | Royal College of Nursing  
 Royal College of Midwives  
 Community Practitioners and Health Visitors Association |
Table 7.3b below shows the number of responses to each principle statement in the survey and a numeric rank calculated from the sum of the scores (range -2 to +2) in the Likert scale. Out of 40 responses, the maximum possible score on the Likert scale would be +80. The scores for principles one, two and three were 78, 77 and 68 respectively, indicating very high levels of agreement across all respondents for these principles. Negative scores indicated disagreement with the principle (principles 10 and 14). Table 7.3c presents the principle statements in rank order calculated from the sum of the Likert scores with the percentage levels of agreement also calculated for each principle (agree + strongly agree / total responses).

**Figure 7.3b Results in survey order**

<table>
<thead>
<tr>
<th>No.</th>
<th>Principle</th>
<th>Responses</th>
<th>Score</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The need to keep proper records is a professional requirement and records must be protected from being lost, damaged or accessed by someone without appropriate authority.</td>
<td>40 (100%)</td>
<td>78</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Patients have a right to expect that health professionals will hold information about them in confidence.</td>
<td>40 (100%)</td>
<td>77</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Appropriate information sharing is essential to the efficient provision of safe, effective care, both for the individual patient and to the wider population of patients.</td>
<td>40 (100%)</td>
<td>68</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Health professionals should make information available to patients about disclosures of their personal health data for purposes of their own care.</td>
<td>40 (100%)</td>
<td>54</td>
<td>11=</td>
</tr>
<tr>
<td>5</td>
<td>In the absence of any objection, patients' consent to information being shared in this way may be implied.</td>
<td>36 (90%)</td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>6</td>
<td>If it should be made clear to patients that others who support the provision of care might also need access to their personal information.</td>
<td>39 (97.5%)</td>
<td>59</td>
<td>8=</td>
</tr>
<tr>
<td>7</td>
<td>Patients may not be aware of disclosures to others for purposes such as health service planning or research and must be informed about disclosures for purposes they would not reasonably expect.</td>
<td>38 (95%)</td>
<td>47</td>
<td>15=</td>
</tr>
<tr>
<td>8</td>
<td>Health professionals must obtain patients’ explicit consent to disclosure of identifiable information for purposes other than the provision of care, unless the disclosure is required by law or justified in the public interest.</td>
<td>39 (97.5%)</td>
<td>67</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>Patients may give implied consent to disclosure of personal information shared within the local Detailed Care Record (DCR).</td>
<td>37 (92.5%)</td>
<td>14</td>
<td>26</td>
</tr>
<tr>
<td>10</td>
<td>Patients may give implied consent to disclosure of personal information shared within the shared Detailed Care Record (sDCR).</td>
<td>39 (97.5%)</td>
<td>-13</td>
<td>27</td>
</tr>
<tr>
<td>11</td>
<td>Health professionals should explain to patients that their shared Detailed Care Record will be shared with the care team, including administrative and other staff that support the provision of care, unless they object.</td>
<td>39 (97.5%)</td>
<td>55</td>
<td>10</td>
</tr>
<tr>
<td>12</td>
<td>Health professionals must respect the wishes of any patient who objects to particular information being shared with others providing care, through the shared Detailed Care Record, except where disclosure is in the public interest.</td>
<td>39 (97.5%)</td>
<td>59</td>
<td>8=</td>
</tr>
<tr>
<td>13</td>
<td>Patient consent should be sought for the creation of a shared Detailed Care Record about them.</td>
<td>39 (97.5%)</td>
<td>35</td>
<td>20</td>
</tr>
<tr>
<td>14</td>
<td>Patients do not have the right to limit the amount of information relevant to</td>
<td>39 (97.5%)</td>
<td>-27</td>
<td>28</td>
</tr>
<tr>
<td>Rank</td>
<td>Principle</td>
<td>Survey order</td>
<td>Score</td>
<td>% agree</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------</td>
<td>-------</td>
<td>---------</td>
</tr>
<tr>
<td>1</td>
<td>The need to keep proper records is a professional requirement and records must be protected from being lost, damaged or accessed by someone without appropriate authority.</td>
<td>1</td>
<td>78</td>
<td>100%</td>
</tr>
<tr>
<td>2</td>
<td>Patients have a right to expect that health professionals will hold information about them in confidence.</td>
<td>2</td>
<td>77</td>
<td>100%</td>
</tr>
<tr>
<td>3</td>
<td>Appropriate information sharing is essential to the efficient provision of safe, effective care, both for the individual patient and to the wider population of patients.</td>
<td>3</td>
<td>68</td>
<td>100%</td>
</tr>
<tr>
<td>4</td>
<td>Health professionals must obtain patients’ explicit consent to disclosure of identifiable information for purposes other than the provision of care, unless the disclosure is required by law or justified in the public interest.</td>
<td>8</td>
<td>67</td>
<td>95%</td>
</tr>
<tr>
<td>5</td>
<td>Refusal to have a Summary Care Record or a shared Detailed Care Record must not affect a patient’s right to treatment.</td>
<td>26</td>
<td>66</td>
<td>97%</td>
</tr>
<tr>
<td>6</td>
<td>Access by health professionals to shared Detailed Care Records should be very strictly controlled on a “need to know” basis. This means that some people can have access to the full record, others to the part that is relevant to them.</td>
<td>16</td>
<td>64</td>
<td>92%</td>
</tr>
<tr>
<td>7</td>
<td>Each healthcare organisation/team should have a nominated guardian responsible for the integrity and accuracy of that organisation’s Detailed Care Records.</td>
<td>20</td>
<td>60</td>
<td>87.5%</td>
</tr>
<tr>
<td>8=</td>
<td>It should be made clear to patients that others who support the provision of care might also need access to their personal information.</td>
<td>6</td>
<td>59</td>
<td>95%</td>
</tr>
<tr>
<td>8=</td>
<td>Health professionals must respect the wishes of any patient who objects to particular information being shared with others providing care, through the shared Detailed Care Record, except where disclosure is in the public interest.</td>
<td>12</td>
<td>59</td>
<td>95%</td>
</tr>
<tr>
<td>10</td>
<td>Health professionals should explain to patients that their shared Detailed Care Record will be shared with the care team, including administrative and other people.</td>
<td>11</td>
<td>55</td>
<td>90%</td>
</tr>
</tbody>
</table>

**Figure 7.3c Results in rank order and level of agreement**
staff that support the provision of care, unless they object.

Health professionals should make information available to patients about disclosures of their personal health data for purposes of their own care. 4 54 87.5%

The information shared should only be that required for appropriate care to be given or continued. 18 54 87%

Each healthcare organisation/team should maintain and be responsible for its own organisational care record (Detailed Care Record) 19 52 87%

However, patients can limit access to certain information about themselves within their shared Detailed Care Record and health professionals must respect their right to do so. 15 51 85%

Patients may not be aware of disclosures to others for purposes such as health service planning or research and must be informed about disclosures for purposes they would not reasonably expect. 7 47 84%

Shared Detailed Care Records should also have a nominated guardian and it must be clear who has the responsibility to maintain and act on the contents of any shared DCR. 22 47 84%

Each healthcare organisation/team should maintain and be responsible for its own organisational care record (Detailed Care Record). 23 36 72%

Patients must be informed that refusal to have a shared Detailed Care Record may be detrimental to their treatment and care. 28 41 87%

The “consent to view model” agreed for the Summary Care Records should be applied to shared Detailed Care Records. 27 36 86%

Refusal to have a shared Detailed Care Record should be recorded as “explicit dissent” in the organisational/team Detailed Care Record and on the “Spine”. 21 31 64%

Patient consent should be sought for the creation of a shared Detailed Care Record about them. 13 35 67%

Healthcare organisations must retain the right to edit, update and amend any information added to their Detailed Care Records from other sources. 25 30 62%

“Consent to view” permission for accessing a shared Detailed Care Record should be time-limited. 24 29 68%

Patients agreeing to “consent to view” for their shared Detailed Care Records should be able to control what health data is shared and with whom it is shared. 17 26 71%

Information from the shared Detailed Care Record may be shared with other healthcare workers when it is for the benefit of the patient and after informing the patient. 18 16 56%

In the absence of any objection, patients’ consent to information being shared in this way may be implied. 9 14 57%

Patients may give implied consent to disclosure of personal information shared within the local Detailed Care Record (DCR). 10 -13 30%

Patients may give implied consent to disclosure of personal information shared within the shared Detailed Care Record (sDCR). 14 -27 21%

7.4 Detailed analysis of responses

A more detailed analysis of responses in score-ranked order of agreement is shown below with histograms to show the spread of responses, broken down by organisational type where that is helpful or differences between group responses are apparent. The percentage of responses in agreement with each statement is also shown (agree + strongly agree as % of all responses).

Information from the qualitative thematic analysis is summarised and provided where it is helpful and indicative of the range of responses. Where there is a wide spread of responses (e.g. principle statements 21 and 25) more detail is given. These responses are displayed in the format:

• **Theme** – “quote” (responding group/organisation).
7.4.1 Principle 1 analysis of responses

Rank = 1
The need to keep proper records is a professional requirement and records must be protected from being lost, damaged or accessed by someone without appropriate authority.

<table>
<thead>
<tr>
<th>Count</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>38</td>
</tr>
</tbody>
</table>

7.4.1 There were 40 responses (100%) to this question with very high levels of agreement to the principle statement. All responses were in the strongly agree or agree range, 40/40 (100%).

The qualitative analysis for principle 1 included responses under the following themes:
- **Difficult to protect** – “Protecting the record is difficult for the community staff who moves from base to base” (nursing organisation).
- **Not clear** – “define ‘appropriate authority’” (Scottish NMAHP group)

---

7.4.2 Principle 2 analysis of responses

Rank = 2
Patients have a right to expect that health professionals will hold information about them in confidence.

<table>
<thead>
<tr>
<th>Count</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>37</td>
</tr>
</tbody>
</table>

7.4.2. There were 40 responses (100%) to this question with very high levels of agreement to the principle statement. All responses were in the strongly agree or agree range, 40/40 (100%).

The qualitative analysis for principle 2 included responses under the following themes:
- **Limits to confidentiality** – “Patients and health professional should be clear about limit of the confidentiality and why they exist” (AHP group)
- **Confidentiality should not be replacement for consent** – “Assurance that data will be kept confidential does not override the need for consent of sharing” (medical group)

---
7.4.3 - Principle 3 analysis of responses

**Rank = 3**

Appropriate information sharing is essential to the efficient provision of safe, effective care, both for the individual patient and to the wider population of patients.

7.4.3. There were 40 responses (100%) to this question with very high levels of agreement to the principle statement. All responses (100%) were in the strongly agree or agree range across the full range of stakeholder groups.

The qualitative analysis for principle 3 included responses under the following themes:

- **Agreement on meaning of “appropriate” and “sharing”** – “Need agreement on meaning of ‘appropriate’ sharing and terminology used for sharing (AHP, nursing and patient groups).

---

7.4.4 - Principle 8 analysis of responses

**Rank = 4**

Health professionals must obtain patients’ explicit consent to disclosure of identifiable information for purposes other than the provision of care, unless the disclosure is required by law or justified in the public interest.

7.4.4. There were 39 responses (97.5%) to this question with very high levels of agreement to the principle statement. All but 2 responses were in the strongly agree or agree range across the full range of stakeholder responses. 37/39 (95%) of responders agreed with this statement. One GP system supplier NUG respondent strongly disagreed with the statement.

The qualitative analysis for principle 8 included responses under the following themes:

- **Consent** – “Data is identifiable then consent should be gained and recorded in the client record” (patient group). “Explanation and obtaining consent is the responsibility of the party requesting the information” (medical defence organisation).
- **Inform patient** – “Patient must know to whom it goes and context of it” (medical defence organisation)

---
7.4.5 - Principle 26 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Refusal to have a Summary Care Record or a shared Detailed Care Record must not affect a patient’s right to treatment.</td>
</tr>
</tbody>
</table>

7.4.5. There were 39 responses (97.5%) to this question with very high levels of agreement to the principle statement. All but 1 response was in the strongly agree or agree range across the full range of stakeholder responses (97%).

---

7.4.6 - Principle 16 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Access by health professionals to shared Detailed Care Records should be very strictly controlled on a &quot;need to know&quot; basis. This means that some people can have access to the full record, others to the part that is relevant to them.</td>
</tr>
</tbody>
</table>

7.4.6. There were 39 responses (97.5%) to this question with very high levels of agreement to the principle statement. Overall 36/39 (92%) of responders agreed with this statement. One GP system supplier NUG respondent disagreed with the statement.

The qualitative analysis for principle 16 included responses under the following themes:

- **Define what is relevant** – “The challenge is what they need to know and who decides” (Scottish NMAHP, AHP, patient groups, medical defence organisation and GP system supplier NUG)
- **Practical difficulties** – “Quite difficult to deliver in practice; can this be achieved through the structure of the records or will one person need to allocate access right?” (professional regulatory body. “But this is complex territory and needs to be carefully tested out” (medical group)
- **Miscellaneous** – “Communication is key to ensure that patients understand what will be seen and by who” (medical group). “Ensuring that confidential information is only accessed on a need to know basis is consistent with ethical guidance” (medical defence organisation).
7.4.7 - Principle 20 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Principle 20</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Each healthcare organisation/team should have a nominated guardian responsible for the integrity and accuracy of that organisation’s Detailed Care Records.</td>
<td>26</td>
</tr>
</tbody>
</table>

7.4.7. There were 40 responses (100%) to this question with very high levels of agreement to the principle statement. The overall level of agreement with the statement was 35/40 (87.5%). One Scottish mental-health nursing respondent disagreed with the statement.

The qualitative analysis for principle 20 included responses under the following themes:

- **Practicality** – “Very hard to see how it would work. How would you know that record is accurate and integral?” (GP system supplier NUG)
- **Caldicott Guardian** – “Is that not the role of the Caldicott guardian?” (nursing group)

---

7.4.8 - Principle 6 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Principle 6</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>It should be made clear to patients that others who support the provision of care might also need access to their personal information</td>
<td>24</td>
</tr>
</tbody>
</table>

7.4.8. There were 39 responses (97.5%) to this question with overall 37/39 (95%) in agreement with the principle statement. One patient organisation respondent strongly disagreed with the statement.

The qualitative analysis for principle 6 included responses under the following themes:

- **Inform patients** – “Patients need to know that other agencies (social services, care agencies) may need information and will also ask for consent” (AHP group). “Patient should be informed when information has been shared” (Scottish NMAHP group).
- **Miscellaneous** – “Who will be responsible for this, when and how” (nursing group). “Only with express consent” (medical defence organisation).

---
7.4.9 - Principle 12 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Health professionals must respect the wishes of any patient who objects to particular information being shared with others providing care, through the shared Detailed Care Record, except where disclosure is in the public interest.</th>
</tr>
</thead>
</table>

7.4.9. There were 39 respondents (97.5%) to this question with overall 37/39 (95%) in agreement with the principle statement. One nursing organisation respondent strongly disagreed with the statement.

---

7.4.10 - Principle 11 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Health professionals should explain to patients that their shared Detailed Care Record will be shared with the care team, including administrative and other staff that support the provision of care, unless they object.</th>
</tr>
</thead>
</table>

7.4.10. There were 39 respondents (97.5%) to this question with overall 35/39 (90%) in agreement with the principle statement. One GP system supplier NUG respondent strongly disagreed with the statement.

The qualitative analysis for principle 11 included responses under the following themes:

- **It is important** – “It is important that patients understand that their record may be viewed by a health care team not just an individual health professional. A consent to view model will ensure that patients understand each time they consent who will have access” (GP system supplier NUG)
- **Health professional/ organisation responsibility** – “Someone should provide patients with this information. Whether the health professional is best place to provide it is debatable, as they may be ill placed to know just who in the organisation might access or reasonably require access to the record. This would seem to be an organisational responsibility” (medical defence organisation).
- **Role based /relevant information sharing** – “The explanation by healthcare staff should clarify that staff access to the DCR depends on their role e.g. admin staff do not access detailed clinical information” (AHP group). “Staff should only have access to the info which allows them to carry out their role” (Scottish NMAHP group).
- **Miscellaneous** – “Health professionals know who the members of the care team are patients may not and they should be told” (Patient Group). “A consent to view model will ensure that patients understand each time they give their consent who will have access” (medical group).
7.4.11 - Principle 4 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Health professionals should make information available to patients about disclosures of their personal health data for purposes of their own care.</th>
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7.4.11. There were 40 respondents (100%) to this question with overall 35/40 (87.5%) agreement with the principle statement. One GP system supplier NUG respondent disagreed with the statement.

The qualitative analysis for principle four included responses under the following themes:

- **Health professionals unaware of audit trail** – “Health professionals do not have easy access to an audit trail of who has accessed the information once it has left the organisation” (GP system supplier NUG).
- **Miscellaneous** - “practically very difficult to achieve” (medical defence organisation).

7.4.12 - Principle 18 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>The information shared should only be that required for appropriate care to be given or continued.</th>
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7.4.12. There were 39 respondents (97.5%) to this question with overall 34/49 (87%) agreement with the principle statement. Two nursing organisation respondents disagreed with the statement. All other nursing organisation responses either agreed or strongly agreed with the statement.

The qualitative analysis for principle 18 included responses under the following themes:

- **Concerns about child** – “There are number of other reasons why information may need to be shared, including ‘as part of early intervention and prevention services; where there are concerns about significant harm to a child or young person’” (nursing group). “On the surface this seems a reasonable statement but there have been many instances where it has been demonstrated that more information sharing would have been beneficial particularly in child protection” (nursing group).
- **Miscellaneous** – “Again care needs change and can be or become complex. The principle is sound but needs to be underpinned by a flexible system in which the patient is fully engaged” (Scottish NMAHP).
7.4.13. There were 39 respondents (97.5%) to this question with overall 34/39 (87%) agreement with the principle statement. One patient organisation strongly disagreed with the statement and respondents from one Scottish NMAHP organisation and one GP system supplier NUG disagreed with the statement. The other patient organisation respondents agreed or strongly agreed with the principle statement.

The qualitative analysis for principle 19 included responses under the following themes:

- **Difficulties** – “It can be difficult for some community staff e.g. community midwives, who may work across a number of organisations” (nursing group). “Defining boundaries is difficult, are district nurses separate to the primary care team? If this happens then we have multiple silos of partial information, so we do need to develop a mechanism for sharing across some boundaries but not necessarily all” (GP system supplier NUG). “However, others who provide services and input to that record, and who may be employed by another organisation, must be able to access the data to support clinical care, audit and service managements along with contract monitoring” (AHP group).

- **Miscellaneous** – “The principle here is that there is an accountable data controller within an organisation, which is consistent with the provisions of the Data Protection Act. However, the quality of data processing and the protection of confidentiality as well as the provision of high quality care to patients will depend on proper procedures being adopted and followed by all individuals who contribute to the care record” (medical defence organisation). “Only those people will be fully committed to the record (in partnership with patients)” (medical group).

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7.4.14. There were 39 respondents (97.5%) to this question with overall 33/39 (85%) agreement with the principle statement. One Scottish NMAHP respondent disagreed with the statement.
The qualitative analysis for principle 15 included responses under the following themes:

• **Patient need to understand the consequence of this** – “Agree but patients need to understand consequences of limiting information and this needs to be properly recorded” (nursing group, medical defence organisation and GP system supplier NUG)

• **Health professionals can override** – “It needs to be clear to patients what this right may be overridden for example when in public interest etc” (nursing and medical group)

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**7.4.15 - Principle 22 analysis of responses**

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<th>Rank = 15 (equal)</th>
<th>Shared Detailed Care Records should also have a nominated guardian and it must be clear who has the responsibility to maintain and act on the contents of any shared DCR.</th>
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7.4.15 There were 37 (92.5%) responses to this question with overall 31/37 (84%) agreement with the principle statement. One Scottish mental health NMAHP respondent and one medical defence organisation disagreed with the statement.

The qualitative analysis for principle 22 included responses under the following themes:

• **Practical difficulties** – “The practical implementation of guardian across organisations using shared record is likely to be challenging. The project should consider lessons from the implementation of information sharing protocols in children services” (nursing group). “The sDCR should be the responsibility of the GP who has ongoing responsibility for the care of the patient” (AHP group).

• **Unclear** – “It is BMA policy that detailed electronic patient records should have one identifiable guardian. The role of the guardian would need to be explored in detail as it will be dependent on the nature of the shared record” (medical group)

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**7.4.16 - Principle 7 analysis of responses**

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<thead>
<tr>
<th>Rank = 15 (equal)</th>
<th>Patients may not be aware of disclosures to others for purposes such as health service planning or research and must be informed about disclosures for purposes they would not reasonably expect.</th>
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7.4.16 There were 38 (95%) responses to this question with overall 32/38 (84%) agreement with the principle statement. Two Scottish NMAHP respondents disagreed with the
statement. One patient organisation and one GP system supplier NUG strongly disagreed with the statement. The other three patient organisations agreed or strongly agreed with the principle statement.

The qualitative analysis for principle seven recorded responses under the following themes:

- **Anonymous data** – “Anonymous aggregated data only” (AHP and Scottish NMAHP groups)
- **Identifiable data** – “If identifiable data / pseudo anonymous / linked anonymous data - required individual consent” (GP system supplier NUG, medical group, patient group).
- **Lack of patient awareness** – “Patients need to be aware of cancer registry, confidential enquiries and epidemiological monitoring as well as clinical research” (nursing group).
- **Difficult** – “As users (doctors / nurses) recording the information may not know this secondary uses of the information” (nursing group)
- **Miscellaneous** – “This information can be conveyed in written material (e.g. leaflets)” (medical defence organisation). “Patient must be informed in time to object” (patient group).

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**7.4.17 - Principle 28 analysis of responses**

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<tr>
<th>Rank</th>
<th>Patients must be informed that refusal to have a shared Detailed Care Record may be detrimental to their treatment and care.</th>
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7.4.17. There were 39 (97.5%) responses to this question with overall 34/39 (87%) agreement with the principle statement. Three respondents from the Scottish MNAHP group and one GP system supplier NUG disagreed with the statement.

The qualitative analysis for principle 28 recorded responses under the following themes:

- **Inform patients** – “It should be explained that they can change their mind” (nursing group). “Patients need to understand that withholding information could affect their care however the benefits of a shared DCR need further exploration” (medical group). “Assume this is a part of discussion about consent in the first place” (patient group).
- **Not like word ‘detrimental’** – “Do not like ‘detrimental’ the benefits of having the record should be further explained and the potential difficulties that not being allowed to share key information can and have meant, to professionals. If no record of care is in place the carers need to work harder. ‘Detrimental’ suggested something almost wilfully negative and punitive” (Scottish NMAHP group).
- **Mention risk to the patients** – “There are risks in sharing records which are never mentioned, other than the confidentiality issue. The risk is that errors of diagnosis are perpetuated or that new conditions missed.” (GP system supplier NUG). “At this stage the benefits and potential risks of a shared detailed care record are not clear and therefore there is no evidence to suggest that failure to have a shared DCR may be detrimental. Information can continue to be shared directly between health professionals as at present” (GP system supplier NUG).
• **Miscellaneous** – “Without such information any refusal of consent would be open to challenge” (medical defence organisation). “Patient decision may slow down communication and decision making but not affect their right to treatment/care” (AHP group). “If there is evidence for this or it believed to be true then patients must be informed” (professional regulatory body).

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### 7.4.18 - Principle 23 analysis of responses

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<tr>
<th>Rank = 18 (equal)</th>
<th>The &quot;consent to view model&quot; agreed for the Summary Care Records should be applied to shared Detailed Care Records.</th>
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![Principle 23 Analysis](chart.png)

7.4.18. There were 36 (90%) responses to this question with overall 26/36 (72%) agreement with the principle statement. Three respondents from a nursing organisation, and one each from a patient organisation and GP system supplier NUG disagreed with the statement. Neutral responses were recorded by all three medical defence organisations, two Scottish NMAHP respondents, one professional regulatory body and one AHP organisation.

The qualitative analysis for principle 23 recorded responses under the following themes:

• **Good practice** – “Promotes good practice and honest culture promoting public confidence in the health professionals” (Scottish NMAHP group).

• **Need patients' consent** – “Patients may well be happy for SCR to be viewed but not DCR, so consent for that should be a separate issue” (patient group). “For most patients the SCR is used rarely and then only in unplanned care settings. So it is appropriate to always ask for permission to view the SCR for many patients with complex or long term condition, the sDCR will be used frequently. Clinical teams should only have to seek permission to view the sDCR on first contact with the patient, then perhaps again periodically e.g. annually” (AHP group).

• **Miscellaneous** – “Patients will be asked at each clinical encounter about the preferences with regards to records sharing. Until we know more detail about the proposals and their evaluation, we would prefer to be neutral on this series of points” (medical defence organisation).

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7.4.19 - Principle 27 analysis of responses

**Rank = 18 (equal)**

<table>
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<th>Refusal to have a shared Detailed Care Record should be recorded as “explicit dissent” in the organisational/team Detailed Care Record and on the “Spine”.</th>
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7.4.19 There were 36 (90%) responses to this question with overall 31/36 (86%) agreement with the principle statement. Two GP system supplier NUG respondents, two nursing organisations and one Scottish NMAHP respondent disagreed with the statement.

The qualitative analysis for principle 27 recorded responses under the following themes:

- **Agree as** – “refusal must not affect a patient’s right to treatment” (GP system supplier NUG). “This would make it simpler to manage, especially when a patient moves to a different area when the potential for mistakes is high” (GP system supplier NUG).
- **Encourage patient** – “But it should explained that they can change their mind” (nursing organisation). “We have a duty to explain our rationale for sharing and encourage patients to share. They should have confidence in ability to judge the need to share” (Scottish NMAHP group).
- **Miscellaneous** – “This implies that agreement should be recorded as ‘explicit consent ’? Will there be a category of ‘implied consent’?” (Patient group). “Sharing of local detailed record and national summary record probably ought to be kept separate?” (GP system supplier NUG). “Preference for ‘opt out ’ as phrase to use rather than ‘dissent’” (AHP group). “Not on the spine” (nursing group).

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7.4.20 - Principle 13 analysis of responses

**Rank = 20**

<table>
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<th>Patient consent should be sought for the creation of a shared Detailed Care Record about them.</th>
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7.4.20 There were 39 (97.5%) responses to this question with overall 28/39 (67%) agreement with the principle statement. Three nursing organisations, two GP system supplier NUG respondents and two Scottish NMAHP respondents disagreed with the statement. The distributions for nursing and patient organisation responses were the most polarised and are shown below, highlighting inter-group variation in the quantitative data analysis.
The qualitative analysis for principle 13 recorded responses under the following themes:

- **Implement consent** – “Implied consent should be okay but there may be situation where patient may prefer that a particular encounter with the NHS is not recorded.” (patient group). “Patients need to be informed but not need their consent for the creation of a shared record as this may ultimately impact in care provision” (nursing group).
- **Explicit consent** – “Consent whether implied or explicit must be obtained” (GP system supplier NUG).
- **Informed patient** – “The patient should be informed of the details of the information collected and whom this will be shared with” (Scottish NMAHP). “Patients should be given every opportunity to read it, check it and discuss with an informed professional and amend if necessary” (patient group).
- **Health professional right** – “Health professionals have the right to create a record even if the patients object” (nursing group).
- **Not clear** – “Have to define how many shared arrangements there are and do we have to consent to each and what is shared with whom” (GP system supplier NUG).
- **Allow patient’s objection** – “Where patient do not agree their decision should respect but they need to understand the potential consequences for their healthcare if they did object” (medical defence organisation). “Not sure that there is a legal or ethical imperative to do this but if patients want to control how their records are stored, and this can be accommodated” (Regulatory body). “Patient should be able to withhold consent for the creation of a sDCR therefore consent must be obtained. If sDCR created on the basis of implied consent then there would need to be sufficient public information programmes” (medical group).
- **Some issues** – “The issue is having consent before sharing and recording appropriately and having this time limited” (GP system supplier NUG).

### Principle 13

<table>
<thead>
<tr>
<th>a) Nurse organisation responses</th>
<th>b) Patient organisation responses</th>
</tr>
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7.4.21 - Principle 21 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Healthcare organisations must retain the right to edit, update and amend any information added to their Detailed Care Records from other sources.</th>
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7.4.21 There were 39 (97.5%) responses to this question with overall 25/39 (64%) agreement with the principle statement. Two nursing organisations, two Scottish NMAHP respondents, one patient organisation and one GP system supplier NUG disagreed with the statement. Neutral responses were received from two regulatory bodies, two Scottish NMAHP respondents, one medical organisation, one AHP organisation and one GP system supplier NUG. The distributions for nursing and medical organisation responses are shown below, again highlighting inter-group variation.

The qualitative analysis for principle 21 recorded responses under the following themes:

- **Allowed edit but**
  - **Have audit trail** – “Some concern about ‘edit’ – all ‘edits’ should have an audit trail” (AHP group), “Provided there is an audit trail showing the original information and how, when and by whom it has been changes” (professional regulatory body).
  - **Need guidelines** – “There must be guideline for amending data. Incorrect data added by other user to a DCR can be dangerous” (GP system supplier NUG).
  - **Preserve the original data** – “This document should reflect the clinical contacts with the patient. If any amendments are necessary then these should be signed and dated so it is obvious when emendations were made and the original version should remain legible” (medical defence organisation). “Organisation must be able to annotate information from other sources but the integrity of the source information and identity of originator must be preserved” (nursing group).

- **Not edit** – “The term edit may be misleading as it could imply changing factual information if a mistake has been made” (nursing group). “Editing and amending the contribution of a specialist by a non specialist would not necessarily a good thing. However an entry about something which the person entering had inadequate experience and was clearly wrong is a completely different matter” (medical group).

- **Some concerns** – “Who will have access to an organisation’s DCR to add information from other sources? Need to be clear that information cannot be deleted or hidden only updated or annotated” (AHP group). “Who holds the master record? Professional responsibility should prevail” (AHP group). “Patients should also have this right in consultation with health professionals. e.g. info from osteopaths, non NHS physio, family history as it becomes known, side effects” (patient group). “A shared DCR based on separate local DCR that share or exchange an agreed dataset would allow each healthcare organisation to maintain the quality of their own records by amending data received from others. But there would need to be controls and rules to prevent the divergence of accuracy between separate local DCRs” (GP system supplier NUG). “Data accuracy is more important in a shared environment. Errors which may be easily noticed within an organisation may be taken as accurate when taken out of context. Agree that having a guardian who is responsible may help in improving accuracy. The amount of ongoing work required to ensure records are accurate and should not be
underestimated and resources will need to be allocated for this purpose” (GP system supplier NUG).

- **Miscellaneous** – “As long as any changes to the record are clearly labelled” (medical group). “It depends on the reasons for doing this. Not if it means that the DCR information becomes inaccurate” (AHP group). “As long as they share this appropriately and can justify changes/edits/inclusions” (Scottish NMAHP group).

**Principle 21**  

a) Nurse organisation responses

b) Medical organisation responses

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7.4.22 - Principle 25 analysis of responses

<table>
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<th>Rank</th>
<th>“Consent to view” permission for accessing a shared Detailed Care Record should be time-limited.</th>
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7.4.22 There were 39 (97.5%) responses to this question with overall 24/39 (62%) agreement with the principle statement. Two Scottish NMAHP responders, two GP system supplier NUGs, one medical organisation and one medical defence organisation disagreed with the statement. Neutral responses were received from two professional regulatory bodies, one each from a nursing, medical, patient, AHP and a medical defence organisation. The distributions for nursing and AHP organisations are shown below, highlighting inter-group variation in responses.

The qualitative analysis for principle 25 recorded responses under the following themes:

- **Practical difficulties** – “Practical implementation could be challenging and place a further burden on staff” (nursing group). “Not clear how this would be managed in practice with thousand of patient’s records and an even greater number of clinical encounters. Furthermore, patients’ ability to change their minds would need to be properly addressed” (medical defence organisation).
• **Time limit** – “When seeking consent to view the shared DCR the patient should be told how long it will last and access should be for the minimum time required” (medical group). “Why this should apply – what if the patient wants to make the permission unlimited in time? As a matter of principle, making the permission or consent “time limited” has no actual legal effect – a patient could change their mind at any time” (medical defence organisation). “Time limited” should be changed to revisited within agreed timescale for review. This is about dialogue with the individual. Ongoing clarification regarding what’s going on and involvement in what’s agreed to be the best course of action” (Scottish NMAHP group).

• **Other issues** – “After first consent further permission could be a relatively straightforward and quick. However patient must be reminded that they can change their minds at anytime without waiting” (patient group). “Too bureaucratic a general principle” (medical group). “The consent to view the sDCR should lapse the episode of care is closed, or annually when there is ongoing care” (AHP group).

**Principle 25** a) Nurse organisation responses  

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b) AHP organisation responses

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**7.4.23 - Principle 24 analysis of responses**

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<th>Patients agreeing to &quot;consent to view&quot; for their shared Detailed Care Records should be able to control what health data is shared and with whom it is shared</th>
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7.4.23 There were 37 (92.5%) responses to this question with overall 25/37 (68%) agreement with the principle statement. Three Scottish NMAHP responders, three GP system supplier NUGs and one AHP organisation disagreed with the statement. Neutral responses were received from two medical defence organisations, two Scottish NMAHP responders and one AHP organisation. The distributions for nursing, GP system supplier NUGs, AHP and patient organisations are shown below, highlighting inter-group variation in responses. Patient organisations clearly are very strongly in favour of this principle. Professional regulatory bodies and medical organisation responders also all agreed or strongly agreed with this statement.
The qualitative analysis for principle 24 recorded responses under the following themes:

- **Practicality** – “Provided the patient understand the governance involved. Could be difficult to manage” (nursing group). “Sounds far too complex” (GP system supplier NUG). “This could be very complicated to administer and impede care” (nursing group). “The practicalities would need to be explored i.e. whether this would create a record, which is too complex to manage” (medical group).

- **Children/ vulnerable people/ sensitive information** – “With some limitation e.g. child protection” (Scottish MNAHP group).

- **Inform patient about implication** – “The option for a patient to restrict access to the sDCR need to be simple for staff to explain and easy for patient to understand. (See SCR model which has develop a set of simple and easy to understand option)” (AHP group).

- **Patient right to refusal** – “Patients should have the right to refuse to share and to discuss what data should be sharable but believe the health professional must be in the equation to prevent the shared record becoming misleading which might put the patient at risk” (AHP group).

- **Some concerns** – “But there are obviously limits to this for example where the health or safety of other people is at risk” (professional regulatory body). “Not sure about ‘control’, decision should be made based on best information about why information would be a benefit if it was shared. people will eventually become comfortable with this” (Scottish NMAHP group).

- **Miscellaneous** – “Promotes open and honest culture and public confidence in the health professionals” (Scottish NMAHP group).

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### Principle 24 responses

*a) Nurse organisation responses*

*b) GP system supplier NUG responses*

### Principle 24 c) AHP organisation responses

### Principle 24 d) Patient organisation

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118
7.4.24 - Principle 17 analysis of responses

<table>
<thead>
<tr>
<th>Rank</th>
<th>Information from the shared Detailed Care Record may be shared with other healthcare workers when it is for the benefit of the patient and after informing the patient.</th>
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7.4.24 There were 38 (95%) responses to this question with overall 27/38 (71%) agreement with the principle statement. Three medical organisations, three GP system supplier NUGs, one regulatory body and one Scottish NMAHP responder disagreed with the statement. Neutral responses were received from one defence organisation, one AHP organisation and one GP system supplier NUG. Interestingly, three of the four patient organisations strongly agreed with this statement. The distributions for medical and patient organisational responses are shown below highlighting inter-group variation in responses.

The qualitative analysis for principle 17 recorded responses under the following themes:

- **Only with patient consent** – “The statement should be about asking for informed consent, rather than ‘informing the patient’” (AHP group). “Rather than ‘informing’ the patient, it would be more correct to obtain the patient’s agreement and respect their objection” (medical defence organisation). “Presumably ‘informing’ the patient will also involve asking for consent, so patient wishes will be observed, whatever his/her decision” (patient group). “Consent needs to be obtained before sharing records” (GP system supplier NUG).

- **Not clear** – “The definition of ‘other care worker’ is not clear. If sharing is beyond what the patient would expect the patient should be asked explicitly, not just informed. Patient needs to understand what is being shared, the purpose and how long for” (medical group).

- **No need to inform** – “Do not believe that the patient who has given consent needs to be informed of the sharing” (GP system supplier NUG).

- **Miscellaneous** – “Communication is key to ensure that patients understand what will be seen and by who. Could not agree more about access rights. Modern health care is delivered by a very mobile set of professionals – with wide ranging roles” (GP system supplier NUG). “The practicalities again seem very difficult to surmount” (medical defence organisation). “Means patient do not have right to object to such disclosure, who would decide what would benefit the patient and on what basis” (professional regulatory body).
Principle 17  

a) Medical organisation responses  

b) Patient organisation responses

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7.4.25 - Principle 5 analysis of responses

In the absence of any objection, patients’ consent to information being shared in this way may be implied.

There were 36 (90%) responses to this question with overall 20/36 (56%) agreement with the principle statement. Three Scottish NMAHP responders, two patient organisations, two GP system supplier NUGs and one nursing, AHP and medical defence organisation disagreed with the statement. The responses from all the groups are shown below highlighting inter-group variation in responses.

The qualitative analysis for principle 5 recorded responses under the following themes:

- **Unaware Patients** – “Patients unaware of objections / not able to object (e.g. unconscious)” (nursing group). “Patients needs to be aware of contents of the record and risk of sharing” (Scottish NMAHP group). “Consent may be inadequate in circumstances where a patient may not have sufficient information to object” (medical defence organisation).

- **Circumstances changed** – “Consent needs to be discussed at each appointment as circumstances can be changed” (AHP group).

- **English as a second language** – “Difficult to talk about consent when English is not a first language” (AHP group).

- **Public awareness** – “Must be supported by a effective public awareness campaign” (GP system supplier NUG).

- **Consent issues** – “Implied consent – if sharing is between health professionals for the direct provision of care but beyond this would require explicit consent” (medical group).

- **Miscellaneous** – “Need flexibility in cases such as child protection” (Scottish NMAHP group). “Clarification on role of patient’s guardian and whether they can object” (patient group).
Principle 5

a) Nursing organisation responses

b) Patient organisation responses

c) AHP organisation responses

d) Medical organisation responses

e) Regulatory body responses

f) Medical defence organisation responses

g) GP system supplier NUG responses
### 7.4.26 - Principle 9 analysis of responses

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<th>Rank</th>
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7.4.26 There were 37 (92.5%) responses to this question with overall 21/37 (57%) agreement with the principle statement. Three patient organisations, three GP system supplier NUG responders, two AHP organisations, two Scottish NMAHP responders, one nursing and one medical defence organisation, disagreed with the statement. Neutral responses were received from two regulatory bodies and two medical defence organisations. The responses from all the groups are shown below highlighting inter-group variation in responses. The contrast between the medical and patient organisational responses is particularly striking.

The qualitative analysis for principle nine recorded responses under the following themes:

- **Provide information to patient** – “Patients need to be aware that local record will be shared” (nursing group). “Patient should be informed in advance and their agreement should be clear” (medical defence organisation).
- **Consent**
  - **Explicit consent** – “At the first point of contact (e.g. GP), patients should be asked if they consent to their health data being share in local DCR” (AHP group). “If this means health professional in the same organisation – unacceptable without explicit consent” (GP system supplier NUG).
  - **Implied consent** – “Given the complexity of records systems, it is difficult to imagine that implied consent would be sufficient protective of patient confidentiality” (medical defence organisation). “Give implied consent for purposes related to their care and explicit consent to other purpose” (professional regulatory body). “Assume to have given implied consent to the sharing of their personal information within the local health care team but cant be assumed to have consented to the sharing of this information with people outside that health team” (patient group).
- **Access with legitimate reason** – “This means people with legitimate reason to access a patients record within DCR (e.g. administrative staff)” (GP system supplier NUG).
- **Miscellaneous** – “Patients are more likely to know people accessing info in the DCR as it is local” (patient group). “Only relevant information should be shared which is different then allowing access of entire local DCR” (GP system supplier NUG).
**Principle 9**

a) AHP organisation responses

b) Nursing organisation

c) Medical organisation responses
d) Patient organisation

e) Regulatory body responses
f) Medical defence organisation

g) GP system supplier NUG responses
7.4.27 - Principle 10 analysis of responses

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<td>Patients may give implied consent to disclosure of personal information shared within the shared Detailed Care Record (sDCR).</td>
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7.4.27 There were 39 (97.5%) responses to this question with overall 12/39 (30%) agreement and 19/39 (49%) disagreement with the statement. The responses from all the groups are shown below highlighting inter-group variation in responses. The patient organisation responses all disagree with this principle statement; otherwise there is a spread of responses within the groups.

The qualitative analysis for principle 10 recorded responses under the following themes:

- **Consent** – “sDCR is a richer source of information and should not viewed without explicit consent (exception – when patients explicitly indicate they do not wish to be asked again for their consent)” (GP system supplier NUG). “Written consent preferred” (AHP group). “Explicit consent is required at the time of referral” (GP system supplier NUG).

- **Patient may worry** – “Patient might be wary of wide sharing” (medical group).

- **Not clear** – “Not sure why the word 'disclosure' has been used here as it begs the question of disclosure to whom. Unsure about what will actually be in the sDCR” (patient group). “Not clear who has access of sDCR and for what purpose” (nursing group).

- **Miscellaneous** – “This is difficult as health professionals can see each other’s entries (e.g. community nurses and community mental health team)” (GP system supplier NUG). “Use ‘consent to view’ model for the DCR” (GP system supplier NUG).

**Principle 10**

a) AHP organisation responses

b) Nursing organisation responses
**Principle 10**

- **c) Medical organisation responses**
- **d) Patient organisation responses**

![Graph for Medical organisation responses](image1)

- **e) Regulatory body responses**
- **f) Medical defence organisation responses**

![Graph for Regulatory body responses](image2)

- **g) GP system supplier NUG responses**

![Graph for GP system supplier NUG responses](image3)
7.4.28 - Principle 14 analysis of responses

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<th>Rank</th>
<th>Patients do not have the right to limit the amount of information relevant to their care or condition that is incorporated into their shared Detailed Care Records.</th>
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7.4.28 There were 39 (97.5%) responses to this question with overall 8/39 (21%) agreement and 27/39 (69%) disagreement with the principle statement. Overall there is a consensus against this statement, as demonstrated in the individual group responses below, particularly among AHP, patient and medical organisations and the GP system supplier NUGs.

The qualitative analysis for principle 14 recorded responses under the following themes:

- **Empowered patient**:
  - **Have right to limit/add the information** – “Patient should have right to limit their health data. The appropriate healthcare professional will need to explain the inherent risks to the quality and safety of their care if the patient makes this choice” (AHP group). “If there is no right to limit the info then patients may prefer to opt out completely” (patient group). “Patient will always have the power to review that information and add a commentary if the disagree with the content of the record” (medical defence organisation).
  - **Able to edit the information** – “Record should not be "edited" by the individual to whom they relate” (medical defence organisation).
  - **Patient can select the information to share/not to share** – “Need system whereby – at patient request very confidential information that is accessed by relevant people only” (Scottish NMAHP group). “Adult patients should be able to limit the information that is incorporated into their sDCR. Children need to be considered separately and the GP should decide whether it is in the best interest for a parent to withhold information on a child’s record” (medical group). “Patient should be able to choose what is held on that record. But strongly disagree with any model that involved the health professional debating with patient what should or shouldn’t be included” (GP system supplier NUG).

- **Clinical judgement** – “It is usually a matter of clinical judgement as to what data is recorded in the clinical record. There may be circumstances where irrelevant information is recorded, Patient will always have the power to review that information and add a commentary if the disagree with the content of the record” (medical defence organisation).

- **Motivate patients by explaining the benefits** – “Where this is done properly and benefits clearly explained surely most people would be willing to have information shared” (Scottish NMAHP group).

- **Some other issues** – “This would affect the professional Dr/patient relationship if the patient thought information they do not want to share is always recorded. The best care is not delivered if information is not shared. Patient should be aware that refusal to share information may have a detrimental effect” (nursing group). “Partial information may be unsafe” (nursing group).

- **Not clear** – “It depends on the controls on what can or can not be shared. With good control some parts of sDCR could be remain within the originating organisation” (GP system supplier NUG).
Principle 14

a) AHP organisation responses

b) Nursing organisation responses

c) Medical organisation responses

d) Patient organisation responses

e) Regulatory body responses

f) Medical defence organisation responses

g) GP system supplier NUG responses
7.4.29 Question 29 on the stakeholder survey asked respondents “What record elements do you consider should be priority areas for shared Detailed Care Records? (Please place in order of importance)”. Responses were categorised into general and specific subgroups and are shown in the figures below.

**Figure 7.4.29a General responses to question 29**

- What should be shared?
- What is the purpose of the shared record – which will help decide what is shared as not all organisations are using shared records for the same purpose?
- Who should have access and to what parts of the records?
- How should a patient be kept informed of access to their records?
- What is the purpose of the shared record – which will help decide what is shared as not all organisations are using shared records for the same purpose?
- How is incorrect data going to be addressed?
- GMC identifies ‘relevant clinical findings, the decisions made, the information given to patients, and any drugs prescribed or other investigation or treatment.’ I don’t think it’s appropriate for the GMC to give detailed advice on this issue?
- What progress has been made on the ‘sealed envelope’, which is not mentioned above?
- Very little more than the Summary stuff. As above Rx / Dx /other

**Figure 7.4.29b Specific responses to question 29 (ranked by priority level and frequency)**

- Medication – current, repeat and recent past
- Allergies etc – adverse reactions, allergies (especially drugs)
- Clinical history – current history/problems, significant past history
- Demographics – patient identifiers, contact details, next of kin, religion, gender, occupation
- Patient awareness/access – patient preferences, sharing status, record accesses and control
- Psychosocial – child protection, risk and social issues, health care choices, vulnerabilities
- Accuracy – data accuracy and correction
- Investigations/results – requests, reports and results
- Assessment/care plans – integrated (e.g. eCAF and ContactPoint), nursing plans
- Current care – key carers, kin and contacts
- Documented activity – letters, referrals and discharges and other correspondence
- Miscellaneous – significant family history, vaccinations/immunisations, screening and health checks

7.4.30 Question 30 on the stakeholder survey asked respondents “Please feel free to add any comments under any of the statements above and make any other comments below.” Responses to this question were analysed as part of the qualitative arm of the study.

The qualitative analysis for question 30 recorded responses under the following themes:

- **Children** – “Records for children need to include who had parental rights and when individual is identified as competent to consent in own right” (AHP group). “How old
do children have to be before parents can no longer access their records? Who judges ‘Gillick competence’, and how is the change of access made? Is it automatic or on request? Similar issues arise with guardianship” (patient group). “How do you safeguard the person who has disclosed from the abuser if they access their child’s full record?” (nursing group).

- **Sharing** - “In systems such as TPP there is no provision of sDCR, so there needs to be a mechanism to mark individual elements for sharing, otherwise the whole record could be shared thereby rendering information available that is inappropriate. Significant amounts of information currently in GP systems was entered in the context of a non-sharing world, and therefore may need to be revisited in the light of sharing” (GP system supplier NUG). “Some contributors felt quite strongly that shared records are not the best way to share information and that direct patient access should have been included” (multiprofessional group). “It would be beneficial for staff working at local level if all agencies adopted the same guiding principles and this would ensure that staff worked together to ensure effective safe sharing of patient information. This would also support and protect staff in the delivery of care” (Scottish NMAHP group). “It is hard to see how, in a SSEPR, it would be possible to share only parts of the record” (multiprofessional group).

- **Record management** – “Healthcare professionals must be aware of their responsibilities when recording, disclosing and accessing patient information. Most patients will require considerable time to understand the implications of the electronic patient record in terms of wider access, sharing and re-use: the NHS must make provision for this requirement with education, support and time for professionals to ensure patient understanding as is required in other practice related to informed consent” (nursing group). “In a SSEPR such as SystmOne and Lorenzo Regional Care, there needs to be agreement on who is responsible both for different aspects of patient care and for management of the health record: the two cannot be separated” (multiprofessional group).

- **Audit trail** – “User interface must fulfil profession specific regulatory and practice requirements; that individual record updates need to be time/date stamped; that access should be simple, restricted to those authorised and presented in an intuitive manner; that the system must be secure” (AHP group).

- **Data for public health** – “You have very largely concentrated on the sharing of data between health care workers. The other major issue is people requiring data for public health or health care planning of one sort or another. There are a number of large private companies and many PCTs trying to access data for these purposes and often with little or no understanding of confidentiality” (GP system supplier NUG).

- **Consent** – “We are in danger of getting too bogged down by the consent to share issue- research with patients in Scotland has shown that patients expect health professionals to share information for care purposes- we have always done it and the fact that we will be using electronic systems does not change that” (Scottish NMAHP group).

- **Not clear term/question** – “It would have been easier to comment if the content of the shared detailed record was known” (nursing group). “It would help if there was information on the variety of different models for implementing sDCRs and DCRs. The Principles and the Practice will surely interact” (AHP group). “It is not clear who would have authority to share information outside direct care or to whom outside organisations such as potential employers, insurance companies, solicitors and the police would need to apply, unless it is established that any of the participants could share information generated by all of the participating organisations” (multiprofessional group).

- **Miscellaneous** – “Sometimes it is the complete record, rather than its component parts that is significant” (GP system supplier NUG). “The roles of “Data Controllers in Common” in the DPA are not explicit” (multiprofessional group). “Patients who have opted out have done so to retain the confidentiality between themselves and their GP
doctor and because of the persistent loss/theft of patients records instil little confidence in the new scheme" (patient group). “Some health communities may be moving towards an integrated DCR solution for all primary and secondary care organisations, without the need for a sDCR. Other communities may be aiming to have a number of information systems for DCRs in primary care/secondary care/mental health/learning disabilities/and childrens services, with a local sDCR accessible by all those different organisations” (AHP group).

7.5 Discussion

The overall response rate to the survey was very high from the full range of stakeholder groups identified by the project team (40/43 = 93%). There was a high level of stakeholder agreement on 24 of the principle statements (see figure 8.3.c), with lower levels of agreement on principles five and nine and disagreement with principle statements 10 and 14.

The level of inter-group agreement was also high for 19 of the principle statements with obvious differences only emerging from the 20th ranked statement (principle 13) onwards as levels of overall agreement also fell. There was a clear trend from patient organisations suggesting that patients do want to actively participate in sharing decisions with lower levels of agreement about the use of implied consent than health professionals (principles 5, 9, 10, 13, 14, 17, and 24). Overall levels of agreement between AHPs, nurses and doctors was high, but some differences emerged as overall levels of agreement with the principle statements fell (principles, 5, 9, 14, 21 and 25). GP system supplier NUG responses became very variable as overall levels of agreement fell (principles 5, 10 and 24). The professional regulatory body responses were generally consistent throughout the survey (apart from principle 14), though the medical defence organisations were rather less so (principles 5, 10 and 21).

The qualitative thematic analysis has provided additional insights into the concerns and expectations of respondents around data sharing and shared patient records. It has also highlighted areas that will require further consideration (such as child protection) that were beyond the scope of this report. The responses to Q29 are particularly interesting as they show that stakeholder priorities for data sharing correlate well with the proposed content of the SCR in England and ECS in Scotland.

The resource constraints around the SRPG project meant that we did not have the opportunity to conduct a fully scientific survey of the stakeholder groups and their various constituencies. Therefore we regard our findings as being indicative of stakeholder opinion rather than genuinely representative.
Appendix

A1 - Shared Record Professional Guidance project, stakeholder consultation and survey

Introduction
Over the past few years NHS Connecting For Health (NHS CFH) system suppliers have implemented Primary/Community IT systems with explicit sharing of a single detailed record by health professionals from different teams and NHS bodies. This has led to rising levels of uncertainty from all sides about the governance, medico-legal and patient-safety consequences of shared detailed clinical records systems.

The purpose of this project is to develop a professionally led set of guidelines for the governance of shared detailed patient records in the primary care domain, that should carry the endorsement of the full range of relevant health professional representative bodies and be promoted by NHS CFH to their clinical system suppliers and all system users.

Definitions

- Organisational (or local) Detailed Care Record (DCR) – a record of everything that is relevant to the care of that patient known to the organisation maintaining the record.
- The Summary Care Records (SCR) is a nationally defined record subset of information meant for first point of contact care.
- A shared DCR (sDCR) is a subset of information derived from contributing DCRs that can be usefully shared.

Context
The governance and guidance of primary care systems has historically rested with general practice, which has assumed supervisory roles for the pragmatic purpose of allowing wider clinical teams access to an effective locally shared electronic record.

The guidance produced is likely to have immediate implications to relieve uncertainty in community settings, and to further encourage the roll-out and fuller use of much needed National Programme for IT in community settings.

The key questions for this project to address are:
1. What are the purposes of shared Detailed Care Records?
2. How can these requirements be delivered safely?
3. What are the principles and practice that ensure clarity, safety and continuity?
4. At what level does responsibility for shared Detailed Care Record system governance lie?

Approach
This project will be undertaken by the RCGP Informatics Group on behalf of the RCGP. The work itself will be undertaken by members of the RCGP Informatics Group, co-opted domain specialists and a team from University of Dundee.

This project is different from other projects undertaken by the RCGP Informatics Group, in that our key aim is to develop guidance that is endorsed by all key stakeholder groups in the primary care setting.
Stakeholders

Stakeholder engagement is essential as we try to develop a professionally led set of guidelines for the governance of shared electronic patient records in the primary care domain. The project steering group has identified and agreed with NHS CFH a list of key stakeholders and interested parties to be consulted as part of the guidelines development process, to include:

- Professional regulatory bodies
- Medical professional representative groups
- Nursing professional representative groups
- Allied Health Professional representative bodies
- Medical Defence organisations
- Clinical system suppliers and users
- The Office of the Information Commissioner
- The Primary Health Care Specialist Group of the British Computer Society
- Patient representative groups

Shared Detailed Care Records Governance – principles

The first phase of the stakeholder engagement process was to identify and contact key groups, organisations and individuals who could respond authoritatively on behalf of the stakeholder organisations. The main aim of this second phase of the stakeholder engagement process is to develop a set of professionally endorsed principles that will help define the clinical and information governance requirements for shared DCRs. We will not try to define technical solutions, but begin to set out clearly the information governance requirements for shared DCRs from a professional and patient perspective within the current legal and ethical framework.

The third stage of the project will be to develop draft professional guidelines based on these principles to support the processes of clinical care in the primary care setting.

At this stage of the project, we are seeking your responses and comments on the set of principles that are detailed below. These principles have been developed from material published by the health professional regulatory bodies and professional representative organisations. We will use stakeholder feedback from this stage of the project to help inform the guidelines development process. We will be consulting you again about the draft guidelines in early 2009 and again later in the year with our draft final report.

Please read the principles below and indicate your agreement or disagreement with the statement by circling one of the number boxes on the scale and please add comments where you think they might be helpful.

Please provide us with the following information:

Your name: ____________________________________________
The organisation you represent: ______________________________
Email address: __________________________________________
Telephone number: ______________________________________
Shared Record Governance Principles

1. The need to keep proper records is a professional requirement and records must be protected from being lost, damaged or accessed by someone without appropriate authority.

   | -2 | -1 | 0 | 1 | 2 |
   |------------------|
   | Strongly disagree| Disagree | Neutral | Agree | Strongly agree |

   Comments____________________________________________________________

2. Patients have a right to expect that health professionals will hold information about them in confidence.

   | -2 | -1 | 0 | 1 | 2 |
   |------------------|
   | Strongly disagree| Disagree | Neutral | Agree | Strongly agree |

   Comments____________________________________________________________

3. Appropriate information sharing is essential to the efficient provision of safe, effective care, both for the individual patient and to the wider population of patients.

   | -2 | -1 | 0 | 1 | 2 |
   |------------------|
   | Strongly disagree| Disagree | Neutral | Agree | Strongly agree |

   Comments____________________________________________________________

4. Health professionals should make information available to patients about disclosures of their personal health data for purposes of their own care.

   | -2 | -1 | 0 | 1 | 2 |
   |------------------|
   | Strongly disagree| Disagree | Neutral | Agree | Strongly agree |

   Comments____________________________________________________________

5. In the absence of any objection, patients’ consent to information being shared in this way may be implied.

   | -2 | -1 | 0 | 1 | 2 |
   |------------------|
   | Strongly disagree| Disagree | Neutral | Agree | Strongly agree |

   Comments____________________________________________________________
6. It should be made clear to patients that others who support the provision of care might also need access to their personal information.

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Comments______________________________________________________________

7. Patients may not be aware of disclosures to others for purposes such as health service planning or research and must be informed about disclosures for purposes they would not reasonably expect.

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8. Health professionals must obtain patients' explicit consent to disclosure of identifiable information for purposes other than the provision of care, unless the disclosure is required by law or justified in the public interest.

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9. Patients may give implied consent to disclosure of personal information shared within the local Detailed Care Record (DCR).

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Comments______________________________________________________________

10. Patients may give implied consent to disclosure of personal information shared within the shared Detailed Care Record (sDCR).

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Comments______________________________________________________________
11. Health professionals should explain to patients that their shared Detailed Care Record will be shared with the care team, including administrative and other staff that support the provision of care, unless they object.

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Comments____________________________________________________________

12. Health professionals must respect the wishes of any patient who objects to particular information being shared with others providing care, through the shared Detailed Care Record, except where disclosure is in the public interest.

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Comments____________________________________________________________

13. Patient consent should be sought for the creation of shared Detailed Care Record about them.

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14. Patients do not have the right to limit the amount of information relevant to their care or condition that is incorporated into their shared Detailed Care Records.

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15. However, patients can limit access to certain information about themselves within their shared Detailed Care Record and health professionals must respect their right to do so.

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16. Access by health professionals to shared Detailed Care Records should be very strictly controlled on a “need to know” basis. This means that some people can have access to the full record, others to the part that is relevant to them.

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17. Information from the shared Detailed Care Record may be shared with other healthcare workers when it is for the benefit of the patient and after informing the patient.

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18. The information shared should only be that required for appropriate care to be given or continued.

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19. Each healthcare organisation/team should maintain and be responsible for its own organisational care record (Detailed Care Record).

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20. Each healthcare organisation/team should have a nominated guardian responsible for the integrity and accuracy of that organisation’s Detailed Care Records.

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21. Healthcare organisations must retain the right to edit, update and amend any information added to their Detailed Care Records from other sources.

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22. Shared Detailed Care Records should also have a nominated guardian and it must be clear who has the responsibility to maintain and act on the contents of any shared DCR.

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23. The “consent to view model” agreed for the Summary Care Records should be applied to shared Detailed Care Records.

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24. Patients agreeing to “consent to view” for their shared Detailed Care Records should be able to control what health data is shared and with whom it is shared

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25. “Consent to view” permission for accessing a shared Detailed Care Record should be time-limited.

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26. Refusal to have a Summary Care Record or a shared Detailed Care Record must not affect a patient’s right to treatment.

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27. Refusal to have a shared Detailed Care Record should be recorded as “explicit dissent” in the organisational/team Detailed Care Record and on the “Spine”.

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28. Patients must be informed that refusal to have a shared Detailed Care Record may be detrimental to their treatment and care.

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29. What record elements do you consider should be priority areas for shared Detailed Care Records? (Please place in order of importance)

a) _____________________________________

b) _____________________________________

c) _____________________________________
30. Please feel free to add any comments under any of the statements above and make any other comments below.

Comments______________________________________________________________________________
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Thank you – if you have any questions please contact either;
Dr Bob Milne SRPG stakeholder engagement lead
Robert.Milne@NHS.Net and r.m.milne@abdn.ac.uk or
Dr Alan Hassey SRPG project leader alan.hassey@gmail.com