The Good Practice Guidelines for GP electronic patient records

Version 4 (2011)

The Good Practice Guidelines for GP electronic patient records v4 (2011)

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Policy	Estates
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Document Purpose	Best Practice Guidance
Gateway Reference	15787
Title	The Good Practice Guidelines for GP electronic patient records v4 (2011)
Author	Department of Health (DH)/Royal College of General Practitioners (RCGP)/British Medical Association (BMA)
Publication Date	21 Mar 2011
Target Audience	GPs
Circulation List	
Description	The Good Practice Guidelines for GP electronic patient records v4 will act as a reference source of information for all those involved in developing, deploying and using general practice IT systems.
Cross Ref	
Superseded Docs	GPG v3.1 [Gateway 5098] GPG v3.1.003 [supplement to GPG v3.1]
Action Required	N/A
Timing	**N/A**
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For Recipient's Use	

Contents

Foreward

The UK has an international reputation for widespread implementation and innovation in the area of GP computing. To a large extent this has arisen through the enthusiasm and efforts of doctors who have seen the benefit these clinical systems can bring to their practices.

Current practice computer systems contain vital records on which patient care depends. As information technology develops and becomes more integrated and interoperable, it is important that practice and Primary Care Organisation staff should be fully aware of the procedures and management arrangements that should be in place to ensure that the dependence on these electronic records is safe and justified. These "Good Practice Guidelines", have been written by national experts who are also users of clinical systems in their own practices. They are intended to support and encourage practices as they continue the move to be becoming "paperless" and beyond.

I welcome the publication of these guidelines and am grateful for the work of the doctors who have developed them.

Dr Laurence Buckman
Chairman,
BMA General Practitioners' Committee

NHS Connecting for Health is pleased to have been able to support the updating of these guidelines at a crucial time for the NHS in our drive to accelerate the 'Information revolution'.

As clinical information exchange with patients, carers and healthcare professionals becomes a reality, I am very pleased that the new guidelines reflect best practice and innovation in the use of health information. This guidance is developed for General Practice, but has impact, lessons and influence across the wider health and care community and is an important update to widely referenced and respected guidance and I would like to thank all clinicians who have contributed to this excellent work.

Charles Gutteridge
Clinical Director
Clinical Division, DH Informatics Directorate

GPs and their practice teams are operating in an increasingly complex world and guidance which helps us to do our job more efficiently and deliver safer care to our patients is very welcome**.**

This resource has been produced by clinicians who know from their own experience what is practical and beneficial to practices and patients.

The guidance provides GPs and patients with reassurance and confidence that the systems we are using are safe, secure and confidential. The RCGP would like to acknowledge the efforts of everyone involved.

Dr Clare Gerada
Chair of Council
Royal College of General Practitioners

Executive summary

A recent joint review by representatives of the Department of Health Informatics Directorate and the BMA & RCGP Joint GP IT Committee (JGPITC) concluded that there was a continuing need for professionally owned, authoritative guidance to update the Good Practice Guidelines for GP electronic patient records v3.1 (GPGv3.1 2005). The new Good Practice Guidelines for GP electronic patient records v4 (GPGv4 2011) would act as a reference source of information for all those involved in developing, deploying and using general practice IT systems. GPGv4 would also need to maintain and update the link between earlier versions of the GPG and the GMS & PMS regulations.

The joint review of the scope and content of GPGv3.1 demonstrated the need for a complete re-write of the guidelines to include all the existing sections, and extend the scope to include new services (e.g. Summary Care Record, Electronic Prescription Service and GP2GP messaging) into the mainstream guidance. The review also concluded that there is a need to develop new guidance in areas such as high quality clinical records and data quality to facilitate records sharing, inter-operability and communication.

From a strategic perspective, GPs are increasingly likely to share their record systems with other health professionals and electronic patient records may have multiple contributors over time. For this reason the inter-operability of records and the quality of the health data they contain will be the central themes of the revised GPGv4, described within a clinical safety framework. The overall GPGv4 project brings together the various chapters and strands that will make up the guidance to ensure that our electronic patient records are "fit for sharing" in a modern NHS.

Principal areas covered in the GPGv4 project are organised under the following chapter headings;
1. Strategic Context for the Good Practice Guidelines for GP electronic patient records v4 (2010)
2. The Purposes of Health Records
3. Clinical Safety Assurance
4. Records Governance
5. Shared Electronic Patient Records
6. High Quality Patient Records
7. Clinical Coding Schemes
8. Data Transfer & Interoperability
   a. The Personal Demographics Service
   b. GP2GP Electronic Record Transfer
   c. Data Migration
   d. Clinical Messaging
   e. The Summary Care Record and Emergency Care Summary

Chapter 1 - Strategic context for the Good Practice Guidelines for GP electronic patient records v4 (2011)

1.1   Introduction

The pace of change within the NHS and the new political and economic landscapes of recent times will have a significant and ongoing effect on the NHS environment. *Equity and Excellence: Liberating the NHS*[1] sets out a radical agenda for changing the structure of the NHS in England, placing GPs at the heart of clinical and budgetary decision-making. An "information revolution" will be required to enable GPs to fulfil these new responsibilities[2].

Set against these realities is the continuing drive to increase the quality, accessibility and accountability of health services and the health professionals who provide them. Good records sit at the heart of high quality clinical care.

General Practice has always been the most computerised sector of the NHS. Electronic patient records are now well established as the preferred means for storing and using patient personal health data to support clinical care, including prescribing, morbidity coding and business processes such as referrals and the Quality and Outcomes Framework (QoF).

1.2   Background

A recent joint review by representatives of the Department of Health Informatics Directorate ("The Informatics Directorate") and the BMA & RCGP Joint GPIT Committee (JGPITC) concluded that there was still a need for professionally owned, authoritative guidance to update and replace the Good Practice Guidelines for GP electronic patient records v3.1 (GPGv3.1 2005). The new Good Practice Guidelines for GP electronic patient records v4 (GPGv4 2011) would act as a reference source of information for all those involved in developing, deploying and using general practice IT systems. GPGv4 would also need to maintain and update the link between earlier versions of the GPG and the GMS and PMS regulations.

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[1] Equity and Excellence
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

[2] An information Revolution http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_120080

1.3   GPGv4 scope and definition

The joint review of the scope and content of GPGv3.1 demonstrated the need for a complete re-write of the guidelines to include all the existing sections, and extend the scope to include new services (e.g. Summary Care Record, Electronic Prescription Service and GP2GP messaging) into the mainstream guidance. The review also concluded that there is a need to develop new guidance in areas such as high quality clinical records and data quality to facilitate records sharing, inter-operability and communication within a clinical safety framework.

From a strategic perspective, GPs are increasingly likely to share their record systems with other health professionals and electronic patient records may have multiple contributors over time. For this reason the inter-operability of records and the quality of the health data they contain will be the central themes of the revised GPGv4, described within a clinical safety framework. The overall GPGv4 project brings together the various chapters and strands that will make up the guidance to ensure that our electronic patient records are "fit for sharing" in a modern NHS.

There are new safety standards issued by NHS Information Standards Board (ISB), which present new requirements for health organisations to manage the safety of applications during implementation and use. These dovetail with requirements on system suppliers to provide systems that are risk-assessed and developed to mitigate patient risk.

The Joint GP IT Committee (JGPITC) has representation from its parent bodies and GP system supplier national user groups from the four home nations. The JGPITC feels it is essential to maintain a UK-wide approach to the GPGv4 project and to GP records inter-operability, which would also ensure we are able to capture best practice from a UK perspective and ensure key stakeholders are engaged.

1.4   GPGv4 Content

The GPGv4 document is published as an executive summary, quick reference guide and full reference report in 12 chapters as below;

1. Strategic Context for the Good Practice Guidelines for GP electronic patient records v4 (2010)
2. The Purposes of Health Records
3. Clinical Safety Assurance
4. Records Governance
5. Shared Electronic Patient Records
6. High Quality Patient Records
7. Clinical Coding Schemes
8. Data Transfer & Interoperability

a. The Personal Demographics Service
b. GP2GP Electronic Record Transfer
c. Data Migration
d. Clinical Messaging
e. The Summary Care Record and Emergency Care Summary
f. High Quality Medication Records and the Electronic Prescription Service

9. A Pathway to Good Paperless Practice
10. Electronic Document Attachments
11. Working in an e-business Environment
12. Education and Training.

Chapter 2 - The Purposes of Health Records

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

2.1 Clinical purposes

Traditionally 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 and improvement.

2.2 Non-clinical purposes

Health organisations also need a patient record system that can be used to meet administrative 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)
- Providing reports and information for third parties (e.g. insurance companies)
- To support claims for benefits and other additional social support
- Recording when and to whom such evidence is provided
- 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).

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 (likely to become a core clinical requirement)
- Support teaching and continuing medical education
- Support clinical governance activities
- Implement security and access control regimes for patient confidential information
- Support professional appraisal and revalidation
- Enable:
    - o Epidemiological monitoring
    - o Surveillance of possible adverse effects of drugs
    - o Clinical research.

2.4   Emerging purposes

Health records created in one health environment are increasingly likely to be accessed for viewing and/or editing in other health environments for example:

- A read-only shared record following an act of publication (e.g. the Summary Care Record [SCR] in England and the Emergency Care Summary [ECS] in Scotland)
- A read-only system giving access to an external electronic health record system (e.g. Graphnet)
- Read and write access to a single logical record - or separate records (e.g. TPP SystmOne & EmisWeb respectively)
- A shared record dependent on messaging (e.g. pathology request and report)
- Interfacing with medical devices : telehealth/telecare

- New requirements for patients to have increasing control of their health records3.

The main health benefits of shared records are likely to be improvements in the quality and safety of care, in access to care or in cost effectiveness.

This has important implications for clinical record keeping in terms of data quality, semantics, clinical coding, staff education and training. Making health records "fit for sharing" will require health professionals to think in new ways about clinical record keeping and what it means to use and create genuinely "inter-operable" electronic patient records that can be safely shared with other health professionals *and* patients.

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3 Equality and Excellence
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf

Chapter 3 – Clinical Safety Assurance

3.1 Introduction

Clinical safety assurance is a broad subject. This section focuses on the clinical safety approach that applies across the NHS in England, issues that are relevant to the safe exchange of clinical information between systems across organisational boundaries, and relevant standards. This is particularly important in terms of health records inter-operability and underpins the data transfer and inter-operability sections of these guidelines (see Chapters 8a-f - data transfer and inter-operability section).

3.2 Clinical safety approach

The factors contributing to increased risk have been described[4] as including:

Organisational factors;
- Management decisions
- Organisational processes
- Corporate culture

Workplace factors;
- Error producing conditions
- Violation producing conditions

Personal factors;
- Errors
- Violations

'High reliability' organisations have been identified that are observed to have less than their fair share of accidents. These organisations tend to use a 'system approach' that deliberately roots out error traps and concentrates on the conditions under which individuals work, designing systems that defend against errors or mitigate their effects. This contrasts with an alternative approach of retrospectively trying to fix them and apportion blame.

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[4] Reason JT. Understanding adverse events: human factors. In: Vincent CA ed. Clinical risk management. London. BMJ Publications 1995.

In England the NHS Connecting for Health (NHS CFH) Clinical Safety Group (CSG) has developed the Clinical Safety Approach (CSA). The CSG aims to nurture an open safety culture that is broadly in tune with the 'system approach' outlined above, to cover all English NHS information systems. Thus recently, standards have been developed that apply to all English NHS organisations and to system suppliers. More will follow (see sections 3.4 and 3.5 on this topic later).

It should be emphasised that no system can ever be made completely safe. In reality it is only possible to reduce risks to levels that are *As Low As Reasonably Practicable* (ALARP principle).

The CSA is a clinically led process that has three stages:

- **End to end hazards workshop** to 'walk through' the processes with which a software module is associated in order to identify those things that may cause harm to a patient
- **Development of a clinical safety case** where hazards identified are scored for likelihood and impact and prioritised according to the resulting risk score. Appropriate 'mitigations' are identified and agreed for all of these hazards.
- **Safety closure report**. At this stage evidence is assembled to demonstrate that all of the mitigations agreed in the clinical safety case have been carried out. The resulting safety closure document is presented to the CSG. Various regulations are in place to prevent systems from being released or deployed until safety closure has been satisfactorily completed.

Despite rigorous application of the Clinical Safety Approach safety issues may still be identified after a system has been deployed. There are mechanisms in place to enable users to report any suspected clinical safety problem so that they can be brought to the attention of the system supplier and, if necessary, the CSG. There should be a well-understood process and culture for logging and reporting clinical safety issues within NHS organisations.

3.3   Clinical safety assurance and inter-operability

This is primarily about the exchange of clinical information between end systems in different organisations through the medium of messaging (e.g. record transfer by GP2GP or pathology messaging, delivering results from laboratories to General Practice). In this situation there is a particular need to ensure that the original meaning of clinical information is preserved through successive transfers. Clinicians at each end of a messaging link are likely to be entering information in different ways on systems that are heterogeneous (i.e. have different information models supporting different structures and possibly different coding systems). In such circumstances clinical information will inevitably be subject to structural transformations and translations so that it will have a different appearance with different ordering / organisation on the receiving system. The arrival of more and more heterogeneous systems (e.g. pathology messaging, the Summary Care Record, GP2GP and the Electronic Prescription Service) that

are required to interoperate with each other, if not carefully managed and tested, will increase the risk of change or loss of clinical meaning. The challenge is to ensure that despite all of these factors, clinical meaning is preserved so that a clinician working on any receiving system will in a timely fashion be able to find all of the information relevant to the patient's circumstances, interpret it correctly and make clinically safe and appropriate decisions.

- Practice teams will require education and training to understand the implications of working in an increasingly interoperable environment (see Chapter 12 – Education and Training)
- The quality of the information held on the originating system is of paramount importance as this may impact on the decision making of everyone downstream (see Chapter 6 – High Quality Patient Records)
- Rigorous, centrally managed, clinically led safety testing is required.

An approach has been developed which depends on trained clinicians, with delegated professional authority. Specially prepared dummy clinical records can be compared line-by-line on side-by-side screens displaying the same record on sending (i.e. before transmission) and receiving systems (i.e. after transmission). The records are set up to include multiple examples of all of the clinical information structures that can be found on the sending system. This testing is underpinned by a documented set of clinical informatics principles, which has evolved over time. It depends on iterations of close collaborative work between clinicians, technicians, project managers and system suppliers. Wherever problems are found, attempts are made to run an end-to-end diagnostic process to identify the cause, to assess likelihood and impact, and then full details are captured in an Issues log.

This approach can, and should, be embedded in the CSA. The Issues log is effectively an extension of the CSA Safety Case. Issues are prioritised and mitigations agreed. There must be documented proof that these have been carried out before the CSA safety closure document is issued.

3.4   Current NHS safety standards for IT systems (DSCN 14/2009 & 18/2009)

In August 2009 the NHS ISB issued two documents designed to establish a software safety management regime in the health sector, which is on a par with safety regimes in similar safety related industries such as aviation or the nuclear industry. This is directly in line with statements the then Chief Medical Officer (CMO) for England (Sir Liam Donaldson) made in his 2006 report in relation to the NHS "learning from other safety industries".

These safety standards (known as DSCN 14/2009 – for suppliers and DSCN 18/2009 – for health organisations) require the proactive risk assessment and mitigation for IT systems used to support health care, but which are not themselves classified as a medical device. GP systems clearly fall into this scope.

The standards are available free and can be downloaded from the Clinical Safety Group website[5].

 In summary Health Organisations (and hence GPs) should:

- Seek to procure systems which comply with DSCN 14/2009 (the supplier safety standard)
- Carefully risk assess the implications to rolling out a new system
- Ensure any risks are properly understood, investigated and mitigated by sensible controls (such as checks on migrated data or local testing to ensure the new system is correctly configured) and
- A clear process for reporting safety issues to the system supplier

The NHS CFH Clinical Safety Group (CSG) provides a more detailed document which GPs can use as an aide-memoire when changing system – the Safer Implementation Guide. This can be accessed from the link provided below[6]. This document has practical information and easy to understand checklists to steer a practice through the key tasks which, if conducted, result in a safe-implementation of a new system.

3.5   Future Safety Standards including changes to the Medical Device Directive

3.5.1 Changes to the Medical Devices Directive
The Medical Devices (Amendment) Regulations 2008 No 2936 which transpose Directive 2007/47/EC (relating to amendments to the Medical Devices Directive) into UK law, were passed by Parliament in December 2008 and fully come into force in March 2010. This amendment is an update to the Medical Devices Directive, which may have ramifications for electronic patient records systems. Any changes tothe interpretation of the Medical Devices Directive will be well publicised via the MHRA web site[7]

3.5.2 IEC80001
IEC80001 is a new systems safety standard, still under development, which will emerge over 2010/2011. This standard will place requirements on a health organisation to properly document and risk-assess their medical IT network. The term medical IT network is only applied to those systems and network components, which interface with medical devices. Only those GP surgeries which have interfaces with medical devices (glucose meters and so forth), where the information from the device is electronically transferred into the Electronic Patient Record via the network (wireless or wired) will be impacted.

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[5] http://www.connectingforhealth.nhs.uk/engagement/clinical/occo/safety/dscn

[6] http://www.connectingforhealth.nhs.uk/engagement/clinical/occo/safety/guide

[7] http://www.mhra.gov.uk/index.htm

The requirements of IEC80001 will not be significantly different from the requirements of DSCN 18/2009, and hence GP surgeries who comply with DSCN 18/2009 can expect not to be adversely impacted in practise by the new IEC80001.

The NHS is taking the lead on defining a guidance document for health care organisations in implementing IEC80001. This will be well publicised and will be in the public domain alongside the new standard.

3.6   Key clinical safety summary points

a)   Clinicians and other users of NHS systems may at times have opportunities to constructively influence decisions that impact on organisational and workplace factors that in turn have a systemic effect on clinical safety

b)   Mitigations tend to consist of a combination of technical solutions and user guidance. For some hazards, particularly those that are dependent on human behaviour or professional 'best practice', the only practicable mitigation may be user guidance alone. Users should be made aware of this guidance, understand why it has been put in place and why it is advisable to follow it

c)   Clinical safety assurance is a distinct and quite separate process from usability assurance. Some clinical safety hazards may appropriately be identified as low priority and not amenable to any practicable mitigation. Users should be aware that a system which meets clinical safety assurance requirements may never the less still have usability issues

d)   Users should report any suspected clinical safety issues that may come to light after a system has been deployed. Primary Care Organisations should all have mechanisms in place to enable reporting of health IT safety incidents to the National Service Desk[8]. When an issue is reported a National Incident Number (NIN) will be provided

e)   Clinical safety is dependent on clinicians and other users receiving appropriate education and training

f)   Good 'data quality' is a very important pre-requisite for safe and effective communications.

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[8] cfh.npfitservicedesk@nhs.net

Chapter 4 - Records Governance

4.1   Information governance framework

This chapter will discuss and advise on the NHS IT governance framework including specific guidance on:

- Legal aspects
- Relevant standards
- Record guidance from health professional bodies
- Consent issues
- Data disclosure
- Retention of records and their associated audit trails.

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 had prime responsibility for supporting improvements to information governance practice in health and social care in England[9](though its statutory functions will eventually be transferred to the Care Quality Commission, following the Arms Length Bodies review in 2010). The NIGB takes the view that no system can have zero risk of loss of data through breakdown of security or 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.

National applications and"spine" connected services such as Choose and Book and the Electronic Prescription Service use a common approach to protect the security and confidentiality of every patient's personal and health care details.The NHS has set out the

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[9] National Information Governance Board www.nigb.nhs.uk

principles that will govern how patient information is held in such systems and the way it is shared. These are outlined in the NHS Care Record Guarantee[10].

Organisations that need to access these services set up Registration Authorities to manage this process. The Registration Authority is responsible for verifying the identity of health care professionals and workers who wish to register to use these services. Once authorised, the Registration Authority issues an NHS Smartcard to individuals[11]. Individuals use their NHS Smartcard and their Smartcard Pass-code each time they log on.

NHS Smartcards help control who accesses these national applications and services and what level of access that they can have. They are similar to a chip and PIN credit or debit card, but are more secure. A user's Smartcard is printed with their name, photograph and unique user identity number. To register for a Smartcard, Registration Authorities are required to ask applicants for identification which satisfies the government recommended standard 'e-Gif Level 3', providing at least three forms of ID (photo and non-photo), including proof of address. Individuals are granted access to patient information based on their work and level of involvement in patient care. Staff will also continue to be bound by professional guidance[12], local regulations, the Data Protection Act and the NHS Code of Confidentiality.

Information Governance provides a framework for handling personal information in a confidential and secure manner to the legal, 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 outside the traditional 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.

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[10] Care Record Guarantee www.nigb.nhs.uk/guarantee

[11] http://www.connectingforhealth.nhs.uk/systemsandservices/rasmartcards

[12] GMC http://www.gmc-uk.org/guidance/

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. These principles apply equally to written records, oral communications and other media (e.g. photographs and x-rays).

4.2   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.

4.2.1 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. (A range of bodies, including the Care Quality Commission, the Audit Commission and Primary Care Trusts, have statutory powers to require disclosure of confidential information, disclosures required for notifiable diseases and under the Abortion Act are examples).

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 (and private) 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[13]
GMC Confidentiality: (and supplementary guidance)[14]

4.2.2 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.

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[13]http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550

[14] GMC Confidentiality http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

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[15]

NHS Information Governance – guidance on legal and professional obligations[16]

4.2.3 Access to Health Records Act 1990

The Access to Health Records Act[17] 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 records of the deceased. The Act allows individuals to add a note to their health record to negate this access right. Right of access may be partially excluded in certain circumstances[18].

Key attributes:

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 records of deceased patients.

Key guidance:

Department of Health guidelines

- The NHS Confidentiality Code of Practice[19]
- Department of Health, patient confidentiality and access to health records[20]
- GMC Confidentiality (and supplementary guidance)[21]
- NHS Information Governance – guidance on legal and professional obligations[22]

4.2.4 Data Protection Act 1998 (DPA)

The DPA[23] 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

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[15] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_074142

[16] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616

[17] Access to Health Records Act 1990 www.hmso.gov.uk/acts/acts1990/Ukpga_19900023_en_1.htm

[18] http://www.legislation.gov.uk/ukpga/1990/23/section/5

[19] http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550

[20] www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/fs/en

[21] GMC Confidentiality http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

[22] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616

[23] Data Protection Act 1998 http://www.legislation.gov.uk/ukpga/1998/29/contents

information and the particular needs of health professionals to communicate that information between themselves.

The DPA provides patients with a right to have copies made available of *their own personal data* held in their health records, within the terms of the Act. The DPA applies to both electronic and paper-based record systems.

The eight principles are listed below.

<u>Schedule 1, Part I, paragraph 1 - The data protection principles</u>

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 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

4.2.4.1 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 would seem that the data controller of each participating organisation has a role and the model 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. This "Determination in common" is where data controllers share a pool of personal data, each processing independently of the other. As with 'joint' arrangements under the DPA, data controllers in common should ideally have written agreements and processes for ensuring that all data controller responsibilities are satisfied (See also Chapter 5.2.5 – Shared electronic patient records).

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 ineffective practice[24]. This creates a tension between the need to share health data for legitimate corporate reasons and preserving patient confidentiality.

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 Care Record

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[24] HSJ http://www.hsj.co.uk/news/acute-care/mid-staffordshire-crisis-quality-of-care-sacrificed-in-ft-bid/2007558.article

Guarantee, published by the NIGB[25] underpins the relationship between patients and those who will have access to their NHS records.

Key attributes:
The first principle of the Act requires that data are processed 'fairly' and 'lawfully'. This means that patients must be informed about how and why information about them is used and who will have access to their information. It also means that the data must be processed in accordance with all relevant laws, including the common law duty of confidentiality, which requires consent for disclosure to third parties.

- The key principles are that data must be;
- Obtained for a specified and lawful purpose
- Not be excessive for the purpose
- And (for sensitive personal data for medical purposes) must be processed by a health professional or an individual with an equivalent duty of confidentiality.

The DPA 'identifies the particular needs' of communication with health professionals and 'a person who in the circumstances owes a duty of confidentiality which is equivalent to that which would arise if that person were a health professional', which may be particularly important as health and social care become more integrated.

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:
Data Protection Act 1998: Further Guidance[26]
The NHS Confidentiality Code of Practice[27]
Department of Health guidance on patient confidentiality and access to health records[28]
NHS Information Governance – guidance on legal and professional obligations[29]

4.2.5 Human Rights Act 1998
The Human Rights Act (HRA)[30] incorporates the European Convention of Human Rights into UK law. The Act identifies 15 human rights in Schedule one and requires 'public authorities' to

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[25] Care Record Guarantee www.nigb.nhs.uk

[26] www.informationcommissioner.gov.uk

[27] http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550

[28] http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/index.htm

[29] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616

[30] Human Rights Act www.hmso.gov.uk/acts/acts1998/19980042.htm

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 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[31]
GMC Confidentiality (and supplementary guidance)[32]

4.2.6 Freedom of Information Act 2000 (FOI)

The Freedom of Information Act[33] 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.

The FOI is not intended to allow people to gain access to private sensitive information about themselves or others, such as information held in health records. Those wishing to access personal information about themselves should apply under the DPA[34]. The Information Commissioner has provided guidance to the effect that health records of the deceased are exempt from the provisions of FOI due to their sensitive and confidential content.

There are specific exemptions in the FOI Act to stop disclosure of personal health information. The following two sections of the FOI Act are the most relevant:

Section 40 – Information which constitutes 'personal information' under the Data Protection Act 1998 (DPA) is exempt from the provisions of FOI if its disclosure would contravene any of the DPA principles. The DPA only applies to living individuals, (However there may be some cases where information about a deceased patient is also personal information relating to or identifying a living individual).

Section 41 – Information that has been provided in confidence is exempt from the provisions of the FOI. There is a general agreement that information provided for the purpose of receiving healthcare is held under a duty of confidence. This exemption applies with regards to access to deceased patient records.

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[31] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616

[32] GMC Confidentiality http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

[33] Freedom of Information Act www.hmso.gov.uk/acts/acts2000/20000036.htm

[34] FOI limitations http://www.ico.gov.uk/Global/faqs/freedom_of_information_act_for_the_public.aspx#f7DFC8EBD-92FB-42E9-B6DA-D3FF0C006F9A

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[35]
NHS Information Governance – guidance on legal and professional obligations[36]
Guidance for Access to Health Records Requests February 2010, page 16, para 54 published by DH[37]

4.2.7 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 in specific circumstances, 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. At the time of writing (December 2012), the Secretary of State for Health is required to consult with the statutory National Information Governance Board (Ethics and Confidentiality Committee) before making any regulations under section 251 (See also Chapter 4.8.1 below).

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 which must be respected.

Key guidance:

Department of Health confidentiality website The NHS Confidentiality Code of Practice[38]
Department of Health, patient confidentiality and access to health records[39]
GMC Confidentiality (and supplementary guidance)[40]

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[35] www.informationcommissioner.gov.uk

[36] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616

[37] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_112916

[38] http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550

[39] www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/fs/en

[40] GMC Confidentiality http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

4.2.8 Electronic Communications Act 2000

This Act[41] sets in place an approval scheme for businesses providing cryptography services, such as electronic signatures and confidentiality services and the processes under which 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[42]

4.2.9 The NHS (General Medical Services Contracts) Regulations 2004[43], the NHS (Personal Medical Services Agreements) Regulations 2004[44] and the APMS Directions[45]

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 PCTs to discharge their responsibilities with regard to wider functioning of the NHS.

These regulations make explicit existing legal and ethical obligations of confidentiality, placing them in the context of primary care contractual arrangements. It does not cover in detail all circumstances in which contractor-held information may be requested, but sets out principles of good practice for contractors of primary medical services and Primary Care Trusts (PCTs) who commission services from them. It also describes circumstances in which Strategic Health Authorities (SHAs) or the Department of Health (DH) may request access to certain contractor-held information. PCTs are required by Directions to comply with the provisions of this Code when exercising certain functions. PCTs should normally seek actively to involve and engage Local Representative Committees in relation to the Code where there are any potential issues of contention or where contractors may require additional support.

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[41] Electronic Communications Act 2000 Electronic Communications Act 2000 (c. 7)

[42] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079616

[43] S.I. 2004/291

[44] S.I. 2004/627

[45] The Alternative Provider Medical Services Directions 2004 dated 21st April 2004.

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 or to obtain express patient consent.

Key guidance:

Department of Health publication:

- Confidentiality and Disclosure of Information: General Medical Services (GMS), Personal Medical Services (PMS), and Alternative Provider Medical Services (APMS) Code of Practice 2005[46]

4.3 Standards

In addition to the requirements of law, there are a range of standards that contribute to the information governance framework. An information standard is a formal document approved and issued by the Information Standards Board for Health and adult Social Care[47]. It defines a technical specification, content, methods, processes and practices for mandatory implementation across health and social care in England. An example of an information standard is the use of the NHS Number[48] in primary care or the introduction of the International Classification of Diseases (ICD) into the NHS[49].

The General Medical Council is represented on the Information Standards Board, ensuring that there is appropriate regulatory input before standards are approved. In addition, the developers of information standards will be encouraged to have the guidance reviewed by the BMA GPC and RCGP Joint GP IT Committee.

Information standards will usually be implemented in the IT systems funded by the Primary Care Trust. It is important to note, however, that there may be instructions for users contained in the information standard. These should be followed by GP practice staff to ensure the IT system is used correctly. The guidance will normally be issued by the PCT or directly by the supplier. An example would be the guidance that accompanied the NHS Number standard that the patient is routinely asked their NHS Number.

GP practices should therefore act upon guidance issued by the PCT or suppliers that is endorsed by an information standard.

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[46] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4107303

[47] Information Standards Board for Health & Social Care http://www.isb.nhs.uk/

[48] NHS Number Program http://www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber/

[49] ICD 10
http://www.datadictionary.nhs.uk/web_site_content/supporting_information/clinical_coding/international_classification_of_diseases_%28icd-10%29.asp?shownav=1

4.3.1 ISO/IEC27001:2005 and ISO/IEC27002:Information Security Standards

The NHS has adopted the ISO/IEC 27000 series of international security standards[50]. ISO/IEC27001 defines the Information Security Management System (ISMS) approach to compliance and ISO/IEC27002 describes the code of practice for information security management and a range of generally accepted good practice security controls.

Although these standards provide a robust and comprehensive approach to the management of information security, compliance may be beyond the resources of many GP Practices. However, it is essential that practices establish the most secure working practices that they can and key elements of information security are outlined and supported within the NHS Information Governance toolkit[51]. Increasingly network and database security will not be in the hands of individual GP practices as systems move to use remote servers. However, important aspects of information security management will remain a practice responsibility.

Key attributes:
Information security needs to be based upon an assessment of risk and covers issues such as access controls, physical security (doors and locks etc), business continuity planning and disaster recovery, capacity management, and the storage and disposal of records

Key guidance:
- Information Security Management: NHS Code of Practice[52]
- Information Governance toolkit[53]
    - (requires an N3 connection for access to downloadable copies of the published ISO standards)
- British Standards Institute[54]

4.4   Other relevant publications

4.4.1 Caldicott Report 1997

The Caldicott review was commissioned to examine the ways in which information was used by the NHS. The report[55] lists 6 principles to apply to indicate the appropriateness of a proposed communication (see below).

1. Justify the purpose(s) of every proposed use or transfer

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[50] This series has replaced and extended the BS7799-2:2002 and BS7799-1, previously known internationally as ISO17799:2000

[51] IGT https://www.igt.connectingforhealth.nhs.uk/

[52] www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_074142

[53] nww.igt.connectingforhealth.nhs.uk

[54] www.bsi-global.com/index.xalter

[55] The Caldicott Report
www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4068403&chk=jsKw07

2. Don't use it unless it is absolutely necessary, and
3. Use the minimum necessary
4. Access to it should be on a strict need-to-know basis
5. Everyone with access to it should be aware of their responsibilities, and
6. Understand and comply with the law.

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 requirement for senior clinical involvement in confidentiality management remain highly relevant[56].

4.4.2 Building the Information Core: A Confidentiality Strategy for the NHS[57]
This document, published in December 2001, sets out the 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.

4.4.3 Confidentiality: NHS Code of Practice[58]
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.

4.5   Governance issues particular to shared electronic patient records

The Primary Health Care Specialist Group (PHCSG)[59]of the British Computer Society has identified a number of areas that require detailed examination and guidance that particularly

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[56] Caldicott Manual 2010
   http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114509

[57] Building the Information Core A Confidentiality Strategy for the NHS

[58] Confidentiality: NHS Code of Practice The NHS Confidentiality Code of Practice

relate to shared electronic patient record systems. These are discussed below (see also Chapter 5 – Shared Electronic Patient Records).

4.5.1   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). Patients may wish to be involved in these decisions (see also Chapter 5.3 – Shared Electronic Patient Records).

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.

4.5.2   Data and record 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 (see Chapter 6 – High Quality Patient Records). 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. 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 (see Chapter 5 – Shared Electronic Patient Records and Chapter 6 High Quality Patient Records).

Data migration presents particular hazards in terms of patient safety and data/record quality. The NHS CFH Clinical Safety Group regularly receive safety incident reports relating to issues encountered during the migration of practices from one clinical system supplier to another. This is key area of clinical risk.

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[59] PHCSG (BCS) CLICSIG conference, 31 January 2009.

Typical incidents include:

- Reactivation of archived prescriptions
- Mapping errors resulting in different unrelated medications being linked (Quinine/Quinadine)
- Issues with preservation of units of measure due to how different systems interpret decimal points and so forth (see Chapter 8c – Data Migration).

4.6   Records and record keeping – guidance from health professional bodies

4.6.1 Doctors

The General Medical Council's[60] (GMC) *Good Medical Practice* guidance for doctors[61] 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[62].

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 (and wherever possible, patients should be informed of such disclosures made without consent).

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 are expected to understand and adhere to corporate information governance and confidentiality policies.

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[60] http://www.gmc-uk.org/

[61] General Medical Council Good Medical Practice (2006) http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp

[62] General Medical Council Confidentiality Guidance (2009)

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 or required by law. Doctors must ensure that anyone to whom they disclose personal information understands that it is provided in confidence, which they must respect.

Using live patient records to support the testing of clinical systems is also considered poor practice unless the patient has been asked and has specifically consented to this use.

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.

4.6.2 Nurses

The Nursing and Midwifery Council[63] (NMC) *Guidelines for records and record keeping*[64] supports the principle of shared records in which all members of the health care 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.

4.6.3 Allied Health Professionals

The Health Professions Council's[65] (HPC) publication *Standards of conduct, performance and ethics*[66] (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.

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[63] http://www.nmc-uk.org/

[64] Nursing and Midwifery Council. Guidelines for records and record keeping. http://www.nmc-uk.org/Documents/Guidance/nmcGuidanceRecordKeepingGuidanceforNursesandMidwives.pdf

[65] http://www.hpc-uk.org/

[66] http://www.hpc-uk.org/publications/standards/index.asp?id=38

4.6.4   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 (or where required by law or in the public interest). 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.

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.

4.7   Consent

4.7.1   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[67]. The duty of confidentiality seeks to regulate types of action (e.g. communication or disclosure) rather than the processing of types of data[68] and is a way of protecting the content of many types of communications that can only be waived by seeking consent from the patient.

4.7.2   Consent and Summary Care Records

The issue of consent has proved controversial for the NHS 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[69] (See also Chapter 8e.2 – The Summary Care Record and Emergency Care Summary, for a more detailed explanation).

4.7.3   Consent and Shared Records

Shared 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

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[67] Rethinking Informed Consent in Bioethics. Neil C Manson and Onora O'Neill, p72. Cambridge University Press. Cambridge 2007**.**

[68] Rethinking Informed Consent in Bioethics. Neil C Manson and Onora O'Neill, p126. Cambridge University Press. Cambridge 2007

[69] UCL SCR Independent Evaluation http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/evaluation

that such patients could benefit from having a shared record 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. Healthcare teams, involved in a patient's care, can access the healthcare records within their local organisation provided the patient has not objected to this. Such consent is implied as part of consent to treatment. Patients 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 amongst the healthcare team providing care to the patient. Most of the "rules" governing such professional behaviours have developed through custom and practice within a national legal, ethical and moral framework.

In some areas, explicit data sharing agreements are being developed which go some way to addressing the shared record issues highlighted here (and in Chapter 5 – Shared Electronic Patient Records). However, this is an area still in its infancy and we are not yet able to offer any guidance here (while acknowledging that this will need to be addressed) See also Chapter 4.2.4.1 above.

4.7.4 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 shared record depends fundamentally on the relationships between patients and their health professionals.

4.8 Information governance and data disclosure

There is a growing demand in the NHS and beyond for practices to disclose clinical information from patient records to support clinical care, audit, health service planning and research. GPs have a responsibility, determined in law and professional standards to safeguard the confidentiality of the patient records that they control, whether it is stored on a practice server or hosted in a data centre. Practices should have a senior member of the practice who acts as Caldicott Guardian[70] and is able to give advice when there is doubt about the best way to respond to a request for data disclosure.

The request may be for information from the paper or computer records, about a single named patient or a group of patients' records. The output is increasingly provided by the practice in the form of a data extraction produced by a computer query. Extractions must comply with the guidelines and the standards laid out by the relevant regulatory bodies[71,72,73]including data

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[70] Caldicott Guardian Manual 2010, Department of Health, 2010
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114509
[71] Confidentiality, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

quality and integrity standards described elsewhere in these guidelines (see Chapter 6 – High Quality Patient Records).

Figure 4.8 - The decision to disclose

As the practice is the data controller for patient records that they hold, they are responsible for every data disclosure and can refuse a request that they do not agree with, although that agreement should not be unreasonably withheld. In making their decision it will help the practice to take a number of questions into consideration:

Note: the terms used in this box are defined in the body of the text.

1. Is there a statutory, court order or other requirement for disclosure?
2. Is patient consent required for the data to be disclosed?
3. If data disclosure is requested without patient consent on the grounds that the data extracted will be effectively anonymised or pseudonymised, are you confident that the data will not be identifiable?
4. If a third party offers to ensure effective anonymisation or pseudonymisation of the data after the data has left the practice, can they be trusted? (Is this a "safe haven"?). Do they have S251 approval? (see Chapter 4.8.1. below)
5. Will only the minimum necessary data be extracted and disclosed and will it exclude any information that is specifically protected at the patient's request?
6. Are the proposed use and protection of the disclosed data by the recipient clear and acceptable and will the data be deleted when the purpose of the extraction is achieved?
7. Will the data be transferred, stored and processed securely?

The practice should also make a judgement about whether:

8. The data to be disclosed is accurate and complete enough for the purpose of the extraction
9. A record of the data disclosed and the date it was extracted should be retained by the practice?

4.8.1 Statutory and common law requirements to disclose data

Disclosure of confidential data generally requires the consent of the patient but there are statutory justifications for the disclosure of patient-identifiable information without consent[74,75]. Examples include the notification of communicable diseases[76] and the existence of a court

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[72] Confidentiality and disclosure of health information tool kit, BMA, 2009.
http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[73] General Practice Extraction Service: Information Governance Principles, NHS Information Centre, 2010.
http://www.ic.nhs.uk/webfiles/Services/in%20development/gpes/20100528%20GPES%20IG%20Principles%20paper%20v1%200.pdf

[74] Confidentiality, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[75] Confidentiality and disclosure of health information tool kit, BMA, 2009.
http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[76] Confidentiality: disclosing information about serious communicable diseases, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_disclosing_info_serious_commun_diseases_2009.pdf

order demanding disclosure. Public interest is another justification but the threshold for this is high in some circumstances, for example the prevention of serious harm or serious crime[77,78,79,80]. The final decision about whether disclosure is appropriate lies with the data controller, in this case the practice. Disclosures for research and health service planning are also reasonable and examples of where the threshold for disclosure is not so high. The GMC provides excellent guidance on these issues[81].

In certain circumstances GPs are contractually required to provide patient identifiable data to PCTs without consent where it is not feasible to anonymise the data or gain patient consent[82,83].

Section 251 of the NHS Act (2006) operates in England and Wales and allows the common law duty of confidentiality "to be set aside in specific circumstances for medical purposes", where it is not possible to use anonymised information and it is not practicable to seek individual consent. The goal must be in the public interest[84] and when the data are to be used for research, the research must have approval of a research ethics committee[85]. Applications to use Section 251 in England are considered by the Ethics and Confidentiality Committee of the National Information Governance Board (NIGB)[86,87]. If the practice receives a request for

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[77] Confidentiality, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[78] Confidentiality: reporting concerns to about a patient to the DVLA or the DVA, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_reporting_concerns_DVLA_2009.pdf

[79] Confidentiality: reporting gunshot and knife wound, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_reporting_gunshot_wounds_2009.pdf

[80] Confidentiality and disclosure of health information tool kit, BMA, 2009. http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[81] GMC Confidentiality: Disclosing records for financial and administrative purposes (2009). http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

[82] Confidentiality and Disclosure of Information: General Medical Services, Personal Medical Services and Alternative Provider Medical Services Code of Practice, DH, 2005. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4107303 Confidentiality and Disclosure of Information: General Medical Services (GMS), Section 17c Agreements, and Health Board Primary Medical Services (HBPMS) Directions 2005 and Code of Practice, Scottish Executive Health Department, 2005. http://www.paymodernisation.scot.nhs.uk/gms/leg_guide/legislation/cop%20confidentiality%20and%20disclosure%20of%20Information.doc Confidentiality and Disclosure of Information: General Medical Services and Alternative Provide Medical Services (APMS) Directions 2006 and Code of Practice, Welsh Assembly Government, 2005**.** http://www.wales.nhs.uk/sites3/Documents/480/The%5FConfidentiality%5Fand%5FDisclosure%5Fof%5FInformation%2DCode%5Fof%5FPractice131005.pdf Confidentiality and Disclosure of Information: General Medical Services and Alternative Provider Medical Services Directions (Northern Ireland) 2006 and Code of Practice, Department of Health, Social Services and Public Safety, 2005. http://www.dhsspsni.gov.uk/code_of_practice_on_confidentiality.pdf

[83] Confidentiality and disclosure of information to PCTs in primary care settings – Guidance for GPs, BMA, 2007**.** http://www.bma.org.uk/images/Guidance+for+GP's+on+confidentiality+and+disclosure+of+information+for+secondary+uses+-+August+2007_tcm41-146813.pdf

[84] Confidentiality, GMC, 2009**.** http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[85] The Health Service (Control of Patient Information) Regulations, Department of Health, 2002 http://www.opsi.gov.uk/si/si2002/20021438.htm

[86] National Information Governance Board for Health and Social Care, Ethics and Confidentiality Committee. http://www.nigb.nhs.uk/ecc/about

data under Section 251, it is acceptable to disclose identifiable data without patient consent but it is good practice to inform the individuals involved as soon as possible[88]. The final decision about whether to disclose the data rests with the practice[89, 90].

4.8.2 Patient consent

Consent from the patient is normally required if confidential data are to be disclosed for purposes other than the provision of care. The GMC, the BMA and the Medical Defence Organisations (MDOs) offer guidance on consent to disclose records of individuals under the age of 16[91,92] or adults lacking capacity to give consent[93,94].

Express consent is given orally or in writing by a person who is fully informed about the purpose and nature of the data that is to be disclosed[95]. Unless there is some other legal justification (see above), it is needed for disclosure of identifiable data that is not for direct patient care[96,97,98] – that is quadrant A in the diagram below (typically called "secondary uses"[99,100]). Common secondary uses for data extracted by queries run against the practice patient database are; health care planning, commissioning of health services, research, education and training. Express consent or dissent should normally be recorded in the patient's record. If consent is provided in the form of a signed consent form or letter, it should be stored in the patient's record, where possible, as a scanned document attached to the electronic record.

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[87]   Confidentiality: Research and other secondary uses, GMC, 200. http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_40_50_research_and_secondary_issues.asp

[88]   Confidentiality NHS Code of Practice, NHS, 2003. http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/codes/confcode.pdf

[89]   Confidentiality, GMC, 2009**.** http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[90]   Confidentiality: Research and other secondary uses, GMC, 2009. http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_40_50_research_and_secondary_issues.asp

[91]   Confidentiality and disclosure of health information tool kit, BMA, 2009. http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[92]   0-18 years guidance: Principles of confidentiality, GMC, 2007. http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_42_43_principles_of_confidentiality.asp

[93]   Confidentiality and disclosure of health information tool kit, BMA, 2009. http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[94]   Confidentiality guidance: Disclosures about patients who lack capacity to consent, GMC, 2009. http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_57_63_patients_who_lack_capacity.asp

[95]   Rethinking Informed Consent in Bioethics. Neil C Manson and Onora O'Neill. Cambridge University Press. Cambridge 2007.

[96]   Confidentiality, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[97]   Confidentiality and disclosure of health information tool kit, BMA, 2009. http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[98]   Informing Shared Clinical Care: Final Report of the Shared Record Professional Guidance project, RCGP and NHS Connecting for Health, 2009**.** http://www.rcgp.org.uk/PDF/Get_Involved_SRPG_final_ref_report.pdf

[99]   Confidentiality and disclosure of health information tool kit, BMA, 2009. http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[100] Confidentiality NHS Code of Practice, NHS, 2003. http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/codes/confcode.pdf

The GMC confirms that it is reasonable to accept an assurance from an officer of a government department or agency or a registered health professional acting on their behalf that the patient or a person properly authorised to act on their behalf has consented[101,102].

If the practice computer system supports access restrictions on specific elements of patients' records, such patient choices should be complied within the extraction[103].

Figure 4.8.2 - The nature and uses of data extracts

A Patient identifiable *data for* Secondary uses	**B** Patient identifiable *data for* Direct patient care
D Effectively anonymised *data for* Secondary uses	**C** Effectively anonymised *data for* Direct patient care

Express consent is required in quadrant A. Implied consent is appropriate for quadrant B. No consent is required in law for data in quadrant C or D.

Implied consent is considered to be acceptable when identifiable information is shared with the health care team or others providing care, including administrative staff, for the purpose of provision of care to the identified patient(s) or it is used for clinical audit by the team providing health care (Quadrant B)[104]. Consent is inferred if the patient can be expected to understand that information will be disclosed for these purposes, the extent of the disclosure and their right to opt out, but they have not objected to the disclosure. If the data are to be processed fairly[105] the information should be made available in a number of ways. Methods of informing patients include posters and standard information leaflets, face-to-face discussion in the course of a consultation, information included in an appointment letter from a hospital or clinic and a letter sent to each patient's home. The Summary Care Record and local sharing of the detailed care record are special examples that are discussed elsewhere in this chapter.

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[101] Confidentiality, GMC, 2009**.** http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[102] Clause 450 of the standard GMS contract and the NHS (PMS) (Miscellaneous Amendments) Regs 2010 (SI 2010/578)

[103] The Care Record Guarantee, NHS, 2009, p16. http://www.nigb.nhs.uk/guarantee/2009-nhs-crg.pdf

[104] Confidentiality and disclosure of information to PCTs in primary care settings – Guidance for GPs, BMA, 2007. http://www.bma.org.uk/images/Guidance+for+GP's+on+confidentiality+and+disclosure+of+information+for+secondary+uses+-+August+2007_tcm41-146813.pdf

[105] Legal Guidance on the Data Protection Act (1998), Information Commissioner's Office http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/data_protection_act_legal_guidance.pdf

Express consent is not required for the disclosure of data when it is effectively anonymised (see 4.8.3 below). The Department of Health (DH) and the General Medical Council (GMC) advise that there is no legal requirement for consent or for patients to have an option to refuse consent to the use of effectively anonymised data from their records for direct patient care (Quadrant C) or other uses (Quadrant D)[106,107]. The former is unusual, most commonly local clinical audit. Secondary uses are more common. The Quality and Outcomes Framework[108,109], local health service planning[110] and research[111] are examples. Some members of the public hold strong views that patients should be able to refuse consent for their information to be used even in anonymised form[112].

4.8.3   Patient identifiable data and effective anonymisation

Every request for data disclosure should include a full explanation of the use for the data and the purpose of the disclosure. It should also be very clear whether the data extracted may be linked to individual patients.

The GMC Confidentiality guidance provides definitions for anonymised, coded information and identifiable information.[113]

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[106] Confidentiality, GMC, 2009**.** http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[107] Confidentiality NHS Code of Practice, NHS, 2003.
http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/codes/confcode.pdf

[108] Confidentiality and Disclosure of Information: General Medical Services, Personal Medical Services and Alternative Provider Medical Services Code of Practice, DH, 2005.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4107303
Confidentiality and Disclosure of Information: General Medical Services (GMS), Section 17c Agreements, and Health Board Primary Medical Services (HBPMS) Directions 2005 and Code of Practice, Scottish Executive Health Department, 2005.
http://www.paymodernisation.scot.nhs.uk/gms/leg_guide/legislation/cop%20confidentiality%20and%20disclosure%20of%20Information.doc
Confidentiality and Disclosure of Information: General Medical Services and Alternative Provide Medical Services (APMS) Directions 2006 and Code of Practice, Welsh Assembly Government, 2005**.**
http://www.wales.nhs.uk/sites3/Documents/480/The%5FConfidentiality%5Fand%5FDisclosure%5Fof%5FInformation%2DCode%5Fof%5FPractice131005.pdf
Confidentiality and Disclosure of Information: General Medical Services and Alternative Provider Medical Services Directions (Northern Ireland) 2006 and Code of Practice, Department of Health, Social Services and Public Safety, 2005**.**
http://www.dhsspsni.gov.uk/code_of_practice_on_confidentiality.pdf

[109] Confidentiality and disclosure of information to PCTs in primary care settings – Guidance for GPs, BMA, 2007.
http://www.bma.org.uk/images/Guidance+for+GP's+on+confidentiality+and+disclosure+of+information+for+secondary+uses+-+August+2007_tcm41-146813.pdf

[110] Confidentiality: disclosing records for financial and administrative purposes, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_disclosing_records_financial_2009.pdf

[111] Good practice in research and Consent to research, GMC, 2010. http://www.gmc-uk.org/static/documents/content/Research_guidance_FINAL.pdf

[112] Summary of Responses to the Consultation on Additional Uses of Patient Data, Research Capability Programme, NHS Connecting for Health, 2009.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_110715.pdf

[113] GMC Confidentiality 2009 http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_glossary.asp

> **Anonymised information** – Information from which individuals cannot reasonably be identified. Names, addresses, full postcodes or identification numbers, alone or together or in conjunction with any other information held by or available to the recipient, can be used to identify patients.
>
> **Coded information –** Also known as pseudonymised information. Information from which individuals cannot be identified by the recipient, but which enables information about different patients to be distinguished or to link information about the same patients over time (for example to identify drug side effects). A key might be retained by the person or service which coded the information so that it can be reconnected with the patient.
>
> **Identifiable information** - information from which a patient can be identified. Their name, address and full postcode will identify a patient; combinations of information may also do so, even if their name and address are not included. Information consisting of small numbers and rare conditions might also lead to the identification of an individual.

There is a variety of techniques that can be used, singly or in combination, to make it less likely that individuals can be recognised from the data.

Data extraction from patients' records is likely to be identifiable after it has been disclosed if:

- It contains identifiers such as name and address, full post code, date of birth or death, NHS number, a local identifier such as a practice computer system ID number, sex, ethnic origin or occupation[114],it could possibly be identifiable if:
- It contains a combination of unusual features that generate small numbers of patients, allowing a specific patient's data to be identified. Even if a query extracts data from a large number of patients, it may be that only a small number of them share certain features, which allow their identity to be inferred.

Care should be taken to ensure that the recipient of data does not have other knowledge that might allow them to infer the identity of individuals from the data. Data should also be checked to ensure that it does not contain free text entries which may directly name the patient or a third party relating to the patient. Where free text is present, it should either be removed or read by a responsible person to exclude specific patient-identifiable material.

A patient's identity is less likely to be at risk and the extracted data more likely to be effectively anonymised if it is only going to be used in controlled circumstances by a small group of users governed by an employment contract and a legal duty of confidentiality than if the data are to be published on a website.

Data can be transformed after it has been extracted in order to make it less likely that individuals can be recognised from it. This may best be done in a safe haven: a physical or electronic infrastructure that provides a high level of security and governance controls for

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[114] The Caldicott Committee Report on the Review of Patient-Identifiable Information, DH, 1997.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4068404.pdf

confidential data to be processed securely. People working in safe havens should be bound by an equivalent code of conduct preventing disclosure of data as health professionals[115,116,117,118].

Ways of transforming extracted data to make it less likely that individuals can be recognised include:

1. **Removal of all the person identifiers.**
2. **Pseudonymisation** - also known as coding, is a process of replacing person identifiers with other values (pseudonyms) available to the data user, from which the identities of the individuals cannot be intrinsically inferred[119,120]. It maintains the anonymity of extracted data while allowing the records about the same individual to be linked using the same unique label or key, often created using encryption processes, for each extraction from an individual's record. The process may be carried out by the GP computer system or by a third party immediately after extraction.

   Pseudonymisation has two weaknesses: the possibility of successfully identifying patients from the rest of the data remains and access to the key or lookup tables used to pseudonymise the data allows the process to be reversed to identify the data subjects. Thus the governance around the pseudonymisation process and transparency about when and how the pseudonymisation may be legitimately reversed are very important.

   Some data extraction services[121,122]use a "two key process" whereby an encrypted key is added to each record before the data leaves the practice and the first recipient adds a second key before the data are used by third parties.

3. **Aggregating data**- so that category totals are displayed instead of individual record values. This can be combined with small number processing: extracted data that is to be published should be checked to ensure that cells containing small numbers (usually less than 5) are changed or deleted before the data are disclosed.

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[115] Confidentiality, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[116] Towards Consensus for Best Practice: use of records from general practice for research, Wellcome Trust, 2009. http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtx055660.pdf

[117] Pseudonymisation Implementation Project (PIP) Reference Paper 1, Guidance on Terminology, NHS Information Centre, NHS Connecting for Health, 2009. http://www.connectingforhealth.nhs.uk/systemsandservices/sus/delivery/pseudo/pipterminologyguidancefv1ajan10.pdf

[118] General Practice Research Database. http://www.gprd.com/contributing/faqs.asp#confidentiality

[119] Confidentiality and disclosure of health information tool kit, BMA, 2009. http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

[120] Pseudonymisation Implementation Project (PIP) Reference Paper 1, Guidance on Terminology, NHS Information Centre, NHS Connecting for Health, 2009. http://www.connectingforhealth.nhs.uk/systemsandservices/sus/delivery/pseudo/pipterminologyguidancefv1ajan10.pdf

[121] General Practice Research Database. http://www.gprd.com/contributing/faqs.asp#confidentiality

[122] QResearch, a new ethical high quality general practice derived database for research, QResearch, **2003.** http://www.qresearch.org/Public_Documents/QRESEARCH_protocol_May03.pdf

4. **Using derivations or banding**- hides the exact original values, e.g. replacing dates of birth by ages, addresses by localities, using partial postcodes.

5. **Shuffling**– creates synthetic data. The data items are shuffled so that the totals and values in the data set are preserved but the links to identifiers are irreversibly broken.

This may be done in the practice or after the data has been extracted and released to a trusted third party who, working in a safe haven, will use software that requires no user to view the data[123,124].

4.8.4   Practice responsibility for the data to be extracted

The practice should have the opportunity to review the data before it leaves the practice. This means that where the data extraction is controlled by an agency outside the practice there should be a period between running the query on the GP system and the disclosure of the data. It should be enough to allow the practice to check the following:

Inaccurate or incomplete data- can be misleading or affect the results of research, commissioning or other secondary purposes. Finding significant errors or omissions in the records may lead the practice to correct the data in the affected patients' records but also look at any systematic problems within practice processes that are leading to the errors.

Minimum dataset - the practice can confirm that only the minimum data required for the express purpose of the disclosure has been extracted. Ideally the data requestor should explain the requirement for every field of data in the extracted data.

Patient withheld data - if the practice clinical computer system supports a method of withholding patient information and a patient has asked for information to be hidden, that data should not be extracted in identifiable form.

Third party data - data may contain information that is confidential to another person. Information about genetic tests or illnesses may point to the illness or likelihood of the same illness in a blood relative[125].

4.8.5   Disclosure after a patient's death

In general the duty of confidence continues after a patient has died[126]. The GMC gives advice on circumstances where relevant information about a patient who has died should be disclosed[127]. Examples include data extraction authorised under section 251 of the NHS Act 2006 or justified in the public interest, such as research, for National Confidential Inquiries or local clinical audit. Where possible the data should be anonymised or coded.

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[123] Confidentiality, GMC, 2009**.** http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[124] Confidentiality: Research and other secondary uses, GMC, 2009.   http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_40_50_research_and_secondary_issues.asp

[125] Confidentiality, GMC, 2009.   http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[126] The Information tribunal case of Bluck v Epsom & St Helier Trust and the case of Lewis v SS of State for Health both give some legal basis to this clear ethical argument**.**

[127] Confidentiality, GMC, 2009.   http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

It is safest to treat confidential information about dead people in the same way as such information about living people is treated. If you are aware that a patient asked for their information to remain confidential, their wishes should usually be respected. If the patient's wishes are unknown, the GMC guidance states that consideration should be given as to whether disclosure is likely to cause distress or benefit to the patient's partner or family or anyone else, whether it is already public knowledge and the purpose of the disclosure.

4.8.6   Data leaving the practice

Data transmission - the practice has a responsibility to ensure that all data extracted from the patents' records are processed securely[128]. This includes making sure that the data leaves the practice securely. If it is to be carried on removable media such as USB memory devices or CD-ROMs, the data must be encrypted (and the key sent separately). If it is to be transmitted electronically, such transmissions must be secure. Once the data leaves the practice, the recipient may take over the responsibility of data controller for the data they hold, depending upon their use of the data.

Data recipients- where the data recipient becomes the data controller for the data, they will assume legal responsibility for holding and processing it securely. That includes following the key principles of the Data Protection Act (1998)[129] for identifiable data. In particular they should only use identifiable data for the purposes for which it has been extracted and it should be deleted as soon as that purpose is complete. It is helpful for the practice to have a clear written agreement with the requestor of the data that states exactly how they will manage the data after it leaves the practice.

The practice should assure itself that the data recipient understands, and can be expected to meet, its legal responsibilities in relation to the data. It is reasonable for GPs to assume that a national government organisation will handle such data correctly[130]. Other recipients may have trusted third party status and their data management handling may be accredited to recognised standards such as ISO 27001 and 27002. The government in their response to the Data Sharing Review accepted the notion of the approved researcher, who works under the same duty of confidentiality as health professionals[131,132].

4.9   Retention of GP electronic patient records and associated audit trails when a patient is no longer registered with a practice

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[128] Legal Guidance on the Data Protection Act (1998), Information Commissioner's Office http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/data_protection_act_legal_guidance.pdf

[129] Legal Guidance on the Data Protection Act (1998), Information Commissioner's Office http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/data_protection_act_legal_guidance.pdf

[130] Confidentiality, GMC, 2009. http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf

[131] Data Sharing Review Report, 2008.   http://www.justice.gov.uk/reviews/docs/data-sharing-review-report.pdf

[132] Response to the Data Sharing Review Report, Ministry of Justice, 2008. http://www.justice.gov.uk/publications/response-data-sharing-review.htm

4.9.1 Background

An agreement was reached between the BMA and the Information Commissioner in 2004 to the effect that GP electronic patient records and their associated system audit trails should be retained by practices indefinitely pending the development of functionality to support transfer of GP Electronic Patient Records (EPRs) and their associated audit trails between systems in a way that would enable both to be integrated into the receiving system. However, it has become clear that the functionality to transfer and integrate audit trails will not be available for the foreseeable future.

A second issue that requires clarification relates to the patient record transfer terminology. The term"GP2GP transfer" is misleading, as it is a **copy** of the record that is sent, not the record itself.

The OIC has made it clear that there can be no exemption to the requirement for GPs to comply with the Principles of the DPA and particularly in this context with the principles relating to not retaining records for longer than necessary and ensuring that retained records are protected by appropriate security measures. The retention of audit trails and patient records by a practice that is no longer caring for the individual concerned must be for appropriate and necessary purposes. In the absence of a lawful basis for retaining these records they should be physically deleted from systems. If there is a lawful basis for retaining records they should be protected by security measures that prevent them from being accessed inappropriately. The Department of Health, RCGP and BMA have stated that there are a number of purposes (see also Table 4.9 below) for which it is necessary to retain and access patient records when a patient is no longer registered with a practice. These considerations apply only where a patient leaving a practice subsequently requires a copy of a record to be sent between systems or locations. Different considerations will apply where a patient moves between practices that use the same remotely hosted system (e.g. TPP SystmOne) where the transfer is affected by simple access control adjustments and there is no interruption in the audit trail.

4.9.2 Clinical purposes

Patients have a tendency to return to practices. Although most returns will probably be after short periods of a few years (e.g. on returning from University) some will be later. The GP2GP project is working on a Version 2 message that depends on the 'old' record plus its audit trail remaining intact in the original practice. That will allow the returning record to be safely merged with the old (existing) record without duplication or unnecessary degradation or disorganisation. In this context "degradation" refers to the inability of some code terms to be safely mapped from one clinical system to another (see chapter 8b.2 – GP2GP Electronic Record Transfer).

This is important from a patient safety point of view, as there is a tendency for the structure of a record to be degraded by passage through successive different systems. Therefore, when the patient returns to Practice A, that part of the record that originally started out from Practice

A will have undergone some degradations and disorganisation as it went through Practices B and C. By adopting the new Version 2 GP2GP solution it will be possible for Practice A simply to reactivate its old record and only to import subsequent additions and amendments. That should result in a better quality record at Practice A - making the record more usable and also safer.

4.9.3 Medico-legal purposes

Providing medico-legal evidence (e.g. to establish or refute allegations of negligence or poor performance) is an essential purpose of record audit trails. Poor clinical performance can only be evidenced in many cases by a review of the records made during an episode of care. Errors or delays in diagnosis, the use of outmoded tests or treatments and failure to act on the results of monitoring or testing can be established or refuted through well-maintained records and their associated audit trails.

Audit trails are physically separate chronological records held alongside the patient EPR and provide a record of the activities of system users and of changes to systems themselves. This record includes, but is not limited to, additions and amendments to patient records and by rolling back all changes it is possible to understand what a record looked like at a particular point in time, what changes were subsequently made and who made them.

Audit trails are the primary tool for supporting forensic analysis and establishing evidence about what was recorded when and by whom. They are tamper proof and intentionally have no functionality to support deletions or amendments, as these would defeat their purpose. It is not therefore possible to specify the components of an audit trail relating to a specific patient record in order, for example, to delete references. The only way to remove a record from an audit trail is to wipe the media holding the entire audit trail clean.

The audit trail in GP clinical systems is specific to each individual system and it cannot be meaningfully interpreted by a different system. It is not therefore transferred between GP systems by electronic message or copied between systems, as is the content of the patient record itself. Crucially, the audit trail retains its usefulness only so long as it can be associated with the system and the records it relates to. Physical deletion of an EPR would render the associated audit trail meaningless.

It is therefore essential that both the audit trail and the patient record that it is associated with must be retained by a Practice even when a patient is no longer registered with that Practice.

DH lawyers advise that although there is technically a time limit in respect of litigation resulting from clinical negligence, there are a number of exceptions or special circumstances which mean that this cannot be relied upon, and litigation can arise many years after the event and therefore that the evidence needed to determine what changes were made to records, by whom and at what point in time must be retained indefinitely. It is therefore necessary that both

the audit trail and the associated patient record be retained indefinitely by a practice, as they are the sole source of forensic evidence.

Access controls should however prevent access to the patient record once a patient has left the practice unless there is an appropriate and necessary purpose and there should be robust governance processes to ensure that this is managed effectively.

4.9.4 Probity purposes

Health records also provide the main, and sometimes sole, evidence of work undertaken by a practice and are required to support claims for payment and bids for resources, both by the practice and also by organisations from which care was commissioned for patients. The financial systems require practices to retain the evidence to support claimed payments for up to 8 years and the process of ensuring that payments made through the commissioning process can also take considerable time to resolve.

4.9.5 Clinical governance purposes

There are also important clinical governance activities that require records to be available and checked and failure to include patients who have left the practice may bias reviews or obscure important evidence (why did the patient leave?). Activity to support professional appraisal and revalidation also needs to include all of a doctor's recent caseload and again it would potentially undermine the process if a proportion of patients records weren't available for review – some practices have patient turnover of 30%+ each year.

4.9.6 Other purposes

Although not in itself a purpose that would justify record retention, the fact that records are being retained for other reasons also means that it is necessary for practices to meet the requirements relating to subject access to retained health records.

It is also likely that access to records will be sought by research interests e.g. UK Biobank and where appropriate authorisation is provided, e.g. explicit patient consent, then access may be required. In many cases this will be achieved through software solutions, e.g. GPES (the General Practice Extraction Service) which will be provided by the Health and Social Care Information Centre.

4.9.7 Access controls

Although the purposes identified above require records and associated audit trails to be retained indefinitely, different staff will require access for these purposes and some purposes will no longer be valid after certain periods requiring changes to be made to the access rights of these staff.

Table 4.9

Purpose	Staff Roles Requiring Access	Access Required for…
Subsequent Clinical Care	Only designated staff involved in patient registration/re-registration procedures	Indefinitely
Practice Management, completing/updating records	All staff whose roles involve record access for registered patients	Three months
Medico Legal & Subject	**Only designated clinical and administrative staff.** **Different staff may be designated for the different purposes**	Indefinitely
Probity		Eight years
Clinical governance		Five years

4.10 The Information Governance Toolkit, & Information Governance Statement of Compliance (IGSoC)

All organisations that provide or support the provision of NHS services need to provide assurance that they have robust information governance and are managing patient records confidentially and securely. This is a requirement set out in the NHS Constitution[133] and in the NHS Care Record Guarantee[134] and also underpins the registration requirements overseen by the Care Quality Commission.

This assurance is provided by organisations completing a performance assessment using the NHS Information Governance Toolkit[135] and by working to make year on year improvements in their performance. The NHS Information Governance Toolkit performance assessment also provides assurance that an organisation is addressing its responsibilities as a user of national IT applications and services (e.g.N3, NHSmail etc) through an additional assurance statement (also referred to as the IG Statement of Compliance - IGSoC) that organisations need to sign annually.

Access to national IT applications and services is not a right, and assurance is needed from organisations connecting to the NHS IT infrastructure, to the effect that they will follow good information governance practice and not put national networks knowingly at risk.

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[133] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113613

[134] http://www.nigb.nhs.uk/guarantee

[135] http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/igsoc/faqs/igt

Chapter 5–Shared electronic patient records

5.1 Introduction

In this chapter we will describe relevant guidelines for the governance, medico-legal and patient safety consequences of shared electronic clinical record systems in the primary care domain. We will consider the implications of sharing health data and records between health professionals in different settings and with patients.

5.2 Shared electronic patient records – background

There has been considerable development of multi-disciplinary care in the GP and community settings over the last ten years. It is now crucial to maintaining and improving health, particularly for those with chronic illness, rehabilitation and palliative care needs. Developing models of information sharing and record systems to support these requirements has been patchy, and not uniformly led by common principles of clinical communication and governance. It was against this background that the RCGP published its Shared Record Professional Guidance (SRPG) report in 2009[136]. This report, underpinned by sound research, is likely to guide and accelerate the processes of information sharing that are crucial for improving care.

5.2.1 The SRPG report

The purpose of the Shared Record Professional Guidance (SRPG) project was to develop a set of professionally-led guidelines that would consider the governance, medico-legal and patient safety consequences of Shared Electronic Patient Record (SEPR) systems in the primary care domain. NHS CFH commissioned this project. The SRPG report outlined a governance framework within which Shared Electronic Patient Record (SEPR) systems should operate and drafted governance principles for such systems.

The original objective was for a NHS Care Record Service in England with a single record for an individual patient that was to be accessible by the GP and by community and local hospital care settings. The vision for the NHS therefore was of a patient-centred, secure, electronic patient record, linked and accessible across (health) organisational boundaries, with patients able to make choices about sharing some or all of the content of their detailed (care) records with health professionals involved in their care. NHS Connecting for Health (NHS CFH) has now moved away from a "replace all" strategy for electronic patient records to a "connect all" strategy, with a plurality of inter-operable systems in place.

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[136]SRPG report http://www.rcgp.org.uk/health_informatics_group/srpg.aspx

Computerisation of health records offers the prospect of rapid sharing of data and information in ways that are not possible with paper records. The potential benefits of this in terms of patient safety, and efficiency and flexibility of healthcare provision have been widely promoted. However there is disagreement about just what should be shared and by what mechanism. The SRPG report literature review found that the main health benefits of shared records are probably improvements in the quality and safety of care, in access to care or in cost effectiveness. However, these anticipated improvements in efficiency, safety, equity and cost-effectiveness of care have not been realised in the few rigorous studies on a large scale anywhere in the world.

Concerns about privacy and consent have been heightened by security lapses in other (non-NHS) national IT projects. This has increased interest in other models of sharing clinical information.

In Scotland, the Emergency Care Summary (ECS) shares clinical information differently. In Europe and the Americas, Kaiser Permanente, shares detailed records in a decentralised way. Existing suppliers in England offer different models of sharing records: these models range from "one patient one record" (which mirrored the NHS Connecting for Health ambition) to models that rely on interoperability of dispersed systems.

Against this background the SRPG project aimed to examine record sharing in a generic way that was not related to particular systems or architectures. The SRPG report was 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 (e.g. SCR or ECS) created by an act of publication from the records of prime entry of one or more individual organisations.

The key questions for the SRPG project to address were:

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

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

5.2.2   What are the purposes of shared electronic patient records?

The vision for shared electronic patient records at the time the SRPG report was commissioned was of a patient-centred secure electronic patient record, linked and accessible across (health) organisational boundaries, with patients able to make choices about sharing some or all of the content of their detailed (care) records with health professionals involved in their care. The SRPG report findings are presented below in sections 5.2.3 – 5.2.6

See Principle 1
(see 5.2.6 below)

5.2.3 How can these requirements be delivered safely?

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

See Principles 2, 3, 4, 5, 6
(see 5.2.6 below)

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

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

See Principles 7, 8, 9, 10, 11, 12, 13
(see 5.2.6 below)

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

See Principles 14, 15 and 16
(see 5.2.6 below)

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

However, patients must not be put under any pressure or coercion to engage in these decisions if they do not wish to do so.

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

- Government
  - To provide an appropriate legal framework within which good clinical practice can be established.

- Clinical professions
  - To ensure that professional guidance is developed and delivered to health professionals working with shared record systems and that this is reflected in professional requirements for registration, training and Continued Professional Development.

- Health organisations
  - To understand the business requirements of the service and commission systems that are fit for purpose.
  - To ensure that high quality clinical and information governance practices are followed.
  - To provide an appropriate education and training framework for staff

- Health professionals
  - To ensure they understand and follow best practice in relation to clinical record keeping and are aware of the particular issues and challenges presented by shared health records.

- Patients
  - Patients are key stakeholders and should participate as full partners in these matters.

The Data Protection Act (see also Chapter 4.2.4 – Records Governance) requires that patients are informed about how and why information about them is used and who will have access to their information. It does not prevent information being used for healthcare purposes providing the principles are satisfied but may prevent health information being used for non-healthcare purposes without a patient's explicit consent. The key points are that the processing (use) of sensitive personal information has to be:

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

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

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

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

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

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

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

The Secretary of State for Health is the data controller for the Summary Care Record in England. For shared electronic patient record systems (e.g. TPP SystmOne) it would seem that the data controller of each participating organisation has a role and the model of a "data controller in common" has been proposed. This is where the data controllers of each participating organisation have a shared responsibility for the total contents of the shared electronic health record. Each organisation contributes some or all of its records to the shared environment(e.g. a database)**,** but does not relinquish any control over its contributions. Through contributing to the shared environment, information is disclosed to other organisations involved in a patient's care. These other organisations may view and copy this data and use it for their own purposes. There is no single data controller responsible for the shared environment so participating organisations are therefore data controllers in common for the information within the shared environment.

Where organisations are data controllers in common, they need to ensure that all data protection requirements are being effectively satisfied. This does not mean that they will each be accountable for meeting all requirements, but there needs to be a clear documented agreement on how requirements will be met. Organisations participating in a model where they are data controllers in common need to be provided with clear guidance on their legal responsibilities and documented agreements covering all DPA requirements need to be developed and put in place. Whilst it is important that pragmatism and efficient use of

resources underpin these agreements, it is also important that every effort is made to ensure that the interests of patients are given appropriate priority.

Therefore the Department of Health have proposed that they draft a generic data sharing agreement or memorandum of understanding, in collaboration with key stakeholders, to be made available for local adaptation where appropriate. We await further details on this from the DH (as at January 2011).

5.2.6 SRPG Principles for record sharing

In the SRPG report the terms Shared Electronic Patient Record (SEPR) and Shared Detailed Care Record (sDCR) are used interchangeably. Here the term Shared Electronic Patient Record is preferred as a generic description for electronic records of prime entry that are shared by two or more legal entities.

Principle 1.
The success of Shared Electronic Patient Record (SEPR) programmes should be measured alongside the operational characteristics of these programmes allowing evaluation of such systems in a wider context.

Principle 2.
Joint guidance on record sharing should be produced and maintained collaboratively by professional regulatory bodies and representative organisations to ensure a multi-professional approach to record quality, consistency and clarity.

Principle 3.
A community using a SEPR system should establish governance rules and processes that ensure the clear allocation of responsibility and define the rules and mechanisms for its transfer. The rules need to be clear on who has responsibility for content and for action based on the record content within and between organisations.

Principle 4.
SEPR systems should be designed to support the governance principles outlined in Principle 3 (above).

Principle 5.
Health professionals should have a shared responsibility for maintaining and assuring data quality in SEPR systems.

Principle 6.
Health professionals should be properly educated and trained to meet their legal, ethical and professional responsibilities for using and managing SEPR systems. This should form part of their ongoing professional development.

Principle 7.
Semantic issues should be considered in the design and implementation of SEPR systems so that meaning is preserved and must be sensitive to issues of language, interpretation and context.

Principle 8.
Governance arrangements should be in place to deal with errors and differences of opinion in SEPR systems.

Principle 9.
Organisations should have the facility to update/correct erroneous information added to their Organisational/Detailed Care Records from other sources, (with the original information retained in the audit trail).

Principle 10.
Content and provenance data should identify unambiguously the originator or editor of each entry in the SEPR.

Principle 11.
SEPRs should to be able to store and present information in styles that meet the particular user's needs.

Principle 12.
SEPR systems should improve the quality and safety of care by facilitating communication and coordination between health professionals and informing best clinical practice.

Principle 13.
SEPR systems should support structured communications between users (e.g. referrals).

Principle 14.
Health organisations should be able to explain to patients who will have access to their SEPR and must make information available to patients about such disclosures.

Principle 15.
Health professionals should respect the wishes of those patients who object to particular information being shared with others providing care through a SEPR system, except where disclosure is in the public interest or a legal requirement.

Principle 16.
There should be an organisational (or team) guardian with clinical and information governance responsibilities for that organisation's shared and organisational Detailed Care Records, in order to assure best practice is followed.

Under Principle 9, the audit trail must be easily visible in such cases, as it can be vital in understanding the patient's past treatment and/or healthcare journey.

Under Principle 15, this can be very difficult in practice. Whether disclosure is "in the public interest" can only be decided at the time and in context.

5.3 Sharing records with patients (Record Access)

Patients have had a right to access copies of their health records made available, for many years though few have chosen to do so. However, the more widespread use of electronic health records, increasing public use and familiarity with new technologies and changing public culture are likely to increase this demand in future.

It was against this background that the RCGP published its report "*Enabling patients to access electronic health records: Guidance for health professionals*" in 2010[137].

Record Access may provide most benefit if used as an integral part of the care process. If patients access their records, particularly in the context of joint decision making in partnership with their health professional, the result can lead to improvements in their care.

It is important that all health professionals understand that new ways of working with patients become possible with electronic records but it is essential to apply these safely and effectively. This document offers sound principles, developed in conjunction with lessons learned, to underpin such changes in clinical practice.

Health professionals have concerns about Record Access raising questions such as the impact it will have on the length of consultations, the way in which records are written, the potential for inappropriate patient access to third party information and the potential for litigation. The RCGP patient record access report addresses these concerns and should provide health professionals with confidence in the process and ways of managing any risks.

5.3.1 Principles of Record Access for patients

> "You have the right of access to your own health records.
> These will always be used to manage your treatment in your best interests."
> **NHS Constitution**[138]

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[137] RCGP Health Informatics Group website http://www.rcgp.org.uk/health_informatics_group.aspx

[138] The NHS Constitution for England, published January 2009, is available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093419 The NHS Care Record Guarantee is available at http://www.nigb.nhs.uk/guarantee

1. Patients should be given appropriate information and opportunities to exercise control over the health care decisions that affect them[139].
2. Giving patients direct electronic access to their health records is one method of sharing relevant information to help them make informed decisions about their health care.
3. Patients should be encouraged to access their own health records and use them to improve their health and care[140].
4. Record access for patients is likely to improve their care and their safety.
5. Where Record Access is implemented, it should be at no cost to the patient.
6. Health organisations should strive to provide a secure mechanism enabling direct record access by patients and when available, inform patients of the facility and how to use it.
7. Health professionals should encourage patients to access their records, withholding information only in exceptional cases allowed by law.
8. Health professionals use health records as a tool to provide care, and patient access, or input, must not impact adversely upon the effectiveness or quality of that tool.
9. Health professionals should withhold confidential third party information from patients before enabling record access.
10. Computer systems suppliers should develop tools to provide patients with secure access to their records.

5.3.2   Record Access benefits

Record Access should enable patients to understand the information in their records, help them make use of that information and be linked to targeted health information and decision support. Patients will find access to their records more rewarding and beneficial if they can use it to learn more about their condition or tests. For example - by linking information to appropriate sites the record can offer patients a portal to a range of facilities with advice on improving health, managing disease and evaluating the care they receive.

Record Access should be considered as an additional way of supplying patients with the information they may require to manage their care. It should not be a substitute for information communicated by health professionals when caring for patients[141] and should not be compulsory. Some patients may not be able to, or may not wish to, access their records.

Record Access has the potential to improve discussions between patients and health professionals, encouraging a more open and honest relationship[142]. If a patient does feel that they do not understand something or that something has gone wrong, they have easy access

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[139] See General Medical Council's Duties of a Doctor at: http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp

[140] This is consistent with the General Medical Council's Duties of a Doctor, and specifically the statement "support patients in caring for themselves to improve and maintain their health"., but is not in itself a GMC requirement.

[141] Fisher B. Bhavnani V. Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. Journal of the Royal Society of Medicine. 102(12):539-44, 2009 Dec.

[142] Pagliari C, Demter D, Singelton P. Potential of electronic personal health records. BMJ. 2007;335:330-333.

to their data and there is no evidence of increased litigation[143,144]. Patients can also share their record with family members or carers as they choose.

Access to medical records may be most beneficial when accompanied by information to improve patients' understanding of the data. In general, self-care and shared decision-making have been shown to improve outcomes and to reduce the use of health services.

5.3.3 Record Access governance

In the UK, under the Data Protection Act 1998[145] and Access to Medical Reports Act 1988[146] patients (including "Gillick competent" children), or anyone authorised by the patient, are entitled to access their health records. The GMC advises doctors to let parents access their children's records if the child consents or lacks capacity and access does not go against the child's interests. There are provisions under the Mental Capacity Act 2005 in England and Wales for access to records of patients that lack capacity.

The Information Commissioner has made it clear that having online access to medical records does not replace formal rights of access under the Data Protection Act (DPA) and patients can still make subject access requests in the usual way.

The two key exceptions for access to information are where it:

- Is likely to cause serious harm to the physical or mental health, or condition of the patient or any other person;
- May relate to, or be provided by, a third person who can be identified from the information and has not consented to the disclosure.

The General Medical Council (GMC) summarises the situation in the following way[147]:

"Section 7 of the Data Protection Act 1998 gives patients the right to have access to their personal information; but there are some exceptions. For example, you do not have to supply a patient with information about another person or that identifies another person as the source of the information, unless that other person consents or it is reasonable in the circumstances to supply the information without their consent. See the Information Commissioner's technical guidance note on dealing with subject access requests involving other people's information[148]."

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[143] Bernstein RA, Andrews EM, Weaver LA. 1981 Physicians' attitudes towards patients' requests to read their hospital record. Medical care 19: 118-21

[144] Cimino JJ, Patel VL, Kushniruk AW., 2002. 'The patient clinical information system (PatCIS): technical solutions for and experience with giving patients access to their electronic medical records', Int J Med Inform. Dec 18;68(1-3):113-27.

[145] Available at: http://www.opsi.gov.uk/Acts/Acts1998/ukpga_19980029_en_1

[146] Available at: www.opsi.gov.uk/acts/acts1988/Ukpga_19880028_en_1.htm

[147] See paragraph 27 of Confidentiality Guidance: Endnotes, available at: http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_endnotes.asp

[148] Available at: http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/dealing_with_subject_access_requests_involving_other_peoples_information.pdf

There is no formal definition of serious harm. The GMC has offered advice in the context of withholding information when seeking consent to treatment[149]:

"You should not withhold information necessary for decision making unless you judge that disclosure…would cause the patient serious harm. In this context serious harm does not mean the patient would become upset, or decide to refuse treatment".

There is some evidence that doctors may be more likely to consider data to be damaging to a patient, than the patients might themselves. Health professionals experienced in Record Access suggest that there are very few items that will need to be withheld. Occasionally it could be the health professional themselves who might come to serious harm if the patient had Record Access. The final decision on whether to grant access should rest with the patient's health professional, who should consider consulting others who have contributed to the record for help in assessing the nature and extent of any risk.

5.3.4   Record Access – copying letters to patients
The Copying Letters to Patients initiative[150], which enables patients to have a copy of all letters written about them, is included as a pledge in the NHS Constitution 2009:

"The NHS commits to share with you any letters sent between clinicians about your care."

This initiative is gradually being adopted across the NHS and is generally accepted by patients and health professionals, with a few exceptions. The Central Consultants and Specialists Committee of the BMA has published guidance for its members on copying letters to patients[151]. The guidance states that although copying letters to patients is not a contractual obligation for doctors, it can bring benefits for example:

- Providing reassurance that clinical correspondence has taken place;
- Ensuring that misunderstandings can be corrected or explained;
- Providing a valuable written point of reference for patients who are unable to remember more complex important information;
- Having a therapeutic potential for patients with mental illness

5.3.5   Record Access – other issues
The RCGP patient record access report[152] provides further detailed guidance in the following areas;

- Preparing for Record Access
    - o   Security, registration and authentication

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[149] See paragraph 16 of Confidentiality Guidance: Endnotes, available at: http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_endnotes.asp

[150] See: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008765

[151] Available at: http://www.bma.org.uk/images/consultantscopyinglletterstopatients_tcm41-190155.doc

[152] RCGP Health Informatics Group website http://www.rcgp.org.uk/health_informatics_group.aspx

- - o Informing patients of the implications of records access
    - o Training
- Making healthcare records accessible to patients
    - o Language and interpretation
    - o Including speculation in the record
- Patient contributions to the health record

The report goes on to provide a number of use cases to illustrate the issues that may arise from Record Access in a number of scenarios.

5.3.6 Record Access – Informing Patients of the implications of Record Access

Patients should be given information about the benefits and risks of accessing their records. They should understand, for example, it could include test results together with an explanation of results, if this information is available. Some of the issues outlined in this paper should be explained simply but fully in information sheets. An agreement that the patient has read and understood the processes necessary to take part in Record Access should be obtained from each patient and kept in the patient's record. There must also be a mechanism for patients to change their mind at any time about having access, the parts they access or the access rights granted to others.

5.3.7 Training

The process of sharing records requires new knowledge, attitudes, skills and practices from health professionals, patients and the wider public. Record Access requires a culture change, which could be a barrier to implementation. Training would be beneficial as part of ongoing professional development. Patients and the public may also benefit from advice on how to best make use of record access (see also Chapter 12 – Education and Training).

Chapter 6 - High Quality Patient Records

6.1   Introduction

Information quality sits at the very heart of these guidelines. Patient care depends on having good patient information at the time that clinical decisions are made. Healthcare cannot be commissioned or planned without good patient information.

This chapter will provide guidance on high quality patient records under the following main areas:

- Information quality and modern general practice
- Capturing information in the consultation
- Capturing information from outside the practice
- Recognising high quality patient records
- System-specific issues
- Data quality and shared records

The representation of health data in patient records is in itself a complex and time consuming process and the tools we use to create the records, from Read codes to the computer systems themselves, are sophisticated but sometimes difficult to use. Nor is it a simple matter to define high quality patient records but a good place to start is to consider the factors that help determine data, information[153] and record quality. In the process it is worthwhile reminding ourselves of the various purposes of health records (Chapter 2). These can be briefly summarised as;

- Clinical –
    - o Facilitate the clinical care of individual patients
    - o Assist in the clinical care of the practice population
- Non-clinical –
    - o To meet administrative, legal, and contractual obligations
- Additional –
    - o Clinical governance, professional development, education and training, commissioning and healthcare planning[154], etc
- Emerging –

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[153] In the context of health records, "data" items might be a set clinical codes. The data becomes "information" when there is associated context

[154] Liberating the NHS: commissioning for patients, Dept of Health, 2010. http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117587

- o Health records created in one health environment are increasingly likely to be accessed for viewing and/or editing in other health environments
- o Patients to have increasing control over their health records

Record quality is not an abstract concept but must be considered in relation to the fitness of information for a particular purpose. Careful recording and well designed systems can help ensure that the record is fit for the range of purposes for which it might be used, but it may not possible to support all purposes equally and where compromise is necessary GPs should remember that the usual main purpose of their records is to support the care of individual patients.

Clearly stating and understanding these purposes has important implications for clinical record keeping in terms of data and record quality, meaning, clinical coding, education and training. It is also at the heart of the conundrum facing those who seek to define and achieve high quality records: how is it possible to create patient records that adequately support many purposes?

The context of modern Primary Care where patient records are created is also complex. An increasingly wide range of people from different professional groups and organisations contribute to each record. The patient record must not only function as a record of events but also as an effective means of communication between members of the team providing care to the patient.

Finally, it is possible to define the underlying characteristics of good quality patient records that identify a practical set of goals that enables data quality to be taught and achieved[155].

6.2   Information quality and modern general practice

Modern primary care has an increasingly multi-disciplinary team approach to its work, which is not contained by the boundaries between the various organisations involved. Practices will increasingly work together in federations and commissioning groups[156][157]. General Practice will have new responsibilities for commissioning services from the rest of the NHS[158]. The traditional divide between "primary" and "secondary" care is also becoming blurred. Effective and reliable use of information from patient records and efficient and informative communications are therefore vital at many levels and in a variety of different contexts. This applies not just to clinical data, but also to demographic, appointments, administrative and other data held for a variety of purposes that are necessary to the various processes that

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[155] PRIMIS+ website http://www.primis.nhs.uk/

[156] Primary Care Federations: putting patients, RCGP, August 2008, http://www.rcgp.org.uk/PDF/Primary%20Care%20Federations%20document.pdf

[157] Liberating the NHS: commissioning for patients, Dept of Health, 2010. http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117587

[158] Equity and Excellence: Liberating the NHS, Dept of Health, 2010

contribute to the running of general practice (See Chapter 8a.3 – The Summary Care Record and Emergency Care Summary).

6.2.1 Data Quality vs Record Quality

Creating high quality records requires not only high quality data, but also that data is arranged in the record to support the various purposes to which the record might be put. As with data quality, record quality depends on the quality of the data recorded, the capability of the GP EPR system and the users' input in the form of using the system to its maximum capabilities and ensuring that the systems and practice for capturing and recording data and supporting text are sound and observed.

To create a good quality record requires a detailed understanding of the capabilities of the system used (at least by those responsible for configuring a system and setting record keeping policies and procedures) so that the particular features provided for structuring the record are used to best effect. GPs should seek system-specific advice, education and training to ensure they adopt best practice for record making and keeping for their particular system (See also Chapter 7 – Clinical Coding Schemes, Chapter 9 – A Pathway to Good Paperless Practice & Chapter 12 – Education and Training).

6.3 Capturing information in the consultation

It is very important to acknowledge that the patient record can only be a representation or summary of reality, whether paper based or electronic[159]. **Information quality in an electronic patient record cannot be expected to exceed that of the information available to be recorded.**

Medical data has a marked degree of inherent variability, uncertainty and inaccuracy[160], some of which is due to use of language[161], some is due to the way that GPs reach diagnoses[162] or select what to record, some is due to the variability in clinical terms used by different healthcare disciplines. Handling these factors is essential for those seeking to achieve high quality data.

It is important for users to understand that modern electronic patient record systems are designed to be both human-readable and machine-readable. We like to read and write stories, so human-readable records will be (relatively) rich in narrative content which is very important for providing context (see below). However, also having high quality data in computable form is critical to enable patient data to be "processed" (e.g. for QoF, audit and decision-support

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[159] RCGP Health Informatics Task Force. Scope EPR Project report 1998.

[160] Teasdale S, editor. Doubt and Uncertainty in the electronic health record. Proceedings of the Annual Conference of the Primary Health Care Specialist Group of the British Computer Society; Worcester: PHCSG; 1994.

[161] Beyth-Marom R. How Probable is Probable? A Numerical Translation of Verbal Probability Expressions. Journal of Forecasting 1982; 1:257-269.

[162] Howie JGR. Diagnosis - The Achilles heel? Journal of the Royal College of General Practitioners 1972; 22:310-315.

purposes). It is essential that GPs consider both these dimensions as they build and maintain patient records (see also 6.3.1 below and Chapter 7 – Clinical Coding Schemes & Chapter 9 – A Pathway to Good Paperless Practice).

It is generally accepted that data derives an important part of its meaning from the context in which it is recorded[163,164] and thus to be meaningful information needs to capture sufficient context to ensure the meaning will be clear to others. Context is complex and includes unrecorded background and assumptions held by the creator of the record, patient and organisational circumstances, electronic patient record structures and record content alongside the data item

It follows that when information is recorded that is likely to be shared with others working in a different setting, particular care needs to be taken to ensure that important context is made as explicit and unambiguous as possible(see Chapter 4.5 – Records Governance).

6.3.1   Coding, structuring and free text

Computer systems are designed to encourage the structured and coded recording of information and provide tools to facilitate this. These tools are designed to speed data entry and ensure consistent structure and coding, which will help ensure that information is easy to retrieve and available in a computable form (see specifically Chapter 9.6.2 & 9.6.3 – A Pathway to Good Paperless Practice) usable by automated facilities in the system.

However, it is not always possible to express clinical information adequately, simply as a list of structured codes and in these circumstance it may be preferable to express information as a clinical narrative recorded in free-text, particular where the primary requirement is that it should convey meaning to another human reader rather than support automated processes.

Where information can be adequately recorded using codes and structured data entry it is generally better to do so, but where this is not possible free-text clinical narrative can be used instead of or to clarify structured data entry.

For detail about coding schemes and how they are structured see Chapter 7 – Clinical Coding Schemes.

All systems allow users to append text entries to Read-coded entries. Text appended in this way has the advantage that it is likely to retain its contextual relationship to the original Read coded entry even after record transfers to different systems. But it may also become truncated or even lost by some systems in unpredictable ways, an example of where 'system quality' may impact on 'data quality'.

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[163] van der Lei J. Use and abuse of computer-stored medical records [editorial]. Methods Inf Med 1991; 30(2):79-80.

[164] McWilliams A, editor. Computer-based patient records in primary care: The substrate of ideals and reality. Proceedings of the Annual Conference of the Primary Health Care Specialist Group of the British Computer Society; 92; 1992.

Text appended to Read coded entries should never change the meaning of the original coded concept.

For example the entry;

      G30.. Acute myocardial infarction   excluded

would be strongly discouraged while the following is quite acceptable

      G30.. Acute myocardial infarction   developed chest pain at work

6.3.1.1 Use of local codes

Local codes are codes that are not part of the standard national code set (Read, CVT3, SNOMED) but which are **generated at a more local level by a particular supplier, health community or practice. Local codes are usually generated to fill a perceived gap in the national set or meet some peculiarly intrinsically local requirement.**

- **Local codes managed by the supplier**

Some local codes are created by suppliers and are essential to support normal system functions but others have been developed to augment Read v2 and CTV3. Such codes cannot be rendered fully interoperable (i.e. cannot be understood if transferred to other supplier systems - see Chapter8b – GP2GP, section 8b.3.4 for further details). Wherever they exist, Read v2 or CTV3 codes should be used in preference to non-Read v2 or non-CTV3 codes and the use of non-Read/CTV3 codes should be deprecated. Some suppliers have embarked on programmes that automatically find their own local codes and replace them with appropriate Read v2 or CTV3 equivalents. Practices are encouraged to avail themselves of these services.

- **Practice generated local codes**

Some systems still allow users to create their own codes at practice level. The creation and use of such codes is strongly deprecated. Where such codes have been used in the past it has often been found difficult for users even in the same practice to be certain of their original meaning. It is deemed clinically unsafe to attempt to transfer such coded information to any site away from the originating practice (see Chapter 8b – GP2GP, section 8b.3.4 for further details). Practices should seek to replace local codes with standard Read codes wherever possible, using appropriate tools from their system supplier.

6.3.2 Problem and Episode Recording

Most primary care record systems are based on a problem-orientated approach although the detailed implementation varies between systems. In all systems, problem titles are Read coded concepts that describe the separate problems that the clinician has identified. Problems may be diagnoses, main symptoms where a pathological diagnosis cannot be made (e.g. headache or abdominal pain), other health issue, life event (e.g. marital breakdown) or major operations.

Problem lists can be built as encounter or consultation records are made, or as information is summarised from paper records, letters or reports. The goal is to build complete and accurate problem lists. Each entry in the patient's problem list should represent a single episode of a problem with an accurate date of onset.

Each system has a method of ensuring that the same Read code can be used for all consultations about the same problem without adding new episodes to the problem list. The principle is to record the episode type of each consultation record. GP systems generally support a set of episode types defined by the RCGP which allow episodes of care to be defined as First, New or Ongoing (FNO)[165]:

- **First**: means it is the first time the patient has presented with this diagnoses ever in their life. There should only be one episode of type "F" for a given diagnosis in a patient record.

- **New**: applies to a new episode of illness relating to diagnoses with which the patient has previously suffered but since recovered. There can be many episodes of type "N" in relation to acute illness; in the case of chronic conditions, there may be a need to encode N for acute exacerbations – e.g. in asthma attacks.

- **Ongoing/Other**: is used when a patient attends and a health issue is discussed as part of the encounter but not it a relationship to "F" or "N". So for example, it may be recorded when a patient attends for a repeat prescription for a long-term condition (e.g. inflammatory bowel disease). Many practices do not record a Read code in such circumstances. (This option was implemented for the RCGP weekly returns service and other morbidity surveys).

Some examples should help to clarify this complex area;

- Diabetes mellitus does not generally resolve once correctly diagnosed. The first encounter at which diabetes was diagnosed should have episode type "F". All other encounters related to diabetes should have episode type "O". Failure to do this may result in massive overstatement of the prevalence of diabetes in the practice.
- An individual might have more that one myocardial infarction (MI). The first should have an episode type "F" while further new MI should have an episode type of "N". However, any encounters relating to an MI that has already been recorded should have an episode type of "O". Failure to do this can result in a record showing a patient has had many more MIs than they actually have.

Some systems possess other functions that allow the user to maintain the quality of the problem lists, and preserve the clarity of the consultation narrative, where the view of encounter records can be filtered by problem title:

- **Evolving problems:** linking problem titles with different Read codes to merge them into one episode. If a diagnosis has evolved (e.g. an initial problem title may be chest pain but need to be changed to angina for the same episode when the diagnosis is confirmed) or synonymous Read codes have been used for different consultations about the same

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[165] Definition in: Morbidity Statistics from General Practice. Forth National Study 1991-92, OCPS, page 16 "Recording consultation type"

episode. This will avoid multiple entries in the problem list for one episode and link the narrative of the consultations on the same problem.

- **Deleting errors:** correcting diagnositic or coding errors by deleting problem Read codes and replacing the deleted problem titles with correct Read codes without changing the meaning of previously recorded consultation records (e.g. chest pain initially diagnosed incorrectly and recorded as angina, later found to be caused by something else).

- **Grouping related problems:** makes long problem lists clearer and enables a more helpful view of the consultation narrative (angina, myocardial infarction and ischaemic heart disease; or appendicectomy and appendicitis) with the underlying pathology being the "group header".

Systems do vary in the way and extent that they implement episode management. This chapter can only describe the principles of problem management. We advise that you check your supplier's documentation or seek system-specific training.

6.3.3   Patient Access and Review

The review of records by patients can be a very effective way of identifying incorrect or missing information in that patient's record. Occasionally patients and healthcare professionals may disagree about what should be recorded in the record and the correctness of individual items. Practices should have polices to deal with such disputes and provide a mechanism to record this dissonance in the record when a common view cannot be agreed [166] (see also Chapter 5 – Shared Electronic Patient Records)

Bearing in mind that patients increasingly have access to records, practices should take care to ensure that as far as is consistent with their own requirements, records are as meaningful to patients as possible[167];

- Avoid abbreviations and acronyms (these may be confusing and have different meanings to patients and other health professionals)
- Avoid medical jargon in free text when plain English can be just as effective. This does not mean that specialist terms should be avoided when they are necessary to support professional use of the record
- Take care that third party information that should not be disclosed to the patient is appropriately protected. This particularly applies to free text entries and attached documents (no GP systems can assure this - as at December 2010).

6.3.4   Common sources of error

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[166] SRPG report http://www.rcgp.org.uk/health_informatics_group/srpg.aspx

[167] NIGB Care Record Guarantee http://www.nigb.nhs.uk/guarantee

- Recording information against the wrong patient. Be particularly aware of common names but remember even uncommon names can be duplicated and these are less likely to be checked. It is good practice to confirm first line of address and date of birth with the patient at the start of the consultation. It is less easy, but no less important, to check that information coming from a source other than directly from the patient really does relate to that patient (e.g. pathology results, hospital letters, record received from previous practice). Parents and children with the same name and living together can be a common cause of confusion. Also beware of twins sharing the same initial, date of birth and address. Ensure you are aware of any naming conventions amongst ethnic minority groups in your practice.

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- Use of the NHS Number (CHI Number in Scotland) can help healthcare staff and service providers match patients to their health records (see also Chapter 8a.4 – The Personal Demographics Service)

- Confusing codes for procedures and diagnoses (e.g. breast neoplasm screen, with malignant neoplasm of female breast or influenza vaccination with influenza).

- Changing the meaning of coded data by appending text, worst of all using text to negate a code e.g. Code = Breast Cancer Text = Excluded.

- False certainty e.g. coding a severe central chest pain as myocardial infarct before the diagnosis has been established

- Confusing family history codes with history of (H/O) codes and actual diagnoses. In general it is best to date diagnostic codes on the date the history is taken that refers to a past event. So "22/11/2010 chickenpox (1975)" means that the history of chickenpox was taken today, but relates to the past date when the patient had the condition (1975). Basically, H/O codes offer no particular value unless it is otherwise impossible to indicate the date the patient had the condition rather than the date of recording "unknown".

- Entering historic information with today's date instead of the actual date of the event / test result

6.4   Capturing information from outside the practice

A modern general practice continually receives large volumes of information from a wide range of sources and in a variety of different formats.

The 'hub and spoke' diagram of sources that feed into the EPR, which is taken from PRIMIS+ training materials, is intended to be illustrative rather than exhaustive. Each of the 'spokes' can be further subdivided and the precise details
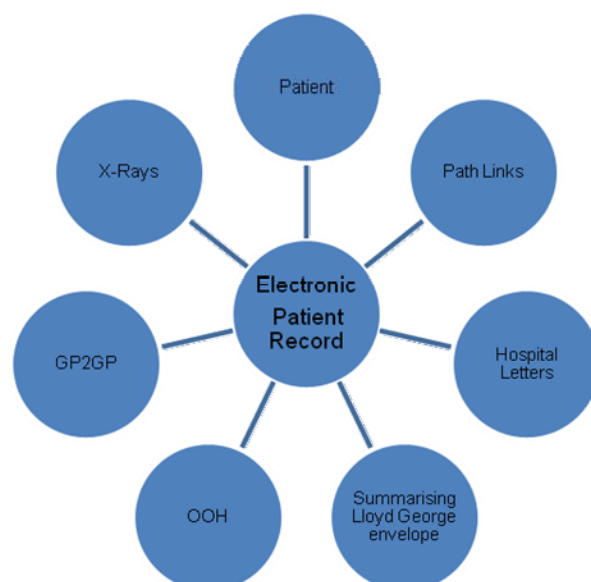
are likely to vary from practice to practice.

It would be both impractical and undesirable to incorporate these large volumes of information into the EPR in their raw state. Much of the incoming information has to be sifted and summarised, capturing the key data in Read codes in the clinical record. The processes that lead to information being entered into the electronic patient record are typically dependent on a range of different members of the practice team each with their own roles and responsibilities (see Chapter 9 – A Pathway to Good Paperless Practice and Chapter 12 – Education and Training).

Any practice wishing to enhance the quality of its electronic patient records will therefore wish to review:

- Sources of information coming into the practice
- Processes and policies for handling each of these sources
- Roles and responsibilities of the practice team members involved in these processes including regular training needs assessment, perhaps as part of an annual appraisal (see also Chapter 9 – A Pathway to Good Paperless Practice and Chapter 12 – Education and Training).
- The clinician-patient-computer consultation is also a key point at which it is essential to capture high quality clinical data, to create and update the patient record (See Chapter 9.7.7 – A Pathway to Good Paperless Practice, Consulting with computers).

The **aim of this review** should be to ensure that;

- All significant information sources have been identified
- Clearly defined processes and coherent practice-wide policies exist and are followed for handling each of these sources
- Individual team members:
    - o Are clear about their roles in these processes and of relevant practice policies
    - o Have appropriate levels of responsibility
    - o Have appropriate knowledge and skills to perform these functions
- Regular reviews or audits are carried out of
    - o Information sources, processes and policies
    - o Staff roles, responsibilities and training needs
    - o The quality of the data extracted from all of these sources.

6.4.1 Issues to consider – an example to illustrate

A case has been made for recognising the complexity of the process of achieving good quality patient records and the characteristics of such a record. It is beyond the scope of this chapter to attempt to provide a detailed breakdown of all of the information handling processes and policies that a typical practice might need to have in place to achieve quality. However, consideration of the 'handling of incoming letters' is provided as an example to illustrate the kinds of issues that should be considered. Other chapters in these Guidelines should be

consulted for specific guidance that relates to data migration (Chapter 8c), GP2GP (Chapter 8b), and other messaging processes (Chapters 8d, 8e and 8f).

6.4.1.1 Handling of letters incoming to the practice

This is primarily a 'back office / administration' function but with wider implications. A variety of letters may arrive in the practice by various means (e.g. post, courier, fax, email or other electronic means). The following checklist is intended to be illustrative rather than exhaustive. Practices should develop and maintain clear policies that address the following questions;

- Does the letter or report need to be filed or attached to the Electronic Patient Record (EPR)?
    - Does the letter need to be scanned?
    - Can the letter be linked to the right patient? (preferably by use of NHS Number)
    - Does the method of filing make the letter easily accessible from the patient record and capable of being retrieved by GP2GP when the patient leaves the practice?
    - What information will be entered describing the kind of letter (e.g. cardiology discharge letter, rheumatology outpatients letter) and how?
- Reviewing the content of the letter, should there be
    - Follow-up actions that should be entered into the EPR?
    - Changes made to (repeat) medication records?
        - Who does these and when?
    - New adverse drug reactions recorded?
        - Who enters these and do they know how this should be done?
    - Content that should be coded into the EPR?
        - Is there a practice policy for what should be coded?
        - Are there clear guidelines about choice of codes?
        - Are there clear rules for the setting of dates (e.g. for actual date of diagnosis, operations or procedures as opposed to today's date)?
        - Are there clear rules for when the episode type should be set (e.g. to First, New, or Ongoing / Other)?
        - Who does the coding?
        - Is the 'coder' appropriately trained?
        - Does the 'coder' know who to ask when in doubt about what to code or how to code?
        - Are there arrangements for holiday / sick leave?
- If, at a later stage (e.g. in consultation with patient), entries are found to be inaccurate or erroneous (see also specifically Chapter 9.7.6 – A Pathway to Good Paperless Practice)
    - Is there a clear policy about who should make corrections and how it should be done?
    - Is there a clear policy about who should make deletions and how it should be done?

It can be seen that if this task is poorly handled then there may be adverse effects on information quality.

- Relevant information may not be recorded or irrelevant information may be recorded.
- The patient's record may be rendered incomplete, inaccurate or out of date, or all three.
- If information is not coded or structured appropriately then it may be inaccessible, for example:
    - Making it hard to find important information when reviewing the patient's record in the consulting room
    - Making it irretrievable by machine searches or audits. Where an adverse drug reaction is not correctly entered there is a particular danger that prescribing decision support will not be triggered with the potential for serious risks to patient safety; this may be setting an "error trap" for a future unsuspecting user (see Chapter 3 – Clinical Safety Assurance).

See also specifically Chapter 9.7.9 - A Pathway to Good Paperless Practice, Document Management.

6.5   Recognising high quality patient records

A high quality record is one that supports the purposes for which it was created and will be used. It needs to contain high quality data and be structured so that the data can be viewed and manipulated in ways that support the uses to which it will be put.

"Information quality" may have complex interdependencies but in practical terms there can be no doubt that it is a real entity, which has a real impact on patient care. The largest repository of evidence for inter-practice variability in recording quality in GP computer records is PRIMIS+[168]. This national project was set up with the specific task of improving "data quality" in General Practice by cascading multi-disciplinary information handling, and change management skills into individual practices. Based on previous work[169,170], "data quality" for PRIMIS+ has been pragmatically defined as having five key attributes (represented by the acronym CARAT):

- Completeness
- Accuracy
- Relevance
- Accessibility
- Timeliness

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[168] PRIMIS+ http://www.primis.nhs.uk/

[169] Teasdale S, Bainbridge M, Horsfield P, Simpson L, Teasdale K, Williams J. JIGSAW - Jumping the Information Gap Solutions at Work. Foundation and quality of care programmes project team; 1998.

[170] Teasdale S. The role of information management training in improving the quantity and quality of data held on GP clinical computer systems [MSc thesis]. University of Nottingham; 1997.

Notwithstanding all of the complexities described above, this is at the heart of the matter that this chapter is addressing.

- **Completeness**

Superficially this seems to be a very simple concept. For data to be "complete" every real world instance of a concept should be recorded. Thus for the diagnosis of diabetes mellitus, every patient known to have diabetes in a given population (e.g. practice registered list) would have that fact recorded. So, completeness equates to the rate of recording of true positive cases. For the recording of blood pressure every patient for whom a blood pressure measurement was deemed necessary would have a record.

The problem in the former case is to determine what is meant by "known to have …" and how to define and code the different types of diabetes and in the latter case to determine who decides which patient's blood pressure measurement is "necessary". The issue of relevance also applies; the actions necessary to detect a diagnosis or to measure a blood pressure are likely only to take place if considered relevant or important to the context or purpose(s) for which the data is recorded.

Areas of the record that may be poorly recorded include; home visits and telephone consultations, information derived from the paper records before the practice went paperless, incoming new patient records, or hospital reports and letters, or data not deemed relevant at the time that it was revealed to or found by the person creating the record. Clearly the thoroughness of the person recording the data, the time available to the record creator and the priority he / she gives to record keeping play a part in the quality of the data. Completeness also has impact on other characteristics of quality of the record and is explored in more detail in Chapter 9 – A Pathway to Good Paperless Practice (specifically section 9.6.2).

Completeness may be affected indirectly by actions of the data recorder. Failing to use a smartcard may impair the Completeness (and also the Accuracy and Timeliness of the patient's Summary Care Record).

- **Accuracy**

While Completeness carries the idea of capturing all real world instances (i.e. the capture of **all** True Positives) the linked concept of Accuracy is about ensuring that every record relates to a genuine real world occurrence (i.e. all recorded instances are True Positives and there are no False Positives). In the case of the diagnosis of diabetes, every recorded case would have to be genuine for there to be 100% accuracy. For diagnoses, there is a particular problem with ascertaining what constitutes "True Positive" which is a separate matter from consideration of what affects the action of recording.

Accuracy is distinguished from Precision. A blood pressure recorded to the nearest 1mm of mercury might be more precise than one recorded to the nearest 5mm, but would not necessarily be any more Accurate unless repeatable and reproducible.

Accuracy includes an accurate representation of the true number of episodes of an event or illness. For example, over-representation of the number of episodes of stroke or myocardial infarction in the record are serious inaccuracies.

It also includes the correct representation of certainty, especially where a diagnosis is uncertain, yet may evolve, change or become certain. Thus accuracy is not an absolute characteristic of data that is permanent once recorded. It requires a continuing process of maintenance, or housekeeping, to reflect a changing understanding of the patient's health problems (see Chapter 9.7.6 – A Pathway to Good Paperless Practice).

When patients review their records they will often spot any missing or incorrect data. They may also disagree about what should be recorded in the record.

Practices should have policies about patient access to their records that cover these eventualities and provide a method of coming to agreement that follows professional and legal standards (See Chapter 5.3 – Shared Electronic Patient Records & Chapter 9.7.6 – A Pathway to Good Paperless Practice).

- **Relevance**

GPs and their practice teams, are most likely to record information if they believe it to be important or relevant to a given context, which they have in mind at the time of recording[171]. This may include direct patient care, commissioning, sharing, Quality and Outcomes Framework, research or medico-legal factors. Relevance is therefore likely to be playing a key role in determining recording behaviour, raising the question of how individuals come to decide what is or is not important or relevant in a given context. This might be amenable to education and training (See Chapter 9.6.2 - A Pathway to Good Paperless Practice).

- **Accessibility**

A given piece of information may be recorded in several different ways. It may be coded or written in free text, which may contain acronyms or abbreviations (see section 6.7). Coding may follow local or national guidelines or may be more unpredictable.

It may match the record display preferences of the system in which it was recorded and/or other systems that may display this data in future, for example after GP2GP transfer (See Chapter 8b – GP2GP Electronic Record Transfer). All these factors will have an influence on the accessibility of the record to future retrieval and use of the information.

In general, structured data (e.g. codified information) will be more rapidly accessible than free text but an exception to this is the aide memoire function of the record, where to the human eye a prose narrative may be far more accessible than a string of codes. Some ways of using Read codes can make the meaning of the record less accessible, particularly the use of

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[171] RCGP Health Informatics Task Force. Scope EPR Project report 1998.

practice-based euphemisms or free text that distorts the meaning of an attached Read code (see section 6.7). Accessibility may affect "timeliness" in the first (non Currency) sense outlined below. Consistent coding within a practice, and ideally beyond organisational boundaries is essential to assure high-quality data, so users always use the same code for the same problem. Templates and forms can help ensure consistency of coding (but not necessarily correct coding!)

(See also Chapter 7 – Clinical Coding Schemes and Chapter 9.6.3 - A Pathway to Good Paperless Practice).

- **Timeliness/Currency**

Timeliness can be used in a number of senses. Records created contemporaneously with the clinical activity they relate to, e.g. immediately after a consultation, are more likely to be accurate than those created later. It may refer to **Currency** which extends the concept of Completeness by requiring information to be up to date. A field containing last year's blood pressure may appear Complete but might only be rendered Current on being updated with the result of today's measurement. It is easy to overlook that the Currency of a record depends not only on the age of a recorded data items but also on the availability of updates. For example, the information in a record might be current but an updating action overdue. An item of information may be described as Timely if displayed quickly and at a time when it is most relevant to a given context.

Finally, it is important not to view information recorded on GP systems as homogeneous. It is the result of the collective action of teams made up of individuals with different roles. Diagnostic, prescribing, administrative, and clinical management information (e.g. blood pressures, serum cholesterols, eye-checks) may each depend on different groupings of people, working in different contexts, and carrying out different actions.

6.6   System specific issues

Each GP clinical system has its strengths and weaknesses and different systems are designed to support particular styles of record keeping. To make the best use of a system it is important that users understand how best to use the system to exploit its strengths and avoid its weaknesses. This can be a particular problem for users moving between systems (see Chapter 8c – Data Migration).

Every member of the practice team should have training in the use of the practice system that is commensurate with his or her role and responsibilities and their training needs should be regularly reviewed. Practices should ensure they have clear policies supported by system-specific training for those users whose roles or responsibilities involve entering information relating to;

- Identifying patients / registration (see Chapter 8a)

- Consultations: it is beyond the scope of this section to go into detail but different systems structure consultations in different ways and this for example, has implications for code use and for the way that the evolution of a 'problem' should be handled (See Chapter 9 – A Pathway to Good Paperless Practice). Users must understand the options provided by their system and have a consistent approach in their use.
- Medications (See Chapter 8f – High Quality Medication Records and the Electronic Prescription Service)
- Problem orientation
- File attachments
- Summaries
- Drug allergies – these are important and worthy of further discussion (see below)

6.6.1 Drug allergies

Transfers of allergy information between same systems generally work well but transfers between different clinical systems do not always result in all allergy information being transferred because allergies can be handled in different ways in different systems. Not all systems use Read codes to record allergy information, some use other code sets to drive their prescribing decision support software. The GP2GP team has developed import mechanisms designed to recognise system specific allergy information that then presents the information to the user for action. However some system specific allergy data may be degraded; where the incoming allergy codes cannot be safely mapped to the receiving system's codes, the allergy data will appear as text rather than as coded data. (See also specifically section 8b.3.2 of the GP2GP Chapter of these guidelines).

- GPs should continue **in all cases** to use their system-specific mechanism for recording allergies. It is **essential** that allergy information is properly recorded on your own system to ensure it can be picked up and dealt with during any subsequent data migration or GP2GP transfer. Receiving systems will have any incoming allergy information that has been entered using the sending system's specific mechanism presented to them as part of a receipt workflow (for detailed advice see references below).

- Transfers of allergy information between same systems generally work well but transfers between different clinical systems do not always result in all allergy information being transferred because allergies can be handled in different ways in different systems. Not all systems use Read codes to record allergy information, some use other code sets and others may use bespoke codes. Translation arrangements are therefore needed. The GP2GP team has developed import mechanisms designed to recognise system specific allergy information that then presents the information to the user for action. However some system specific allergy data may be degraded; where the incoming allergy codes cannot be safely mapped to the receiving system's codes, the allergy data will appear as text rather than as coded data.

- **It is essential that practices understand clearly and unambiguously that to be transferrable (interoperable) across different clinical systems, adverse drug reactions MUST be entered in a way that interacts with the native prescribing decision support system - and that users MUST enter the information relating to degraded adverse drug reactions in an imported record in such a way that it interacts with their clinical system prescribing decision support software.**

The GPC issued its own guidance on the use of Read codes to record allergy information in 2006[172]. (See also Chapter 8b – GP2GP Electronic Record Transfer and Chapter 12 – Education and Training, of these guidelines).

6.7   Data quality and shared records

Greenhalgh's UCL team and Wyatt at Dundee have both produced important reviews of the literature in relation to data quality and shared records since 2008. Greenhalgh led the review of data quality in the Summary Care Record[173] that was published as part of the SCR evaluation programme in 2008 and in 2010. Wyatt's review was published as part of the RCGP's Shared Record Professional Guidance (SRPG) project in 2009[174] and focused on issues relating to shared detailed care records (See also Chapter 5 – Shared Electronic Patient records, of these guidelines).

6.7.1   Data quality in Shared Detailed Care Records
From his literature review, Wyatt concluded that there was little published evidence of health benefits from Shared Electronic Patient Records. However, when they do occur, there are probably improvements in the quality and safety of care, in access to care or in cost effectiveness. 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.

Wyatt's review emphasised the importance of proper organisation and labelling of data items in shared records. He also emphasised the importance of understanding the effects of meaning, interpretation and semantics of data as well as, data entry, coding, import and translation when working with shared records across professional and organisational boundaries. He concluded that;

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[172] Guidance note from GPC January 2006 - Advice from the GPC – Allergy recording in GP clinical Systems

[173] Data Quality Evaluation for the Summary Care Record: An independent evaluation by University College London. Byrne et al 2008. http://eprints.ucl.ac.uk/178880/

[174] SRPG Reference Report (Chapter 5) http://www.rcgp.org.uk/health_informatics_group/srpg.aspx

"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".

Wyatt's literature review specifically examined issues of data and record quality in shared record systems and emphasised the importance of the following dependencies in contributing to shared-record quality;

- Defining an acceptable standard of data quality within and across professions and organisations
- The role of audit 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 records (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
- The completeness of the data in the record will also depend on the access rights provided to professionals by the system.

6.7.2 Data quality in the Summary Care Record (SCR)

The UCL study[175] was focused primarily on ways of driving up the quality of general practice data over time, in the context of the SCR. Their findings highlight the need to assess data not just in terms of whether it is right or wrong, but also on its capacity to be misleading.

Crucially, the UCL study emphasised the importance of clearly understanding the scope and purpose for which records are to be shared before being able to make any useful statements about appropriate data quality standards. The implications for this include the reputational damage that might occur (to the SCR) where shared record data is perceived to be poor, resulting in the possibility that such shared systems might therefore have low uptake. The UCL report emphasised that;

- Good quality data does not just happen
- Practices need training and support

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[175] Data Quality Evaluation for the Summary Care Record: An independent evaluation by University College London. Byrne et al 2008. http://eprints.ucl.ac.uk/178880/

This study made an important statement about improving the quality of patient records (in the context of the SCR);
"Audits do provide diagnostic information about data quality in the patient record. The data they provide has indicative value as to the likely source of systematic mistakes in data production. These indicators can then be used to drive a process of organisational change that will lead to the production of good data. A combined process of audit and intervention is the most effective way to improve the clinical usability of data in the SCR"

Their review concluded; *"that the best possible standards of data quality will be obtained through the use of ongoing audit and intervention cycles"* and also recommended that a national strategy for data quality be established.

6.8   Conclusion

To write high-quality patient records, it is essential to understand the various purposes for which those records will be used and the factors that contribute to make the records fit for purpose. As well as those factors, described in this chapter (and Chapter 5 – Shared Electronic Patient Records), the care and skill of the record keeper and the capabilities of the particular clinical system being used, contribute to the quality of the record.

Record keeping polices and user training should be designed to make the best of the system being used and it is essential to understand that assuring and maintaining data and record quality is an ongoing process, requiring active audit and intervention, supported by validated tools, expert resources (e.g. PRIMIS+) and an ongoing education and training strategy.

Leadership and teamwork are both essential pre-requisites for building high-quality patient records. Someone in the practice team has to take responsibility for driving forward the data/information/record quality agenda. Practices need to create an environment where they continually strive to improve their data quality.

Finally, the quality of patient information only becomes truly apparent when the information is used. Practices, PCOs (and their successors), should ensure that mechanisms are in place to enable these insights to be applied to the continuous improvement of record quality.

Chapter 7 - Clinical Coding Schemes

7.1   Coding schemes in current use

This chapter provides information and advice on clinical coding systems used in UK general practice under the following headings:

- Coding schemes in current use
- Future standardisation (SNOMED-CT)
- Features of Read codes
- General issues relating to terminology use

N.B. In Chapter 7 of the Good Practice Guidelines;

- "Chapter" – will refer to chapters of these Good Practice Guidelines
- "chapter" – will refer to a chapter of the Read Code classification ("Chapter" at the beginning of a sentence)

Electronic records in General Practice have had coding schemes at their heart since the 1980s, in some cases even earlier. More than 520 million separate coded entries were added to England's EPRs in 2006. This is approximately double the volume of ten years ago, and the year-on-year trend clearly shows an increasing amount of coded data in use (see graph)[176].

In the 1980s, personal computer schemes were in their infancy, and had (by today's standards) tiny memories both in terms of computer RAM and disc storage. Two of the earliest clinical classification or coding schemes developed specifically for computers were OXMIS (now effectively obsolete) and the READ codes developed by Dr James Read, a GP in Loughborough.

Coded entries per registered patient per year
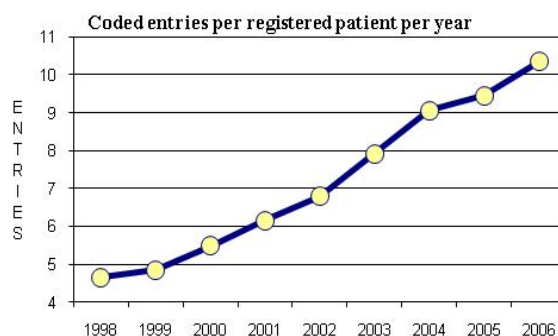
The principal reason for "coding" at that time was to reduce the memory required to store patient records by replacing the full-text description of commonly recorded clinical concepts (described in English by a "term" [an English word or phrase]) with short codes (typically 4 or 5 alpha-numeric characters). A second important feature of coded concepts in practice was that only a few characters needed to be typed for the complete text of matching clinical concept descriptions to appear on the screen for selection. Thus, clinicians didn't need to become

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[176] Source: The Health Improvement Network (THIN): 26,870,342 coded items added in 2006 to the records of 2,596,459 patients registered to 339 practices in England (RCGP reported 10,352 practices in England in 2005; Population of England 50,762,900 in 2006).

proficient in typing entire descriptions, and so records could be created more quickly -even during the consultation - and with fewer typing mistakes.

In 1987, the Joint Computing Group of the RCGP and GMSC adopted the then named Read Clinical Classification as the standard coding scheme for GP records in the UK[177].

7.2   Future standardisation of coding schemes across health care SNOMED-CT

At the time of writing this chapter in 2010, there is the imminent prospect that the NHS scheme of coding will migrate to the new NHS standard, SNOMED-CT (SNOMED Clinical Terms) over the next 2-5 years. SNOMED-CT is a terminology which is the result of the merger of two competing terminologies at the end of the 1990s; SNOMED-RT - Systematised Nomenclature of MEDicine Reference Terminology, (from the College of American Pathologists in the USA), and CTV3 - Clinical Terms Version 3 (from the UK, and at the time of merger in 1999 the responsibility of the NHS Information Authority). CTV3 is the direct descendent of Read Version 2 (RV2 – see below): it contains the same content (and more) but delivered in a technically different way. The merged product, SNOMED CT, is therefore also a descendent of RV2 and so has the same content, and more besides.

The real benefits of SMOMED-CT implementation, in allowing all health sectors to communicate and share data more reliably will only come when it is the native coding scheme for all clinical systems.

7.3   Features of Read Codes

Read codes are the predominantly used coding scheme in General Practice at the time of writing this chapter (June 2010). There are now only really two official flavours of the Read codes: the Scottish and English releases. These differ only in certain aspects of the codes and terms available within chapter 9 (administrative codes). Practice- or supplier-specific local codes have created hundreds of subflavours (see 7.4.6 below).

7.3.1   4 Byte Read (Read version 0)
The original 4-Byte Read codes are now no longer maintained or released, and so are now obsolete. As implied in the name, this terminology used four characters in each code. Each code uniquely identifies the term or concept, and also fixes the term in relation to other terms in the scheme.

Allowable characters in the code include A-Z, a-z, 0-9, with the exception of i, o, I, O, i.e. a total of 58 options.

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[177] JCG 20

In the 4-byte set this gives a total of 58^4 or 11,316,496 possible unique concepts, though in practice fewer than 90,000 were ever used. Synonyms were also provided for in the 4-byte set, but although this allowed increased breadth of expression for clinicians, there was no means of identifying a synonym uniquely other than with the free text string recorded. By 2009, no 'live' systems were known to still use this terminology and it was discontinued. However, many live systems will contain records that include some data originally entered on a 4-Byte READ system (typically, during the 1990s or earlier). By now, this legacy data may have been moved several times between different systems. It is known that some of the early migrations - in particular those from 4-Byte Read Codes - were not always accurate.

7.3.2   Read codes Version 2 (RV2 - also known as the 5 byte, or unified set)
The 5-Byte Read scheme (RV2) is the most commonly used version of the Read codes in UK systems. In this version, which became known as the 5-byte or 'unified' set, an extra character was added to the code to increase the possible number of different codes up to 58^5 or 656,356,768.

Whilst 656,356,768 may be the theoretical maximum number of symbols, because of RV2's strong hierarchical structure and the way that structure is represented within the codes themselves, it isn't necessarily the case that we could actually fit and properly organise that many clinical concepts within RV2. Certain sub-hierarchies are already demonstrably 'full' and/or no longer properly organised.

The codes are revised by the UK Terminology Centre (UKTC) every six months (monthly for the RV2 drug dictionary). The total number of codes in RV2 today (the October 2010 release) is 94,937 and the current rate of growth is approximately 1200 new codes per annum. However, 98.85% of all new additions to the primary care record are typically expressed using codes from a set of just 10,000 commonly used codes, although the membership of this set drifts over time.

From a technical perspective, RV2 has many more similarities than differences with the pre-existing classifications, particularly ICD-9 and OPCS. Not only do all three arrange their codes in 'chapters', but RV2's particular chapter organisation and content for the Diagnoses chapters (A-V) deliberately mirrors that of ICD-9 and 10 very closely, to facilitate the mapping between them. Chapter 7 of RV2 (Procedures) is similarly very close to OPCS-4.5. The important differences are therefore primarily in RV2's extra content not found in either ICD or OPCS, including for example, the drug, administrative, sign and symptom codes, and the occupation code chapter 0 (although, empirically, not all of these additions are actively or reliably used today in UK primary care).

7.3.2.1   Chapters in 5-Byte Read (RV2)
RV2 codes are arranged in chapters. Diagnoses are arranged in chapters A through to V, (excluding I and O, which do not exist), and other categories of code are in chapters 0-9

The chapter headings in RV2 are:

A. Infectious/parasitic diseases

B. Neoplasms

C. Endocrine,nutritional, metabolic, andimmunological diseases

D. Blood/blood forming organs diseases

E. Mental disorders

F. Nervous system/sense organ diseases

G. Circulatory system diseases

H. Respiratory system diseases

J. Digestive system diseases

K. Genitourinary system diseases

L. Pregnancy, childbirth, and puerperium

M. Skin and subcutaneous tissue diseases

N. Musculoskeletal and connective tissue diseases

P. Congenital anomalies

Q. Perinatal conditions

R. Symptoms, signs, ill defined conditions[178]

S. Injury and poisoning

T. Causes of Injury and poisoning

U. External causes of morbidity andmortality

V. Unspecified conditions.

And the other chapters are:

0. Occupations

1. History and symptoms

2. Examination and Signs

3. Diagnostic procedures

4. Laboratory procedures

5. Radiology/physics in medicine

6. Preventative Procedures

7. Operations, procedures, sites

8. Other therapeutic procedures

9. Administration.

7.3.2.2   The 5-Byte Read Hierarchy

One of the most powerful features of many clinical classifications and terminologies, including the 4- and 5-Byte Read Codes, is the structure using hierarchies. RV2 organises its coded clinical concepts into a hierarchy, thus allowing both primary encoding of conditions at different levels of detail *and* the ability to later retrieve coded information from the electronic record's

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[178] These are the [D] codes used to record uncertain diagnoses in symptomatic terms

database using this hierarchical structure. The hierarchy of Read is known as a *typology*, or *"is a"* ("is a type of") hierarchy. See Example 1.

EachRV2 code represents a term or short phrase describing a health-related concept. For example, in the Respiratory diseases chapter we can see a hierarchy for asthma:

Figure 1 : Hierarchy for Asthma
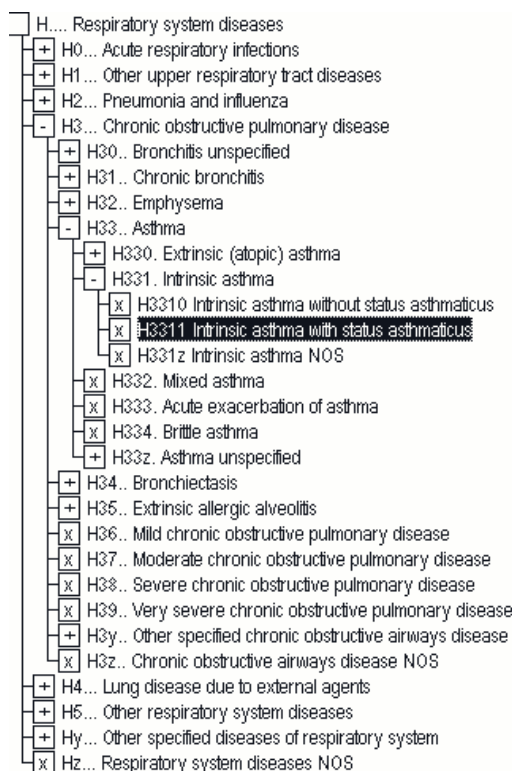
Hierarchy level	Read Code	Term
1	H	Respiratory system diseases
2	H3	Chronic obstructive pulmonary disease
3	H33	Asthma
4	H331	Intrinsic asthma
5	H3311	Intrinsic asthma with status asthmaticus

In this example from the 5-byte GP set, it can be seen that data is more and more detailed at each successive hierarchical level. This tree-branching hierarchical structure enables the clinician to have not only the ability to encode his/her patient's clinical data in detail (or not), but also to later collect information from the target population of the practice, by searching for codes at more general levels of detail. He/she can ask his computer system to search at level 1 to find all the respiratory diseases recorded in the database, level 2 to find all cases of COPD, level 3 at a more specific level (asthma), and so on. Much more sophisticated searches can be performed. Notice the dual function of the code-for both unique concept representation, and fixing the concept's position in the hierarchy.

While this represents an "ideal" view of hierarchies and the functions they might support, in practice things are inevitably more complex. For example, retrieving all patients with a code beginning 'A1' – ie all hierarchical descendents of [A1... Tuberculosis] from the infectious diseases chapter - will NOT reliably give you everybody with TB, because:

- Late effects of TB are under AE0..
- TB of bone is duplicated under N306, N305 and N304.
- Congenital TB is Q4024
- Various organ specific sequelae of TB are distributed widely throughout the classification.

In practice, almost all patients with a code indicating TB infection are actually coded directly to A1… itself, but a smattering of 1411., 65Y9., 65V9. and N304. encodings exist to be missed by the unwary. This phenomenon is encountered in many general clinical queries.

7.3.2.3   Terms in 5-Byte Read (RV2)

Like 4-Byte READ,RV2 allows the use of both preferred terms and synonyms (different terms with equivalent meaning e.g. *myocardial infarction* (preferred term) and "*heart attack*" (synonym). RV2 allows rapid look up of commonly used terms, using keys and partial text strings.

(i)   indexed keys (also called abbreviations). Commonly used terms are indexed by a "key" which may be up to 10 characters long.

(ii)   Some systems allow the user to look up concepts using only the beginning of words in the complete term (e.g. "myoc inf" would retrieve 38 codes relating to *myocardial infarction*plus one relating to *acute myocarditis - influenzal).* This functionality is system specific, so try to find out from colleagues how look-ups are optimised on your practice system.

Word equivalence tables can be used with any terminology, so that common variant or misspellings may still find the term searched for (e.g. foetus - fetus, cancer – malignancy, tumour – mass). Although a standard (but incomplete) set of keys and word equivalents are published by the UK Terminology Centre with the RV2 release, most system suppliers use their own sets instead but these are all slightly different, giving different results for users' search strategies on different systems (relevant to those working with different clinical systems). In addition, suppliers may also allow customising of keys at each site, which can help individual practices code consistently but will be a further obstacle to NHS wide uniformity.

The design parameters for 4-byte Read set a limit of 30 characters of text for any term to describe a concept. This enabled all 4-Byte Read terms to be displayed over two columns on the 80-character-wide computer displays of the day. This (at times challenging) limit was increased in RV2, such that an option of a 60 and/or 198 character spelling variant of the same term was also allowed. (This extended file structure was developed in 1991, and is known as the Version 2 file structure).

Example of 30-, 60- and 198-Character term variants of the same term

Read Code:38Du1   Term Code:00

Term30:   IAPT phob sc - Cer si fr pa di

Term60:   IAPT phobia scale - Cert situ fear panic attak distres symp

Term198:   Improving Access to Psychological Therapies programme phobia scale - Certain situations because of a fear of having a panic attack or other distressing symptoms

Additionally, in RV2, a clinical idea or concept coded by a Read Code can also be expressed by more than one term (synonyms). One of these is designated the "preferred term", and given a 2-digit "term code" value of "00". Further synonyms are represented with 2-character term

codes. These are normally numeric and in the range 11 – 99[179](example 2), though a minority of term codes are alphanumeric (1A, 1B etc). This enables the exact term (preferred or synonym) which the clinician intended to record, to be persistently stored, retrieved or transmitted intact, thus preserving the language used at the point of patient contact. A concept, expressed in the language actually chosen by the clinician at the point of patient care, is thus most properly expressed as the Read Codeplus the term code (i.e. 7 characters in all, not 5). This is especially true because of the 'pseudo-synonym' problem described below. Although RV2's synonym encoding would have been workable in theory, in reality significant errors have crept into the RV2 release data concerning synonyms. Broadly, two problems will be encountered:

1.   Pseudo-synonyms – terms that are not true synonyms

Casual scrutiny of RV2will reveal many instances of synonyms of preferred terms, which are not true synonyms. In the examples below, the code G30.. combined with the term code 13 does not mean the acute event of a heart attack, but rather a condition that may occur at some interval after the original heart attack. None of the different term codes for N245. are synonyms of each other.

READ CODE	TERM CODE	Term30	Term60
G30..	00	Acute myocardial infarction	
G30..	11	Attack – heart	
G30..	12	Coronary thrombosis	
G30..	13	Cardiac rupture - MI	Cardiac rupture following myocardial infarction (MI)
G30..	14	Heart attack	
G30..	15	MI – acute myocardial infarct	MI – acute myocardial infarction
G30..	16	Thrombosis – coronary	
G30..	17	Silent myocardial infarction	
N245.	00	Pain in limb	
N245.	11	Ankle pain	
N245.	12	Arm pain	
N245.	13	Foot pain	
N245.	14	Hand pain	
N245.	15	Heel pain	
N245.	16	Leg pain	
N245.	17	Shoulder pain	
N245.	18	Thigh pain	
N245.	19	Pain in buttock	

The UKTC has determined that at least 3.7% of all RV2 5-Character codes have at least one non-synonymous term, but also that the phenomenon is relatively concentrated in that portion of the RV2 code-set most actively used by GPs. Of the top 10,000 codes by use (collectively accounting for 99% of the EPR), at least 11.3% have at least one non-synonymous term. 27% of these are cases of commonly used V2 synonyms but that properly have a different meaning to the preferred term for the same 5-character V2 code. Some of the more commonly used RV2 synonyms that don't mean the same as their preferred term include:

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[179] Actually, in practice, all synonym term codes used in the official RV2 data begin with a 1 or a 2. Higher term codes may be encountered 'in the wild', but these are either instances of data corruption or originate from local, or supplier-wide (e.g. TermCode='99') extensions to the RV2 data.

CODE/TERM CODE COMMONLY USED…			…DOES NOT MEAN THE SAME AS		
662..	12	Hypertension monitoring	662..	00	Cardiac disease monitoring
N245.	17	Shoulder pain	N245.	00	Pain in limb
66C9.	11	Weight loss advised	66C9.	00	Target weight discussed
8H7..	12	Referral to nurse	8H7..	00	Other referral
663..	11	Asthma monitoring	663..	00	Respiratory disease monitoring
1A...	12	Urinary symptoms	1A...	00	Genitourinary symptoms
62...	11	Antenatal care	62...	00	Patient pregnant

Whilst there are mechanisms to try and prevent the loss of meaning and misreporting for such situations, they are not always successful. It is therefore worth trying to avoid using "non-synonymous synonyms" whenever possible.

2. Duplicates - same term but different code

UKTC has determined that RV2 includes approximately 5700 cases where one code and term code-pair apparently means the same thing as a completely different one. Many of these are inherited from The International Classification of Diseases (ICD), where the same problem exists when the same clinical concept needed to be in two different chapters. Others represent authoring errors in RV2.

Some of the pairs more commonly in active use by GPs today include:

1C13.	00	Deafness	66U..	11	Hormone replacement therapy
F59..	11	Deafness	8B64.	00	Hormone replacement therapy
9877.	11	Injection given	N245.	13	Foot pain
85D..	00	Injection given	1M11.	00	Foot pain

Both the above problems – pseudo-synonyms and duplicate concepts - increasingly hamper efforts to extract value from RV2-encoded data. However, because of other design limitations of RV2, these errors cannot be corrected within RV2 itself. Part of the fundamental design rationale for CTV3 was not only to create a terminology free of these errors, but also one within which it was possible to correct new errors as they arise in future. The issue remains an important reason why the NHS recommends replacement of RV2 with a still more sophisticated alternative (SNOMED-CT).

Table 7.3.2.4 Abbreviations used in some Read terms

Abbreviations used in some Read terms:	Meaning	Notes
NOS	Not otherwise specified	Classification term from ICD – *avoid use if possible*
NEC	Not elsewhere classified	Classification term from ICD – *avoid use if possible*
EC	Elsewhere Classified	Classification term from ICD – *avoid use if possible*

Abbreviations used in some Read terms:	Meaning	Notes
[D]	a symptom used as a working diagnosis	Birmingham Research Unit of RCGP. Used in sentinel practice network[180]
[M]	Morphology concepts relating to histology of tumours only	*Use only if encoding morphology from histology results*
[SO]	"Site of" intended operation (not symptom of)	Use should be limited to this category of entry
[V]	From ICD9 "reason for visit" codes	From ICD classification

7.3.3 Clinical Terms Version 3 (CTV3)

Clinical terms version 3 (previously called Read Codes version 3) is now used by two systems in England: TPP's SystmOne, and HealthySoftware's Crosscare. The October 2010 release of CTV3 contains 298,102 concept identifiers, of which 55,829 are retired or extinct and should not be used (or present only in historical records). CTV3 is growing at a rate of around 6,200 new concept identifiers annually (though many of the new codes relate to new pharmaceutical products in the READ Drug Dictionary; the rate of addition of non-drug content is only slightly more than the 1200 added annually to RV2).

CTV3 built upon RV2's clinical content and aimed to incorporate a comprehensive set of clinical concepts for use across both primary and secondary care. It was introduced in the mid 1990s after consultation with over 50 specialist groups across medicine, nursing, midwifery and allied health professions.

Unlike 4- and 5-Byte Read, the dual function of the central 5-character concept code has been abandoned In CTV3: neither the hierarchical position of the concept, nor any of the associated terms, is directly defined by the code. Critically, this enables concepts to have more than one parent concept, and thus effectively allows a single concept to appear in more than one part of the hierarchy, but with only one Read Code. In retrieval of information from the patient database, this has obvious advantages notably:

- The code becomes only a unique identifier of a concept
- The position of the concept in a hierarchy is not code dependent. This is now defined by tables, which list parent – child concepts in a table. Clinical Terms Version 3 contains a hugely increased number of concepts, terms and synonyms in comparison to the previous Read code schemes above. This is because the CTV3 scheme was designed to include a comprehensive set of concepts to cover the whole of health care, not just primary care.

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[180] Practices in the network are asked to code each problem in the consultation with a diagnostic code, i.e. a code beginning with a capitalised letter. In cases where a diagnosis is uncertain, there is a series of [D] codes which enable symptoms to be differentiated from symptomatic diagnoses

In order to provide backward compatibility, CTV3 is a "superset" of previous versions of the Read codes, meaning that all previous concepts and terms exist within CTV3. Mapping tables now exist between Read 4-byte and Read 5- byte, Read 5-byte and CTv-3, Read 5-byte and SNOMED-CT, and CTV3 and SNOMED-CT.

Clinical concepts are still arranged in a hierarchy. Instead of using the code, the position is defined in parent-child tables in the Version 3 file structure. This also allows more than five hierarchical levels, though in practice, nine levels have rarely been exceeded. The hierarchy which is built up from the parent-child relationship tables is called a typology, or "is-a" hierarchy, as a <child concept> is-a (type of) <parent concept. e.g. <Asthma> is-a <Respiratory Disease>.

CTV3 terms have their own 5-character term code, each of which codes for a triad of a 30-, 60- and 198-character length variant of the same description (as in RV2). CTV3 term codes all begin with the letter Y or y.

Content errors can be fixed in CTV3. At each successive 6 monthly release, UKTC can move codes and terms within the hierarchy independently of each other, or withdraw (retire) them from active use entirely. However, this flexibility comes at a price. Previously captured data, and previously authored reporting query definitions, need to be modified each time there is a new CTV3 release, to substitute instances of retired or otherwise deprecated content with recommended current replacements. Failure to do this may lead to incorrect querying behavior (principally, codes that used to be returned in response to stock queries no longer are, so that some patients are missed). A more elaborate version of the same functionality is part of SNOMED CT.

7.3.3.1 Qualifiers, added detail and Clinical Terms Version 3

The amount of detail required in a comprehensive thesaurus is overwhelming, and in order to cope with this, CTV3 adopted a scheme whereby fine detail may be added to 'core terms' by adding extra codes, or 'qualifiers'. Thus, the complete clinical description is recorded as a bundle of codes, rather than only one. For example, in order to encode a 'pain in the *left* ankle' you would record 3 codes:

X75sF (Ankle pain) : XM0Rs   (Laterality)= 7NB32 (Left)

The full set of core terms, qualifiers and the linkages between them is called a "post-coordination" schema. The set of core terms without qualifiers or linkages is also known as the "pre-coordinated set". These features of pre- and post-coordination are also carried forward to SNOMED-CT (although naming conventions change somewhat).

7.3.4 SNOMED CT

SNOMED CT came into being in 2000 as a result of the merger of CTV3 and SNOMED RT. The latter began life with a pathology orientation (SNOP) in the 1960s but grew over the

decades to incorporate veterinary medicine and, eventually, mainstream clinical medicine. In 2007 SNOMED CT became the property of the International Health Terminology Standards Development Organisation (IHTSDO), a not-for-profit organisation currently sponsored by its nine original member countries and the six that have since joined.

The technical characteristics of SNOMED are in many respects extremely similar to CTV3: codes and terms have their own, separate identifiers; concepts have a preferred term and multiple synonyms; individual terms can be up to 255 characters in length (but there's no longer any notion of different character length variants of the same term); single concepts can appear in multiple places in the hierarchy; concept and term codes can be moved and retired; and there is a more elaborate system of 'qualifiers' supporting post-coordination. Like CTV3 before it, many of SNOMED's codes for complex clinical concepts are additionally internally 'modeled' to be equivalent to bundles of more general codes. Thus:

> 423827005|Endoscopy (procedure)|

…is also (within the system) known to be directly equivalent to the bundle:

> 71388002|Procedure|:
> {260686004|Method|=129433002|Inspection - action|,
> 424226004|Using device|=37270008|Endoscope|}

Newer features of SNOMED include more powerful ways of defining and referencing arbitrary fragments of the content. For example, the set of diseases that are of interest to a particular outpatient clinic that can be referred to using Choose and Book. There are also additional apparatus to support international collaboration.

As almost all of RV2s clinical content and terms were carried through into CTV3 (minus, so far as possible, all pseudo-synonyms, duplicates or ambiguous terms), and similarly all of CTV3s content is carried through into SNOMED CT, anything that can be coded in RV2 can also be coded in SNOMED using a single SNOMED code. The reverse, however, is not true. SNOMED contains codes for many clinical concepts that may be useful to GPs, but that can not be represented in RV2 at all or (though less commonly) in CTV3. It also contains many concepts needed by specialties outside primary care.

7.4   General issues relating to terminology use

7.4.1 Concept or term selection

Unlike ICD, neither 4-Byte READ nor RV2 nor CTV3 were ever intended to be published in a book format, as they are intended as a mechanism of recording clinical information on computer. This 'computer orientation' enables (and requires) different strategies and techniques for finding the right code. You can't leaf through the codes in a book, and something different to a 'back of the book' index is needed.

On typing in a term or string of characters, RV2 browser software typically presents the user with lists of possible terms to choose from, where each displayed term is linked to a unique underling code which may or may not also be visible. At no time is there an unavoidable need to look up the codes themselves, or commit them to memory (though many clinicians do), and in many systems the selected code itself is not necessarily seen. Having chosen the term, the appropriate code is stored in the background, while the term used is presented to the clinician in the clinical record.

7.4.2 Variability of coding choices

It was originally intended that the need for detailed knowledge about coding and classification by the clinician would be unnecessary. Clinicians should be able to enter whatever free text phrase (or fragments of such a phrase) come to mind at the keyboard, in the section of the record where Read coding functionality is enabled, and without having to worry about the particular choice of words entered or the exact meaning of the term or code actually selected from the search matches returned by the system.

However, inspection of the coded records resulting from this approach finds very wide variability, both in terms of what gets coded at all and in the particular codes chosen for the same clinical phenomena but by different clinicians (or by the same clinician on different days).

A significant cause of different clinicians selecting different codes is *how* the list of possible codes to choose from is presented to the clinician. Chiefly, this means in what order – alphabetical, or more commonly sorted according to some notion of which codes are selected most frequently. Although such 'coding velocity' statistics might theoretically be fixed and common across multiple practices, more usually each installed system actively 'learns' what codes the clinicians using it typically select, and constantly tunes the result lists it presents accordingly. This strategy may speed local term selection, but it can have the effect of perpetuating and to some extent exaggerating the (mis) coding habits of individual practices or clinicians and the idiosyncratic variability between practices.

There are also user interface differences between systems in how much of the hierarchy around individual code/term choices is displayed by default, and how easy it is to walk around the local term hierarchy from a code that's nearly right to find one that's exactly right.

The extent of variability in coding practices (different codes for the same problem, or no code at all) is a significant problem for many of the agencies tasked with extracting value from GP records. Despite the not insignificant annual effort that clinicians are collectively putting into coding their patient encounters, less clinical value can be extracted from large collections of records than might be hoped or expected. To improve on this situation, GPs, practice staff and system suppliers are already spending time on education and training to understand and use the coding interface properly, rather than as a natural language translation device. However, more training, more sophisticated systems and more sophisticated terminologies such as SNOMED CT will be required. Practice managers and data quality staff involved in "data

curation" for QOF and other 'data driven' NHS business processes are perhaps most acutely aware of the problem.

7.4.3 Codes or Text?

The advantages of coded data entry, when used in the record, compared to free text are as follows;

- Speed of data entry is quicker
- Ambiguity of free text is diminished
- Lexical confusion is diminished (cold (as in URTI) vs. Cold (feet), cold agglutinins etc.)
- Once entered, data are significantly more readily searchable and retrievable than text, because of the inherent structure of the code
- Information may be entered and retrieved (by running database queries or reports) in specific detail or in general detail because of the codes' hierarchical structure
- Stored codes may be used by the record system for purposes of decision support

In some circumstances there is no substitute for narrative text, for example when explaining details of the onset of depression, or as a reminder of a patient's home circumstances. Narrative provides important clinical context and detail that cannot be, need not be, or is too time consuming to encode.

Remember that increasingly, records may be shared. In general, it is thought that free text entries are less safe to be shared because they may contain sensitive information inadvertently. (See also "exclusion subsets" in this Chapter - 7.5 below). Retrieval of free text information in database searches is highly unreliable and slow.

Figure 7.4.4 - Issues to remember with coded terminologies

There are many codes in the thesaurus. It is better to have agreement with one's colleagues locally, and indeed wherever codes are shared, which codes should be used in a particular circumstance. For example in the case of asthma, consider whether it is truly important (or realistic to achieve accurately) to seek to record in code at such a granular detail as "intrinsic asthma" (or is "asthma" sufficiently expressive)?

Given the collection, storage and retrieval of codes at an organisational level is extremely important, it may be wise to ensure consistent coding by ensuring all clinicians use a template or protocol in specific circumstances, for example when entering data important for long term condition recall, immunisations, QOF data, and so on. Be aware, however, that locally crafted templates provide another means to reinforce locally idiosyncratic coding choices. Unanticipated requirements to interoperate outside the original locale may be unusually complex or difficult to fulfil.

Many systems allow free text to be associated with coded concepts. Never add free text which alters the meaning of the coded concept. For example;

G30.. Acute myocardial infarction(code) excluded (text)…
would be strongly deprecated while the following is quite acceptable
G30.. Acute myocardial infarction(code) developed chest pain at work (text)…

(See also Chapter 6.7.2 – High Quality Patient Records)

7.4.5 Codes for other categories

All the examples provided so far use diseases or diagnoses. However, Read Codes and SNOMED also cover operative procedures, tests and test results, prevention and administrative terms, drugs and much more. Practices find them useful as tools with which to recall patients for preventative screening and the management of long term disease, and they have been helpful in the achievement of consistently high immunisation rates in target populations throughout the UK.

7.4.6 Local codes

An important issue for all users of coded terminologies is the provision of "local codes". These are codes, which are not universal in the coding scheme, but are used in a limited number of practices, or only in a single practice, or limited to a single system supplier. The standard way of representing a local code in Read is in its chapter @.... . Systems suppliers may provide a user-base wide set of local codes (Egton codes in EMIS is an example, or Y codes in TPP SystmOne[181]).

Such codes may be useful for a local administrative purpose or if there is an urgent need for a new code, which has not yet been incorporated into the latest version of the codes centrally. For example, if a new important flu variant is diagnosed, it may take a few days for this to be incorporated and so a local code might be added temporarily as a placeholder, and when an appropriate national code is created the local codes may be replaced.

In general local codes should be avoided wherever possible, as they will cause issues of interpretation when coded information is exported from the practice, e.g. in GP2GP (qv), Summary Care Record, etc. Most suppliers that enabled local code creation are now engaged in activities to obtain official central codes to replace the commonly encountered local codes found in live records.

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[181] NB CTV3 proper include hundreds of thousands of codes beginning with Y or y; but they are (almost) all term codes not concept codes. Some cases of confusion have arisen because users have come across these and thought they were TPP (concept) local codes.

7.4.7   Search engines and RV2/CTV3 Termcodes

MIQUEST can only search on Read codes (Read 2 & CTV3) and is blind to term codes / termIDs. MIQUEST searches can therefore only be set up on the assumption that a given Read code will only represent the preferred term. There are real world failing cases for this assumption (see the N245. example at 7.3.2.3 above). It is a particular problem when a 'synonym' term text is patently not a true synonym of the preferred term. The classic example of this is where there is a term in RV2 "myocardial rupture", a "so-called" synonym of myocardial infarction.

Some GP system searches are also similarly unable to run searches at the termcode / termID level and so are similarly affected. This has implications for audits and maybe also for DSS, and is also a challenge for cross mapping, for example when moving from a system using RV2 to CTV3 or SNOMED-CT. In these cases, the ideal map is not just concept to concept, but concept and term to concept and description (the word used in SNOMED-CT for a term).

7.4.8   Conceptid-termID binding

Principles underpinning clinical safety assurance of messaging demand that the ConceptID termID and original term text should be preserved in successive transfers to minimise risk of human and machine understanding drifting apart.

7.4.9   The use of codes in the context of record structure.

In terminologies, concepts are given semantic tags, which define a default "clinical context" for a concept, such as "disease" (as in chapters A-T in RV2), symptom, procedure, and so on. Depending on which GP system is used, the information model of that system may allow the storage and retrieval of coded information in other than the default context. In other words, if users wish to record a diagnosis of "headache" (whilst evaluating the cause of a patient's headache), it would be possible to record the *symptom code* for "headache" as a *placeholder*, until the diagnosis of the patients headache is clarified, then replace "headache" with the disease code for "migraine". However, it is important to proceed with caution, as some systems cannot differentiate between symptoms used as diagnostic codes from the default context of "symptom". In those systems, a code from chapter "R" – a [D] code – can be used. This is the reason such codes were created.

7.4.10 Using codes and hierarchies to store and retrieve health data

As described above, the real power of hierarchical terminologies such as Read, CTV3 and SNOMED-CT, lies in the ability to report on individuals and groups of individuals who share characteristics, which are coded on the system. It is possible to identify all patients who are diagnosed with a disease (for example Diabetes mellitus), and identify all of that group that have been seen for a disease review (in this case diabetic review) over a period of time (say the last 13 months). It is also possible to measure the number of patients who have a given condition and who have had a specific blood test measured in a given period; and what proportion have had a result in the normal range (in our example what percentage of the

practice diabetic population has a recorded HBa1c of <7.0mmol/l recorded in the last 13 months).

The example used also illustrates the value of the coded terminology in assessing performance and outcomes under the Quality and Outcomes Framework (QoF).

Other examples might be tracing patients with a particular diagnosis who are being treated with a particular drug, for example who are the patients in the practice with a diagnosis of osteoarthritis who are receiving regular medication with a non-steroidal anti-inflammatory drug (NSAID)?

The hierarchy also allows searches for patients under a broad category (e.g. Ischaemic heart disease) even when their conditions have been coded much more specifically (e.g. inferior myocardial infarction).

7.5   Sharing coded information

As electronic communication of health information develops, new considerations arise related to how we code information on our practice computer systems. We can now transfer entire patient records from one system to another when a patient changes practice (as in the GP2GP record transfer), and post summary information to the Summary Care Record on the "Spine" , or send messages which include free text and coded information from point–to-point in electronic messages, and even secure email. Another example is the automatically generated insurance report.

Such transfers of information are often partly automatic, and might contain large amounts of information selected by code types. In general it is wise to consider the following when sending coded information out of the practice;

- Be very careful about any free text comments and notes exported. It is all too easy to miss a telephone number, and address or a reference to a third party and divulge sensitive personal information inadvertently
- Consider whether ever to allow free text comments out of the practice in automatically generated reports
- In some cases exclusion subsets will be applied to extracts from a coded record. It is wise to ensure at least one clinician or senior member of practice staff is conversant with Read codes and exclusion subsets to advise clinicians how to code and how to avoid disclosure of specific information inadvertently.
- Always try to check what is being released under your authority as carefully as possible.

7.5.1   Specific audits and reports written for export of practice data
In addition to the above there are mechanisms to write queries outside the practice which can extract specific information about individuals or groups of patients based on their

characteristics coded in the record. The most commonly used system is MIQUEST (Morbidity Information Query Export Syntax). Built in to this system is a mechanism to anonymise the patient (year of birth and first 3 characters of the postcode is the maximum specifiable detail for an external query), and the ability for the query to be scrutinised before being run, and the ability to see a copy of the extract before it is released. Practices are advised to use this functionality of MIQUEST to prevent inadvertent disclosure of sensitive information to a 3rd party. Never allow a query written by someone you do not know and trust to be run on your practice system.

In the future, a new query system is expected to be introduced, currently being developed on behalf of the NHS Information Centre (NHS IC) under the name of the GP Extraction Service (GPES)[182].

7.5.2 Codes and system-to-system messaging or system migration – guidance

It is neither appropriate nor possible to try to discuss this important issue in great detail here, as there are areas of surprising complexity involved when migrating data from one coding scheme to another (see Chapter 8c – Data Migration). Members of the informatics community of the RCGP and the GPC have developed considerable expertise in this field, and advise the NHS carefully about the rules and practical issues which must be observed for safe migration of data. Try to be aware of the following when the practice system is undergoing a migration to another system, and also bear it in mind when receiving a GP2GP message from a system with a dissimilar code scheme to your own (so called heterogenous transfers – See Chapter 8b GP2GP Electronic Record Transfer):

1. There are mapping tables for the following cases;
    a. Read RV2 to CTV3
    b. CTV3 to Read RV2
    c. Read to SNOMED-CT
    d. SNOMED-CT to Read
    e. CTV3 to SNOMED-CT
    f. SNOMED-CT to Read RV2

2. For the above, a map at the code level is only acceptable if the term encoded for by the map target {code + termId} combination is identical to the original text of the term associated with the original coded concept and termId, OR if not identical then it has been clinically assured to carry the same meaning or a sufficiently similar meaning.

3. If this is not the case, then the rules endorsed require the original text on the originating system to be carried to the target system, but no code in the target system is activated. This process is called "degrading to text", and a resulting entry in a GP2GP record transfer is referred to as a transfer degraded record entry (see Chapter 8b – GP2GP Electronic Record

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[182] GPES http://www.ic.nhs.uk/gpes

Transfer). It ensures that the actual text present on the original system is always seen in the new practice, but coded concepts with differences in meaning cannot be queried or reported

4. In all cases we recommend that the originating code and text is stored and viewable on the target system

7.6   Preparing to move to SNOMED-CT, what to expect

The experience of the last 30 years has taught us that healthcare computing is harder than it looks. New technologies, including SNOMED CT, have been devised so far as possible to fix the known failings of the older ones. There is some near-term risk in adopting these more advanced solutions whilst they are still to some extent in development but, conversely, unless they are adopted they cannot be tested and improved. SNOMED CT has emerged as the only serious contender for an international standard 'next generation' clinical terminology. The resulting collaborative international working around the emerging standard offers the prospect of faster, larger scale and more robust testing and development than could happen were the UK to continue building its own unique terminology products.

SNOMED CT is already deployed into live clinical systems in England, including into the Choose and Book application, the NHS Summary Care Record, hospice implementations of CrossCare, a tablet PC system for use by paramedics first on scene, an A&E reporting system and all major suppliers of new hospital systems including iSoft's Lorenzo and Cerner's Millenium products. In primary care it forms the foundation of EMISWeb while other suppliers are actively developing next generation systems.

At the time of writing, it seems likely that the major GP suppliers are likely to produce and seek to deploy systems supporting SNOMED-CT. Below is a brief account designed to offer a flavour of the considerations involved in the move to SNOMED-CT.

Past experience of migration from one coding scheme to another has yielded useful lessons that inform us about the needed steps to achieve successful migration. System suppliers are likely to rely heavily on this experience in order to optimise the adoption of SNOMED. So we are likely to see that the original text associated with a code in the record will be retained, as well as the original concept code and term code or description code. Not only will this help the user with the provenance of the information, but will be invaluable if a record needs to be transferred back to a different coding system in the future (e.g. when a patient moves practice or if a practice changes system.

In addition, GP suppliers will take great care to minimise the impact of change from the user's perspective. One consideration with SNOMED-CT is the size of the scheme (300 000 concepts, 1 million descriptions). As a result of this there are at least 2 significant matters for practices to consider:

- Selecting a new code from the much bigger scheme without being lost in huge lists of specialist concepts, or not choosing the same concept each time for the same issue.
- Reporting using the hierarchical structure, which is different to both Read and CTV3 (significantly different from RV2, but more similar to CTV3)

In order to cope with this, GP system suppliers are likely to create a "subset" or "refset" of SNOMED codes which is very similar to the set of codes in their current system. They are likely to impose on this set of codes a "navigational hierarchy" similar to the original scheme.

So if a practice moves from RV2 to SNOMED-CT, the read codes and term codes would be preserved alongside the equivalent SNOMED-CT concept and description codes. In addition, retrieval of data from the database would be equivalent to the form of retrieval before the migration. Issues would clearly arise as new concepts, which are in SNOMED-CT but not the previous schema begin to be used, as then the retrieval queries will have to be expressed in a way specific to SNOMED-CT concept retrieval.

In essence this proposed implementation strategy will allow SNOMED-CT to be used with minimal disruption to the clinician, but it also allows system suppliers to control the pace of adoption of SNOMED-CT. Purists may say that it will slow the pace of developing truly SNOMED-CT native systems. Time will tell how effective this predicted strategy will pan out.

A third and important consideration with SNOMED is in regard to "post-coordination". Most (possibly all) of the concepts we currently use in Read Version 2 and Clinical Terms Version 3 will be carried forward to SNOMED-CT because of the "superset principle". This implies that initially at least, GP systems will be more or less fully functional even without the need to cope with post coordination. However many concepts, for example those used in many surgical procedures, do not exist as single pre-coordinated concepts within SNOMED-CT. So, concepts for laparascopic procedures are made up of several linked concepts such as <laparoscopic approach> + <appendicetomy>. In addition, for spine compliant systems, allergies are "conventionally" represented (for the NHS) as <substance allergy> + <substance>; similarly adverse drug reactions are represented as <drug adverse reaction> + <drug [DM+D] code>. However the GP supplier wishes to represent these things within the clinical system, the supplier must be able to transform the concepts into the "Proper" post-coordinated expression when sending information to other parts of the NHS.

Eventually we may expect that these systems will be able to cope with the full expression of SNOMED in pre-coordinated forms, post coordinated forms, and be able to compute equivalence of identical concepts represented in different ways.

7.7   The International Classification for Primary Care (ICPC)

The World Health Organisation has accepted ICPC-2 mainly as a reason for encounter classification[183]. ICPC-2 classifies patient data and clinical activity in the domains of General/Family Practice and primary care, taking into account the frequency distribution of problems seen in these domains. It allows classification of the patient's reason for encounter (RFE), the problems/diagnosis managed, interventions, and the ordering of these data in an episode of care structure. ICPC is widely used in other national jurisdictions, but not in the UK.

Figure 7.8 - Glossary of words and phrases relevant to this chapter

(Health) Classification	A categorisation of (health) concepts
Code	A label given to a (health) concept
Coding	The process of assigning codes to a record
Concept	The notion of an idea relating to a patient's health
Conceptual Classification	An extensible set of concepts
Description	The word or phrase attached to a concept to describe its meaning in language
Dictionary	A list of words with their definitions
Interface Terminology	A terminology designed for use in a particular application
Lexicon	A list of words used in a field of work without definitions

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[183] WHO http://www.who.int/classifications/en/

Chapter 8 - Data Transfer and Inter-operability

8.1 Introduction

This section of the guidelines focuses on data transfer and inter-operability. We will describe the processes involved in a variety of data transfer scenarios and will also provide guidelines for how to handle incoming data transfers in a timely and safe fashion. We will make reference to other sections of the guidelines where they impact on the safe and useful sharing of information.

8.2 Clinical safety assurance

The Clinical Safety Assurance process described in Chapter 3 of these guidelines underpins the professional approach to assuring the quality and safety of health data in an environment where we are striving to make health data and patient records genuinely inter-operable.

8.3 Chapter organization

Chapter 8 is divided into 6 sub-chapters (8a-f) covering the following areas of functionality:

8a	The Personal Demographics Service
8b	GP2GP Electronic Record Transfer
8c	Data Migration
8d	Clinical Messaging
8e	The Summary Care Record and Emergency Care Summary
8f	High Quality Medication Records and The Electronic Prescription Service

Chapter 8a - The Personal Demographics Service (PDS)

8a.1 Introduction

The Personal Demographics Service (PDS) is the national electronic database of NHS patient demographic details in England, used by NHS organisations to enable a patient to be readily identified by health care professionals and associated quickly and accurately with their correct medical details[184]. The PDS does not hold any clinical health record information or other sensitive data items such as ethnicity or religion, but is the route by which patients will be identified and linked to their medical records held on the NHS "Spine".

8a.2 Access & security

Only authorised health care professionals, with a Smartcard, are able to access the PDS database and information contained within a patient's PDS record is only available to NHS staff where;

- They are authorised to use the system
- They have located the correct patient using their demographics details or NHS number (this may involve identifying the correct patient from a picking list of possible matches)
- There is a justified business reason for doing so.

Local demographic data can be derived from the PDS and may not require a smartcard to access it.

Further restrictions are in place to perform certain tasks on patients' demographics details held on the PDS[185].

This means that patient identification through PDS ("tracing") and updating of patient information held on the PDS ("synchronising" or "syncing") are only available when users are using their Smartcards. Being able to accurately identify patients is an essential first step in making appropriate health data available across different care-settings.

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[184] http://www.connectingforhealth.nhs.uk/systemsandservices/demographics/pds

[185] The PDS a guide for general practice http://www.connectingforhealth.nhs.uk/systemsandservices/demographics

8a.3 PDS tracing

Correctly identifying patients through the PDS is crucial to accessing and updating other "Spine" services such as the Summary Care Record (SCR – see Chapter 8e), Choose and Book and the Electronic Prescription Service (EPS – see Chapter 8f). This requires use of a Smartcard by staff trained to use the PDS "trace" facility to correctly identify the appropriate patient. Your GP system supplier implements the PDS trace facility on your system and training is usually provided as part of the induction to using Spine services (e.g. SCR, EPS & GP2GP). While these implementations are broadly similar there are some system-specific features that users should familiarise themselves with.

Practices will often use the simple trace facility first to return a list of possible patient matches. Where a simple trace returns several possible (or zero) definite matches, users may then access the advanced trace facility to refine their search and try for a confirmed match. Not all GP systems make it clear whether the simple or advance trace facility is being used.

It is essential to match patients across several data fields to get a positive match and we advise that current best practice to achieve (near) certain identification requires a confirmed match in all the following data fields;

- Last name (or family name)
- First name (calling name)
- Date of birth
- NHS number
- Sex (administrative gender)
- Address (including postcode)

This may be more easily achieved by using the PDS advance trace facility as the default search option, to reduce the risk of patient misidentification or non-identification.

Suppliers tend to determine the functional flow of tracing. Simple trace is still recommended by suppliers to be the first thing to try, as it gives the least risk of a false-positive match.

N.B. The (algorithmic) advanced trace facility allows tracing of patients even where blank spaces or other characters have accidentally been included in PDS data fields, corrupting the PDS database. For example, this would facilitate the tracing of patient "John" "Smith" where his data is held on PDS as "John " "Smith" (note the blank space after "John"). You should be clear how your supplier implements this facility in your clinical system.

Future versions of some GP systems may include the facility to create a new record on the PDS, including allocating a new NHS Number, when tracing fails to give a positive match. This may result in duplicate records being created, which presents potential clinical risk and generates work to identify and merge the PDS records. We recommend that practices restrain

from using these facilities until further notice, while enhancements are made to GP systems and the PDS to improve tracing. The vast majority of patients will have a PDS record and NHS Number, and it is recommended that practices consult the local back office/PCT for specialist assistance in tracing and if necessary creating a new record.

8a.4 The NHS Number (England & Wales)

Within the NHS, the NHS Number is the only national unique patient identifier. It is used to help healthcare staff and service providers match patients to their health records. Everyone registered with the NHS in England and Wales has his or her own NHS Number[186] (The equivalent in Scotland is the Community Health Index [CHI] number[187]).

The key purpose of the NHS Number is to improve patient safety by using the NHS Number to link patients to their records. The NHS Number should be present in all active patient records and determined as early as possible in the episode of care. The use of the NHS Number is fundamental to improving patient safety across all patient care settings by;

- Reducing clinical risk, caused through misidentification and misallocation of   patient information.
- Resolving some of the barriers to safely sharing information across healthcare settings.
- Assisting with long-term follow-up processes and audit.
- Reduce the risk of creating duplicate records.

The NHS number should be used in all patient-identifiable communication crossing organisational boundaries, so GPs should include it on referral letters, pathology, radiology and other request forms leaving the practice, whether electronic or on paper.

Best practice[188] would suggest that all NHS organisations should;

- Use the NHS Number as the national patient identifier, or the NHS number in conjunction with a local hospital or GP system number
- Use the NHS Number in all correspondence, notes, wrist-bands and care processes
- Put processes in place to ensure that patients can know their own NHS Number and are encouraged to make a note of it.
- Inform patients of their NHS Number (in writing) whenever they register as a new patient.

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[186] http://www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber/

[187] http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/Delivery-Improvement/1835/1865/1852

[188] http://www.nrls.npsa.nhs.uk/resources/?entryid45=61913

8a.5 Data quality

The PDS has been implemented to enable NHS patients to be quickly and accurately identified and associated with their correct medical records. This depends crucially on NHS staff in general and GP staff in particular to check and maintain accurate information.

Generally speaking, many patients will be well known to practice staff and most interactions with the surgery team will not require formal checking procedures. But it is good practice to ask patients to confirm their name, date of birth and address when dealing with them over the phone or face-to-face, when they may not be known to staff or their names are common and easy to confuse (e.g. "John Smith"). This also helps to create a practice culture where demographics data quality is likely to be high and the rates of patient misidentification low.

For new patient registrations, this process begins when the patient completes a GMS1 form. This information is then used to enable the transfer of the patient's medical record from their previous GP practice (see also Chapter 8b – GP2GP Electronic Record Transfer). Practices are strongly advised to ensure that;

- The GMS1 form is checked in the patient's presence to ensure that it is readable, accurate and complete, including the address where they were last permanently registered.
- The GMS1 is accurately transcribed into the system
- If known the patient's NHS Number is used.

It is extremely important that the information provided is accurate and complete. If incorrect or insufficient information is provided;

- The patient's demographic record may not be found, resulting in delay of transfer of the patient's medical record
- The patient may become mis-associated with another PDS record resulting in confusion of the patient's personal details and health data with important clinical safety consequences
- The patient may be unable to access other services reliant on PDS (e.g. Choose and Book and the Electronic Prescription Service – see also Chapter 8f – High Quality Medication Records and the Electronic Prescription Service).

Some practices ask newly registering patients to provide documentary proof of identity and address (e.g. passport & utility bill) to assist registration processes and assure data quality, but this approach may not be appropriate in all primary care settings. The education and training of practice staff is absolutely essential to ensure a robust approach to demographics data quality.

Table 8a.5   Completing the GMS1 form (demographics data)

Data item	Format	Notes
NHS number	10 digit number	Use only modern 10 digit numbers, do not use other numbers (e.g. Scottish CHI number)
Last name		Enter full official last names (i.e. family name)[189]. Check spellings carefully and consistently when registering families
Previous name		Enter any previous surname (e.g. maiden name), if more than one, enter the most recent, listing others in comments field
First names		Enter full official first names when known, otherwise enter initials
Title	Mr, Mrs, Miss, Ms, Dr, Rev	Please seek guidance for other titles not in regular use (e.g. from local Back Office)
Gender	male/female	PDS records "administrative" gender. This is essential (e.g. for cancer screening programmes)
Date of birth	dd/mm/yyyy	Use only accurate data
Place of birth	Town – if UK Country – if non-UK	Use only accurate data, do not enter "unknown"
Home address		Use full permanent address & postcode
Previous address(es)		Use full address where patient was last registered with a GP, including postcode. This is essential to transfer GP records. Do not enter "unknown"
Previous GP practice		Name of GP registered practice at previous address
Previous GP's address		Address of previous GP practice
Date of entry into UK	dd/mm/yyyy	Is this the patient's first registration? If not, staff should record the original date of arrival and place of registration
Ex-service personnel		Provide service number and enlistment date

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[189] Guidance on ethnic naming conventions.
http://www.connectingforhealth.nhs.uk/systemsandservices/data/dataquality/resources/dqm002408.pdf

Chapter 8b - GP2GP Electronic Record Transfer

At the time of writing (December 2010) more than 58% of all English GPs have the facility for electronic transfer of patient records between practices, so called GP2GP record transfer enabled. This chapter will provide advice and guidance in the following main areas:

- The rationale for electronic GP2GP record transfer
- The nature of electronic GP2GP record transfer
- The limits of electronic GP2GP record transfer
- General clinical safety
- Electronic and paper GP2GP record transfer
- GP2GP record transfer – good practice guidelines.

Currently the GP2GP record transfer project continues in development and specific advice (which will be updated from time to time) will be made available from the GP2GP website[190].

8b.1 The rationale for electronic GP2GP record transfer

The overwhelming majority of U.K. general practices now use their computer systems for recording patient record information in whole or in part. The GP electronic record was "legitimised" in 2000 following the construction of a previous version of these Good Practice Guidelines. Paradoxically, the widespread use of electronic patient records has resulted in deterioration in the completeness and integrity of patient record information at the point of transfer of care between practices. This results from a variety of causes whose main headings are;

- Patient records that are an unpredictable mix between paper and electronic.
- The inability to transfer the electronic part of the record except as a print-out from the 'old' practice and the consequent need to re-key information (with its associated error factors) at the 'new' practice.
- Variable professional skills and assiduity in recording information within both paper and electronic versions of the record
- The abandonment of paper as the medium for the prime record in favour of the electronic medium.

The net effect of the above places difficulties on 'new' practices in identifying salient information in transferred records and in incorporating that information within the new record.

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[190] http://www.connectingforhealth.nhs.uk/systemsandservices/gpsupport/gp2gp/goodpractice

This is known to have significant, but un-quantified resource implications for practices. There is also widespread anecdotal evidence of resulting adverse effects on patient care.

The rationale for the electronic transfer of records is therefore;

- As a support for electronic records in general practice and their general benefits in terms of decision support and audit/governance abilities.
- To obviate the need, as far as possible, for re-keying of paper-based information for new patients and thus reduce resource implications
- To reduce the risks to patients arising from the transfer of confusing records
- To support the continuity of electronic patient records as the patient moves from practice to practice (including the completeness, integrity and accessibility of patient record information).

8b.2 The nature of electronic GP2GP record transfer

Electronic patient record systems in general practices in England are provided by the commercial sector. They are regulated by GP Systems of Choice (GPSoC). At the time of writing this update to the Good Practice Guidelines, six different commercial suppliers are known to be involved in this provision[191].

Each of the systems so provided is designed differently and older systems were not constructed with the requirements of clinical data interchange in mind. In consequence, the data structures and data views are heterogeneous (see discussion in Chapter 8c – Data Migration) and so there is no single simple mechanism that can be constructed that will allow the passage of structured clinical data of 100% accuracy and integrity between these different systems.

GP2GP record transfer is carried out using an electronic message, which specifies a common "architecture", expressed using the HL7 standard, into which the various systems concerned may map their data structures in a form which is mutually comprehensible. What this means in simple terms is that there is a common convention for the representation of;

- Record Encounters; what constitutes a single transaction with the record such as a surgery consultation, a letter received from outside the practice, an investigation result etc.
- Names for these encounters; e.g. Home Visit, OOH Consultation, Surgery Consultation etc.
- Headings within these encounters
- Complex clinical constructs; e.g. Investigation batteries, Blood Pressure Results etc.
- Code mappings; e.g. from various sets of medication codes
- Codes and associated text

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[191] http://www.connectingforhealth.nhs.uk/systemsandservices/gpsupport/gpsoc/systems

- Major modifiers of clinical meaning; e.g. Uncertainty, Allergy, Family History.

In addition, there are rules, that require the degradation of structured clinical information to text where, in any instance of a record transfer, it is not possible for a system to safely map structured content (e.g. Read Codes) from one system to another.

The net effect of the above is to allow records to be transferred in a form which is 100% human readable and preserves as much of the structure of the record as possible thus reducing the need to re-key information. There remain however, some elements of current electronic records, which cannot currently be transferred in completely structured form in every case because of different conventions for describing them on different systems or different coding schemes used.

8b.3 The limitations of electronic GP2GP record transfer

There are four particular aspects of current GP records where the record transfer process needs to be supplemented by additional rules or processes, if fully safe and usable records are to be reconstituted on receiving systems. There are also further limitations to be aware of that affect the appearance and/or usability of the record.

8b.3.1 Medication information

There are currently three different coding schemes for the representation of medication information on GP systems. Transfer of that information can be achieved by adherence to a combination of rigorous mapping rules and associated automated machine checks against those rules. Experience within the GP2GP record transfer project shows that adherence to those rules allows for a very high degree of reliability of transfer – approaching 100% but, crucially, not actually reaching that point.

The principal reasons for failure to reach 100% reliability are;

- The multiple coding schemes used
- Failure of previous code mapping exercises (see Chapter 8c - Data Migration)
- The multiple coding scheme problem cannot be overcome until the NHS implements a common coding scheme for drug information on all electronic record systems. Even then, however, there can probably never be a guarantee that legacy medication information held on computer systems was always reliably coded, particularly when those codes resulted from a historical code mapping exercise. While this is a problem that will reduce over time following the introduction of a common coding scheme, it has effects on record transfer expectations and associated good practice, that are discussed below.

In addition to managing medications that do not transfer automatically, there is a need to transfer the responsibility for prescribing to an appropriate user at the 'new' practice. GP2GP applies the following rules;

- Repeat medications which were 'current' at the time when the patient left the 'old' practice will be de-activated on import
- Review dates will not be transferred from 'old' to 'new' practice
- Suppliers will offer the means to users with appropriate prescribing rights easily to identify and re-activate / authorise 'current' medications selectively
- Any 'current' medication that has been degraded to text will be brought to the user's attention

Past issues of medication are normally grouped in EMIS systems but this grouping is lost when the data is imported back into EMIS systems.

DM + D is now the preferred standard for handling medicines and devices and all current GP systems are capable of mapping such information to and from DM + D. The trend towards DM + D becoming increasingly integrated into GP systems has been accelerated by projects such as the Electronic Prescription Service (EPS). (See also Chapter 8f – High Quality Medication Records and the Electronic Prescription Service).

8b.3.2 Allergy information
For a number of reasons it is not currently possible in every case to exchange information about drug allergies between all systems in a way that preserves interaction with prescribing decision support.

Within the GP2GP record transfer project a set of rules has been constructed which allows for every instance of a recorded allergy to be clearly identified as such[192] when the associated information cannot be incorporated directly into a different receiving system. This information is presented to the user so that it can be modified into a form which conforms to that required by the receiving system. The aim being to ensure that this allergy information will trigger appropriate warnings during future prescribing events.

It is essential that practices understand clearly and unambiguously that to be interoperable (in the GP2GP sense) adverse drug reactions MUST be entered in a way that interacts with the native prescribing decision support system - and that users MUST enter the information relating to degraded adverse drug reactions in an imported record in such a way that it interacts with their clinical system prescribing decision support software.

(See also Chapter 6.6.1)

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[192] The GP2GP definition of a 'drug allergy' covers every instance of a record entry of an adverse drug reaction that triggers the 'native system' prescribing decision support system. The aim is to ensure that appropriate entries are made on the receiving system that will trigger its 'native system' prescribing decision support system

Any drug allergy information which has been degraded to text or which cannot be properly represented on the receiving GP system as an allergy will be brought to the user's attention.

For reasons of clinical safety it will not be possible to issue any medication on the receiving system until appropriate action has been taken for every drug allergy degrade and the degrade has then been deleted.

This has implications for good practice, which are discussed below.

8b.3.3 Business specific information

There are and will be from time to time, aspects of GP electronic record keeping that are designed to support specific business processes relating to terms and conditions of service and/or remuneration such as Quality and Outcomes Framework (QOF), immunisation and cervical cytology call/recall targets. For most of these processes, either different systems have different conventions for their representation or users create idiosyncratic methods for handling them or both. This has two broad consequences at the point of transfer of the information.

Firstly, while it is always possible to transfer the raw data that supports, for instance, cervical cytology call and recall between systems, it may not be the case that information can be recreated on a receiving system so that it supports that system's own call and recall functions. During the course of the GP2GP record transfer project, a general template for handling cervical cytology information was proposed but this has not yet been implemented and, until such a common view is held, practices will continue to have to do additional work to make such information completely useful when received from a different system.

Secondly, individual practices may create internal reports to support things like target payments based upon an internal practice agreement as to what codes will be used. These code-lists will not necessarily be the same as those used by a receiving practice following transfer.

The good practice effects of this are discussed below.

8b.3.4 General record view

Users should be aware that information imported via GP2GP from a previous practice may not obey rules on the receiving system, in terms of appearance, layout or ordering, to which users are accustomed. This will necessitate some changes in the way that records are viewed so that important information is not missed.

As discussed elsewhere (see Chapter 8c – Data migration) transfer of information between different systems will result in an alteration in the way that information is viewed and navigated by the receiving system. This does not necessarily have any adverse effect upon the process of patient care, provided that clinical users of the systems understand that this is the case and interpret the record accordingly.

- **Duplication, transfer degrades and order changes**

One of the inevitable consequences of heterogeneous record transfer (transfers between different types of GP system) is that the incoming record may have a very different appearance on the receiving system from that on the sending system. This is because the receiving system will not always be able to replicate structures native to the sending system. Where structures (e.g. Vision forms) cannot be faithfully represented on the receiving system their content will be imported and displayed as text. This text will typically be a concatenation of the field descriptions and entries from the original form. Sometimes the same (or similar) information may be displayed twice. Where information is coded in the incoming record using a coding system that is not recognised by the receiving system (e.g. Egton code or Emis drug code) the information will be converted into a transfer degrade. In the receiving system the original text will be displayed but the original code will be replaced with the most appropriate transfer degrade code. The sending system may be able to support consultation entries that string together sequences that consist of text followed by code followed by text etc. A receiving system that can only display one code at a time followed by one piece of text will typically re-order the information displaying each code on a new line followed by its original text followed by a label 'prefix text' followed by the prefixed text. Despite these duplications, degrades and order changes the original meaning is usually clear. There is no need to edit out these irregularities

- **Local codes and transfer degrades**

There are broadly two kinds of local codes;

- System wide and managed by the supplier.
- Practice generated

The former can be transferred without degrade where sending and receiving practices use the same system. However, they lead to transfer degrades in any other heterogeneous transfer. In the interests of improving the quality of record transfers suppliers are being asked to reduce the use of these codes. Practice generated codes will always lead to transfer degrades so their use should is strongly discouraged. Where they have to be used the associated text should always have a clear, unambiguous meaning that will be understandable to any user in the future, bearing in mind that the patient may change to a different practice.

- **Consultation structures**

No two types of GP computer system support the same consultation categories and at least one system offers no categories at all. As these cannot be rendered completely interoperable this results in items being displayed under unusual categories and also to changes in ordering when compared with the sending system. However, typically the original meaning is easily understood.

- **Values, units, ranges, and abnormality indicators changed to text**

Units are not fully interoperable between different systems. Where a receiving system cannot 'understand' units, the value, units, range and abnormality indicators may become converted to text. While such strings may be perfectly understandable to humans it is important to understand that the computer will not be able to handle values converted to text, for example, when running searches or showing a sequence of results graphically.

- **Cross mapping limitations**

At present not all systems involved in GP2GP record transfers use the same coding system for representing medications but all systems are capable of translating medication information between their native medication coding scheme and DM + D. However, even the best quality cross map breaks down where a medication cannot be represented either in DM + D or in a native coding scheme resulting in medication transfer degrades. Any receiving system following GP2GP processing rules should be able to recognise medication transfer degrades and display these in the appropriate part of the record. The original term text should be preserved so that the original medication entry will at least be human readable. Thus when medications are initially reviewed appropriate action may be taken.

In future it is possible that clinical information will be transferred between systems using different coding schemes (e.g. Read v2, CTV3, or SNOMED). This will inevitably act as a potential source for further transfer degrades.

- **Linkages between different elements of the EPR**

While best attempts have been made to extract information about linkages between different elements of the record it has proved difficult to reconstitute these reliably. Some elements that the user might normally expect to find linked may not be so. As examples, linkages to problem headings and to referral documents will not be fully reconstituted on the receiving system. This may necessitate searching the record more thoroughly (e.g. for relevant documents) than might be necessary for a 'native' record

- **Degrades to text**

These will occur where an importing system cannot effectively emulate structured information and this is mainly a problem where sender and receiver systems are different. The rule is that such information will be degraded to human readable text which will preserve the meaning. While human readable meaning may be preserved any automatic function dependent on structured as opposed to textual entries will be lost. There are various situations where this may occur and the following are examples:

   o Term Codes: Some term codes exported from EMIS systems cannot be recognised on import to InPS Vision and so are degraded to text. This may occur where term codes have been used in the process of migrating EMIS practices from 4 byte Read to Version 2 Read

o Qualifiers: Some InPS Vision forms carry qualifiers which are extracted as text. On import to an EMIS system the forms cannot be reproduced so that the qualifier information appears as text

o Dates: Some InPS Vision forms carry contextualised dates (e.g. disease register forms) which will be degraded to text on import to an EMIS system

o Medications: Some medications (e.g. mixtures) cannot be represented in the NHS standard Drugs, Medications and Devices dictionary (DM + D). Where sender and receiver systems are different the details will be degraded to text

o Allergies: Where drug details cannot be represented in DM + D and the sender and receiver systems are different, the details will be degraded to text

- **Dates**

Typically, observations in GP records are displayed with a single uncontextualised date usually on the left hand side of the screen. This date may have been changed by the user at the time of data entry for a variety of different reasons (e.g. the observation was made on a date that differs from the system date). In most cases this will not have important clinical consequences. However, it should not be assumed that other practices will change these dates according to any particular set of rules. Therefore dates that are not associated with an explicit context should be interpreted with care. Some dates do have a clear context (e.g. plans, recalls) both in sender and receiver systems.

InPS Vision holds contextualised dates in a small subset of its forms (e.g. 'date of last fit'). Where the record is transferred between InPS Vision systems the display of these dates will be preserved in context. Where the record is transferred to any system that can only handle one date (e.g. EMIS LV system) such dates will be degraded to text which will be displayed with the rubric and any other text. Thus in text the context of the date will be preserved. The left hand date may be changed to this same "effective date".

We hope future GP systems should be better able to contextualise dates and that future versions of the message will be better able to handle that context.

- **Complex consultation text – EMIS system**

EMIS users in Consultation view can construct complex strings of text and coded information. This construct can be passably recreated on re-import to an EMIS system but users may see line returns in unusual places.

It has proved very difficult to represent this construct meaningfully when the information is imported to an InPS Vision system. Currently InPS Vision users will see a series of coded entries interspersed with text. Code and text may not appear in the same order as in the originating EMIS system, which can sometimes make such entries difficult to interpret. Selection of a different record view may help. Further work is in progress to ameliorate this.

8b.3.5 Attachments including documents

The GP2GP definition of an attachment includes any file that is separate from the main body of the electronic record but with an explicit link embedded in the record. This link must enable the location of the source file to be identifiable from within the record. All such attachments should be extracted in parallel with the main body of the record and transferred by the GP2GP transfer process to the next practice. At the receiving practice all such attachments should be accessible from within the record once it has been filed. However, there are currently limitations;

- The Spine Transaction and Messaging Service (TMS) currently only operates with a restricted list of file types. Where an attachment is of an unsupported file type it cannot be sent across the TMS to the next practice. In such a case a 'placeholder' will be sent instead of the file[193]
- The TMS currently has a message size limit of 5 Mb. If the total size of the record plus all attachments exceeds this limit then the GP2GP record transfer will fail totally[193]
- The TMS currently limits attachments to a maximum of 99. If this limit is exceeded then the GP2GP record transfer will fail totally[194]
- Some Third Party document management systems employ their own application programming interface (API) to interpret the address in the embedded link in order to determine the true location of the file. Unless the GP system supplier can access this API at the time of extraction the file will not be found. In this case only a placeholder will be sent on to the next practice[195]
- Contextual information (e.g. meaningful name or descriptive notation) is not currently interoperable between different GP systems so that at the receiving system it may be impossible to tell the nature / content of any document without first opening it. At present this limitation is unavoidable because no standard for naming and categorising documents operates in the GP domain.

8b.3.6 Handling of pathology (PMIP) results

- **Dates**

PMIP results may have as many as four associated dates when received from the pathology laboratory. However, because the present GP2GP HL7 message cannot contextualise dates, this limits the number of dates that can be forwarded to the next practice to just one. The rule adopted sets this as the date that the specimen was received by the laboratory.

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[193] In all of these cases a 'Large Message Solution' is expected to overcome these limitations but even so it may still be impossible to open some file types in the receiving system if the necessary application is not installed

[194] In all of these cases a 'Large Message Solution' is expected to overcome these limitations but even so it may still be impossible to open some file types in the receiving system if the necessary application is not installed

[195] In at least one case this problem can be solved if the sending practice upgrades its document management system to the appropriate version. In other cases there may still be work to be done between individual document management system suppliers and GP system suppliers

- **Units, ranges and abnormality indicators**

PMIP results when transmitted from the pathology lab will typically be accompanied by their own units, normal ranges and where appropriate, abnormality indicators. These will vary from laboratory to laboratory. For individual results to be correctly interpreted it is therefore vital that this information be preserved as originally sent. The rules adopted for GP2GP transfers of PMIP data are as follows:

   o The PMIP units, ranges and abnormality indicator (if present) as originally received from the laboratory must be extracted from the 'old' practice and sent along with the value of the result to the 'new' practice

   o On import, the 'new' practice system must preserve PMIP units, ranges and abnormality indicator (if present). It must not substitute 'native' units or ranges nor change the abnormality indicator or insert an abnormality indicator where none was originally sent by the laboratory.

While these rules will facilitate human interpretation of individual results they may not assist machine interpretation for example where automatic searches are performed on values without taking into account differing units and ranges.

8b.4 General clinical safety

Systems engaging in GP2GP record transfer are required to adhere to some processing rules on receipt of a GP2GP message, to reduce the potentially adverse effects of the above limitations (see also Chapter 3 – Clinical Safety Assurance)

8b.5 Electronic and paper GP2GP record transfer

The transfer of paper GP records alongside electronic ones will continue for the foreseeable future for a variety of reasons, which include;

- The variable penetration of use in general practice of electronic records for direct patient care
- The majority of patient information from outside practices remains paper-based
- The variable degree to which such external information is incorporated into the electronic record
- The variable degree to which historical patient information native to practices has been incorporated into electronic records.

The net effect of this is that, while electronic record transfer will reduce the need to re-key information, it will not remove the onus on receiving practices to enter historical information present in the paper records if deemed appropriate and clinically significant.

However, when a patient deregisters and re-registers elsewhere and GP2GP record transfer is active, the EPR will typically be sent to the 'new' practice within minutes of re-registration while the request from the Primary Care Organisation (PCO) for return of the paper notes will not arrive for days / weeks. If in the interim the 'old' practice has clear evidence that the 'new' practice has successfully imported the EPR received via GP2GP transfer (e.g. receipt of a transactional message from the receiving practice acknowledging that the GP2GP process led to the EPR being successfully imported)[196]then in this case there would be no 'good practice' requirement to print out the EPR and place it in the Lloyd George envelope. In all other cases the EPR should continue to be printed out. Practices should be aware that they will need to seek permission from the PCO to transfer patient records to the next practice by a medium other than paper.

8b.6 GP electronic record quality

However carefully electronic records are kept, errors in their content will sometimes be present. The following examples are already known to have occurred;

- Erroneous codes added by a secretary from an inbound letter
- Erroneous diagnostic code added by a doctor on "hearsay" from a third party
- Erroneous codes added as a result of a flawed data transfer mapping exercise
- Automatic code entry as a result of software misinterpretation of inbound electronic messages
- Missing or incomplete significant data
- Data summarised from Lloyd George notes that relates to a different patient's clinical information (see also 8b.7.1.3 below).

(See also Chapter 6 – High Quality Patient Records)

8b.7 GP2GP record transfer - good practice guidelines

The following guidelines apply to the electronic transfer of GP records in current technical and organisational circumstances.

8b.7.1 Workflow

8b.7.1.1 Links with registration business process
The GP2GP record transfer process, although triggered by the patient registering at a new practice, is quite separate from the registration process. The message transfer process

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[196] Unfortunately at the time when these guidelines were being written GP2GP version 1.1a did not support the necessary transaction messages to support this. However, this may change in which case instructions as to how and where the relevant transaction message can be found will be system specific and therefore should be sought from the system supplier. Note that it will be necessary also to resolve the issues relating to file attachments outlined in section 8.3.3.5

employs the Personal Demographic Service (PDS)[197]and the Spine Directory Service (SDS). A number of checks are carried out to ensure that the correct record will be requested for the correct patient from the correct previous practice and that the patient has registered at a genuine practice. The electronic message carrying the patient's record is conveyed securely across the N3 network into the Transaction and Messaging Service (TMS) and then out again across the N3 network to the new practice. Only users with the appropriate role and access level will be able to trigger the GP2GP process and even then, only if they have logged on to the system using their smart card.

A chain of events is triggered when the patient registers. Firstly the Personal Demographics Service (PDS) is used to run a patient trace. By using key information such as surname, date of birth, sex, and NHS number, the correct patient is identified on the PDS. Following this, the patient's previous practice is automatically identified. An automatic check is performed using the Spine Directory Service (SDS), which holds essential information about NHS organisations, to find out the exact electronic location of the previous practice and to check whether or not it is GP2GP enabled. If the previous practice is not GP2GP enabled then the GP2GP process stops and the registration process simply reverts to a paper based record transfer. If the previous practice is GP2GP enabled then an electronic request is sent to the previous practice using the EHR request message.

At the previous practice a series of events takes place automatically;

- A check is performed to confirm that the patient's record can be found
- If the record is found then a check is run against the SDS to obtain the routing details of the patient's new practice
- An electronic acknowledgement is sent to the new practice
- A check is run against the PDS to check that the patient has in fact registered at this new practice
- Finally, assuming that the previous checks have returned satisfactory responses, the patient's electronic record is automatically extracted and conveyed by the EHR extract message across the N3 network and the TMS to the new practice.

The GP2GP record transfer process is designed automatically to fetch the patient's record safely, securely and quickly from the previous practice. Typically the record will arrive within minutes of the patient completing registration (See also Chapter 8a – The Personal Demographics Service).

8b.7.1.2 Automatic sending of the record by the previous practice
At registration when patients sign the GMS1 form, or a similar locally devised form, they are effectively instructing the new GP to retrieve their records. It can be argued that neither the previous nor the new GP have any 'say' in this process, so the new GP is in effect being

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[197] http://nww.connectingforhealth.nhs.uk/demographics

instructed to get the patient's records. This explicit statement gives the new GP the right to retrieve the newly registered patient's records from the former GP, whatever the record format. For these reasons the strict legal and regulatory arrangement is that as soon as the patient is accepted by the requesting practice, they have assumed responsibility for the patient. From that point onwards the patient is no longer a patient of the sending practice and that practice has no right to deny the registered GP access to what is now his/her patient's record.

During the development of the GP2GP record transfer process two issues were considered;

- Whether to have an automatic process that extracted the record from the sending practice without intervention from the sending practice, or whether to have the sending practice 'allow' the request and determine whether the record would be extracted, i.e. in some way be able to stop or deny the request
- Whether the extraction should occur immediately or at some other (delayed) time, e.g. 24 or 72 hours later.

These issues were considered and debated by the full General Practitioner Committee, the Royal College of GPs, the GP2GP Project Board and the GP2GP Clinical Safety Team. The unanimous view of all of these bodies was that the electronic record should be extracted and sent, automatically and immediately, in response to the EHR request message.

8b.7.1.3 Handling of electronic patients received in error
This guidance has been developed by the GP2GP project and the Joint GP IT Committee to advise practices how to reduce the risk of making an erroneous record transfer request and advising practices and PCTs how to manage such erroneous requests when they do occur. Erroneous record transfers usually occur when patients are incorrectly identified when registering with a new GP practice. This may result in a request being made for the wrong record via a GP2GP transfer and a patient being inappropriately deducted from their true registered general practice.

- **Registering new patients**
Correctly identifying and registering new patients on the demographics database (PDS) is the absolutely key step in reducing the risk of erroneous GP2GP record requests being made. When completing the GMS1 registration form, practices should carefully check the accuracy of patient data and try to provide as much information as possible, preferably including the NHS number when it is available. The GMS1 should be checked in the presence of the patient to check its legibility, completeness and accuracy. If a patient cannot be positively identified, practices might consider asking registering patients to provide formal identification and proof of recent address to ensure that correct GP2GP record transfer occurs. If in doubt, registration should be deferred and advice sought from the PCT or Patient Services Agency (PSA).

- **Erroneous transfers and the sending practice**

Most erroneous transfers come to light when the patient contacts their practice (the sending practice) for an appointment or prescription, to be told they are no longer registered. Sending practices should contact their system supplier helpdesk to report the erroneous transfer. The practice should also contact their PCT (Patient Services Agency) to request that the patient's registration be reinstated and consider informing the patient what has happened.

- **Erroneous transfers and the receiving practice**

The practice requesting the record (the receiving practice) may also identify that they have the wrong record, or are informed by their supplier helpdesk that they have registered the wrong patient. Practices should contact their PCT (PSA) to advise them of the erroneous transfer and with the support of the PSA and supplier helpdesk, arrange to "roll back" the clinical system so that the erroneous incoming GP2GP record is deleted and no erroneous patient details remain in the receiving practice. The receiving practice should consider whether an erroneous transfer should be considered as a practice critical incident, to reduce the risk of further such errors.

8b.7.1.4 Arrangements for returning patients – the 'A – B – A' scenario

Where a patient returns to re-register at Practice 'A' the previous electronic record including demographic entries should still exist. This forms a special case known as the 'A – B – A' scenario and leads to the following challenges:

- Practice 'A' must ensure it does not hold duplicate records for the patient (i.e. both the original and the newly received records).
- The need to keep duplication, disorganisation and degradation of the content of the original existing record at Practice 'A' to a minimum when attempts are made to merge this with the incoming record from 'B'
- The need to apply all changes to the record deliberately made by any user since the patient left Practice 'A'
- The need for any merging process to have an automatic default that is deemed to be clinically safe.

At the present time these challenges cannot be satisfactorily met. Therefore a constraint is applied. Until further notice users should expect that GP2GP record transfers will not take place for returning patients. Instead, the original record at practice 'A' should be reactivated. Work is currently in progress to develop an intelligent, safe 'merge' of records for returning patients. The main aim will be to preserve all of the changes that have resulted from deliberate actions by a clinician since the patient left Practice 'A' but to minimise the duplications, degrades and disorganisation to the pre-existing record (at Practice 'A') that result from the automatic processes of heterogeneous GP2GP record transfer (transfers between different GP systems). A secondary but important aim will be to maximise the chances of achieving long, unbroken chains of electronic record transfers and generally to improve the quality of these transfers.

8b.7.1.5 Parallel running with paper records

At this point in time although the number of non-computerised practices is very small a significant part of the GP estate in England is not GP2GP enabled. Nor are there arrangements in place for cross border electronic record transfers. For this reason paper records must continue to follow the patient.

GP2GP enabled practices remain contractually bound to follow standard practice for the handling, storage and return of paper records.

8b.7.2 Organisational implications of the GP2GP record transfer process

The GP2GP record transfer process can be considered in a series of stages each of which needs to be supported organisationally by the practice. The precise details as to how these stages should be managed and by whom will depend on the practice. However, particular attention should be paid to the checks outlined in section 8b.7.5 and the general principles enumerated in section 8b.7.6 (below) should be followed.

The stages might typically follow in this sequence:

Stage 1- Registration process / PDS trace and triggering of the automatic EHR request process

It is vital that staff involved with the registration of patients should understand the process, and the need to be logged on with a Smartcard. To minimise the risk of mismatching patients they should be thoroughly trained in the use of the PDS trace. (See section 8b.7.1 above). In this context, they should be aware of the importance of using the patient's NHS number wherever possible.

Stage 2 - Initial check of incoming records leading to filing in a timely fashion

All systems provide a facility to preview the incoming record before it is filed into the database. Some systems provide facilities to filter this preview in various ways (e.g. to identify drug allergy or medication degrades) and to give an impression of the overall quality of the record. The record should be checked to ensure that it is not obviously the wrong record for a patient of the stated age and gender. It is not possible in any way to alter the incoming record at this stage. However, in exceptional circumstances (e.g. if it transpires to be the wrong record or if the record is deemed to be of such poor quality as to be useless), the user has the option to reject the record and to opt for the practice to start building a new record for the patient. In the majority of cases the aim should be to file the record without delay so that the patient and attending clinicians can benefit from having access to the record as early as possible (e.g. have access to information about current medications and drug allergies). Any entries that have been made to the patient's record prior to filing should be checked against the previous record after filing and any inaccuracies or duplications should be appropriately handled. It follows that the earlier the record is filed the less the amount of checking that will need to be done.

Stage 3 - Fixing of any degraded drug allergies in the incoming record so that prescribing is unlocked

The GP2GP record transfer process has been designed to minimise the risk of drug allergy information being lost or over-looked leading to inappropriate prescribing. As drug allergies are represented in different ways in different systems it is inevitable that degraded drug allergies will occur. These will not interact with prescribing decision support.

After filing, the presence of even a single drug allergy degrade will therefore lock down prescribing making it impossible for any medication to be authorised / prescribed until the degrades have been appropriately processed.

Different systems provide users with different tools to identify these degrades, to enter the allergy in the appropriate way, and then to delete the degrade. These actions are recorded in the system audit trail. It is vital that everyone who has access to the record before these degrades have been processed fully understands the importance of handling them in the proper way. Following preview and filing some practices may choose to give the processing of these degrades a high priority so that time can be saved in the first consultation.

Stage 4 - Reviewing and re-authorising medication (typically with the patient)

At the first consultation immediately after registration time is likely to be at a premium. As a minimum:

> a. A conscious check should be made to ensure that the demographic details belong to the consulting patient and that the correct electronic record has been filed into the practice system for this patient.
> b. The accuracy and appropriateness of current medications and allergies should be checked with the patient.
> *N.B. Medications may not be prescribed from an incoming record until;*
> > *i All drug allergy degrades have been processed (see above)*
> > *ii Medications have been reviewed and (re) authorised by a prescriber in the new practice*

Stage 5 - General review of the record with the patient to check and correct any missing information or inaccuracies

The prime objective here is to ensure that from the patient's point of view the record is complete and accurate (see also Chapter 8b.7.6 below). In particular, if not already done;

> a. A conscious check should be made to ensure that the demographic details belong to the consulting patient and that the correct electronic record has been filed into the practice system for this patient

b. Any interim record information that may already have been entered on the receiving system should be checked against the incoming record

c. Any current medication or allergy information should be checked for accuracy

Stage 6 - Review of paper record to look for and back load missing information

Typically this will be a 'back office' activity similar to the 'summarising' activity performed for paper-based transfers. The main objective should be to find important information in the paper record that was not entered into the electronic record at the previous practice.

There should be no need to check the computerised printout from the previous practice, as the GP2GP process will have transferred all of this information.

It is likely to be more rewarding to check for any summary card and to check hospital letters. Practice staff should resist the temptation to make cosmetic changes to the incoming record (see also Chapter 8b.7.6 below).

Stage 7 - Business specific information review

The aim of this 'back office' activity is to review the record to ensure that it contains necessary entries to support practice business processes (e.g. cervical cytology call / recall). In this case, because individual practices have different ways of managing their various business processes it is very likely that changes will need to be made to the record. However, these should be kept to a minimum. This activity can be carried out in parallel with the other activities outlined above.

Stage 8 - Keeping filing of incoming results and correspondence up to date

In contrast to all of the above points, which relate to the receiving of records this relates to the practice's role as a sender of records. Practices often have no advance warning that a patient has moved and registered elsewhere. As GP2GP record transfer is an automatic process notification that the record has already been transferred to the next practice may be the first indication that the patient has moved (see also Chapter 8b.7.1.2 above for discussion of automatic sending of records). It is therefore good practice to keep filing of all incoming results and correspondence up to date. In the event that pathology results have been received into the practice and matched but not yet actioned, the GP2GP transfer process will forward all such results to the next practice. However, the requesting clinician remains responsible for ensuring that any action appropriate to a result is taken even though the patient has moved on to the next practice. To the receiving practice the results will appear to have been actioned. To the sending practice the results will still be displayed as awaiting action.

If urgent action is needed it may be necessary to contact the new practice. PCTs or PCAs should be able to assist in this and practices should be clear about the procedure to be followed in such cases.

8b.7.3 Training

Practices should ensure that all of the processes outlined in section 8b.7.2 are integrated into their general operations and managed effectively. There should be clear policy about what each of these functions should entail and who will perform each of them. Roles should be clearly defined and appropriate system access levels set up, commensurate with experience, training and responsibility, to enable users to carry out these roles. The team members concerned should have undergone appropriate training. In particular:

- A responsible member of staff and a deputy should be identified to take the lead within the practice and be trained in the processes involved in GP2GP record transfer
- The Practice lead should identify how the processes outlined in 8b.7.2 will be integrated into general practice operations and undertake a training needs assessment of the people involved. In particular this should address:
  - Registration process and PDS trace
  - Initial check of records on receipt and filing
  - Handling of drug allergy degrades
  - Reauthorisation of medications / identification of what was current medication in previous practice
  - Review of paper records, what to backload, how to achieve this and keeping changes to incoming records to a minimum
  - Dealing with business specific information
- All users of the practice system should be trained in what to expect from electronic record transfer and, in particular, from the limitations outlined in section 8b.3 of this chapter.
- More generally, all members of the clinical team and relevant members of the administrative team should be familiar with these good practice guidelines prior to commencement of GP2GP record transfer
- Practices should identify a date from which they will implement GP2GP record transfer and all members of the practice should be informed of the date of commencement of GP2GP record transfer.

8b.7.4 Non-computerised practices

Although the number of non-computerised practices has become very small not all record transfers between practices are capable of being covered by GP2GP electronic record transfer. Therefore it will be necessary to continue to exchange paper records for the foreseeable future. (see above Chapter 8b.7.1.5 – Parallel running with paper records)

8b.7.5 Validation

This is about 'fitness for purpose' of the incoming record and relates to things that should be done as soon as possible after the incoming record is received;

- Check that both demographic information and the associated electronic record relate to the patient
- On preview confirm that the record is of adequate quality to file

- Check compatibility and consistency between any interim record already made and the filed incoming record
- Process any drug allergy degrades
- Reauthorise medications and address any medication degrades
- Check business specific information and amend entries to align with practice processes but resisting the temptation to make any changes unless they are absolutely necessary from a safety, usability or business process point of view.

8b.7.6 General principles - summary

- The quality issues identified in section 8b.6 above require practices to have in place mechanisms aimed at reducing or eliminating the impact of externally received erroneous data.
- The practice's natively created record should be maintained in line with these "Good Practice Guidelines for General Practice Electronic Patient Records v4 (2011)"
- Practices should review their organisational arrangements so that they are able to support the processing of incoming records as outlined in section 8b.7.2 above.
- In particular, the incoming record should be subject to validation checks as identified in section 8b.7.5 above.
- Practices should recognise that patients themselves are generally the most competent to judge the accuracy of their own historical information, and should consider ways of enabling patients to comment on the content of their records at specific points in their experience such as their first visit after registering or at the point of referral to hospital.
- Practices are provided with functionality on their systems that will allow them to review but currently not to alter incoming records before they are filed. They are currently presented with a choice of either filing the record into the practice database or rejecting it in which case it will persist as an attachment to the patient's new record. The choice to reject should only be exercised rarely.
- Practices are provided with further functionality to assist them in making some essential changes to the record after filing (e.g. degraded drug allergies – see below)
- There is a need to review and, in some cases to make further alterations to the information in those records after filing (See sections 8b.7.5 and 8b.7.2). When doing this the responsible user should ensure that;

    o **Incoming record information is not modified beyond what is necessary to make it safe and usable on the receiving system**
    o **Incoming record information is never deleted unless deemed to be unsafe in terms of its accuracy or comprehensibility**

- When paper records are subsequently received they should be reviewed by a GP or other appropriately trained member of staff and amendments made to the electronic record where appropriate.

Chapter 8c - Data migration

8c.1 Formalising the process of data migration

The Data Migration Improvement Project (DMIP) was set up to improve the quality of data migrations between source and target systems using different software, typically provided by different suppliers. Under GP Systems of Choice (GPSoC) arrangements, individual suppliers' data migration processes are assessed against a set of requirements developed by DMIP. These requirements are predicated on a clearly defined end-to-end process and careful planning. They effectively set a standard for all data migrations between GP systems. The aim is to minimise disruption to practices and to keep the loss and modification of information resulting from the data migration process to a minimum thereby reducing risks to patient safety.

8c.2 Data migration process

A well-organised data migration process should progress through the following stages;

Stage 1 - Preparation and planning
Stage 2 - Extraction of data from source system
Stage 3 - Transformation / translation of data from source system format to target system format
Stage 4 - Import of transformed / translated data to target system
Stage 5 - Handling of exceptions and review of data in target system
Stage 6 - Iteration as necessary of steps 2 – 5 until a satisfactory result is obtained at step 5
Stage 7 - 'Cut over' to target system
Stage 8 - Back-loading to target system of any data collected during the period of time from the final source system data extraction to target system 'cut over'
Stage 9 - Review of information in target system in 'live'
Stage 10 - Final sign off

These stages are considered in more detail below.

8c.2.1 Preparation and planning
This is the most important stage as the smooth running of the whole process is dependent upon careful planning. The preparation and planning should start from the point at which a decision is being made as to whether or not the practice system should be changed (i.e. the decision upon which the need to undergo data migration depends). In particular it should take full account of the possible disruption to established practice routines that may result. A typical modern general practice will have modified its business processes over the years to the extent

that almost every aspect of its work will now be more or less dependent on its computer system. It has been suggested that the overall efficiency of a practice will typically drop at the time of migration and then take up to six months to recover to its original level. Reasons for this include the need for;

- Members of the practice team to become familiar with the workings of a new system
- Some tasks to be carried out differently.

It is therefore important to identify which aspects of the practice's work are likely to be most affected, for example in the reception area, consultation room or back office, and then to work out effective ways of making the necessary transition. Particular consideration should be given to the training needs of both clinical and non clinical staff.

The actual process of data migration will itself make demands on practice resources. Practices should consider nominating a lead person to work with the target system supplier, who would start with the planning process and then go on to manage and coordinate the involvement of practice resources at successive stages. The supplier should be able to provide a template outlining all of the processes in sequence, the points at which practice input will be required and the nature of that input. The plan should include clear milestones, define roles and responsibilities and identify how communications will be managed. In particular it should cover;

- Unambiguous definition of what information must be migrated
- Clear identification of what information will not be migrated
- Discussion of known incompatibilities between source and target systems and how these should be handled
- Business continuity arrangements. Depending on the process followed by the supplier, one backup is likely to be identified as 'final'. Details about filing of pathology results, letters etc before this final backup should be agreed with the supplier. There may be a period between the time of this final backup and the time of 'cut over' to the new system when any entries made on the source system will never be migrated to the new system. Some suppliers are able to take an incremental backup which sweeps up all such entries and migrates them to the new system but others do not do this.   It is important to discuss this in detail with the supplier and to determine the likely duration of any such period. There may be a need to maintain an alternative recording system (e.g. on paper) of all key transactions during this period so that these can eventually be 'back-loaded' into the new system after 'cut over'. It so, the arrangements should be carefully planned and communicated to the whole practice. This time gap should be kept as short as possible (i.e. days)
- Clarity about the practice's current system back-up routine including any encryption measures: there will be a need for full backups to be provided at specific times as the data for migration is usually extracted from back-up tapes
- Clear policy on the handling of updates (e.g. of Read codes / drug codes / source system patches etc.) during the data migration process

- Maintenance of any existing interfaces with other Practice IT systems / equipment
- Conformity with current clinical safety approach (at the time of writing the NHS Connecting for Health Clinical Safety Approach)
- Compliance with Information Governance best practice
- Cataloguing and explanation of tools etc. to be used (e.g. cross maps / means of finding irregularities in source data, determining the quality of information migrated to target system)
- Maintenance of access to the original source system during and after the migration process so that where necessary patient records can continue to be accessed. This is likely to require liaison with the PCO.

8c.2.2 Extraction of data from source system
The supplier may at different times wish to request a full backup of practice data. These should be planned to occur at times that cause minimum disruption to practice business.

8c.2.3 Transformation / translation of data from source system format to target system format
Carried out by the target system supplier (or by a third party on that supplier's behalf) usually away from the practice.

8c.2.4 Import of transformed / translated data to target system
In the early stages this may be done away from the practice. The new target system should be set up at an early stage in the data migration process with a 'dummy' database available for training and familiarisation. This should be separate from any database into which live data may be imported.

8c.2.5 Handling of exceptions and review of data in target system
The supplier may be able to offer a choice as to what should be done with parts of the data that cannot be automatically transformed / translated from the source system format to the target system format. This may result from differing structures, differing coding systems, use of the system or practice local codes. There should be close collaboration between supplier and an authorised member(s) of the practice. See below for iterative nature of this process and the importance of reviewing the quality of the data migration.

8c.2.6 Iteration as necessary of steps 2 – 5 until a satisfactory result is obtained
The majority of this work will not involve the practice. In general most of the transformation / translation will be automatically carried out by the supplier (or by a third party on the supplier's behalf) through the use of a piece of pre-existing software known as an 'adaptor'. However, there will be a need for some practice input at various points (e.g. where the supplier can offer a choice as to what should be done with parts of the data that cannot be automatically transformed / translated to the target system). It is important that this input should be forthcoming from an authorised member of the practice with (delegated) authority who may wish to involve other members of the practice when appropriate. The practice should not allow the final 'cut over' to take place until satisfied with the quality of the data migration.

8c.2.7 'Cut Over' to target system

It should be noted that at this point the target system becomes the primary record system for the practice (i.e. used in place of the original source system).

8c.2.8 Back-loading to target system of any data collected during the period from time of final data extraction from source system to time of 'cut over' to target system

See above 'Business continuity' under 'Preparation and planning'.

8c.2.9 Review of information in target system in 'live'

Practices should participate actively in reviewing the migrated information in the 'live' environment. Typically suppliers will have procedures and/or tools that can demonstrate that all patient records on the source system have been migrated and that simple searches (e.g. for QOF points, diagnoses etc.) yield comparative numbers. These should have been covered during preparation and planning.

8c.2.10 Final sign off

At the time of writing, under GPSoC rules, the data migration must be signed off both by the practice and by the PCO. Practices should ensure that they have thoroughly reviewed the information in the new system and are satisfied with the results. Practices **must** undertake a comparison of records between the old and new systems as they retain ultimate responsibility under the Data Protection Act for ensuring that the data has been migrated correctly (see Chapter 4.2.4 – Records governance).

Chapter 8d – Clinical Messaging

8d.1 Introduction

This chapter will address clinical messaging supporting day-to-day patient care, which involves the sending of data to and from GP systems. Advice and guidance will be issued under the following headings:

- Processes involved in handling clinical messaging data transfers
- Pathology messaging
- Radiology messaging
- Out-of-hours messaging
- Other messages

An important part of the safe and effective use of clinical data received from elsewhere is to have an appreciation of the limitations such data may have, as a consequence of the methods of their capture in a remote system, and their subsequent transformation, transfer to and incorporation into the GP system. Mention will therefore be made of 'health warnings' practitioners should bear in mind, when using data originated elsewhere.

These days, it is common for diverse mechanisms to support a particular business flow of information, guidance will be offered on the system-independent processes needed to handle such data and information transfers.

8d.2 Background

The messaging discussed here is the transfer of clinical data between computer systems, the data being structured (organised, coded in whole or in part, and assembled) to a standard observed by both systems. This structuring means that the receiver can 'understand' all or part of the data's meaning, as if they had been entered directly onto the user's clinical system.

Every practitioner will be acquainted with the laboratory investigation reports, standards for which were developed in 1993-5 and which now have near-universal implementation after the Pathology Messaging Implementation Project (PMIP). GP2GP record transfer and then GP Summary Care Record uploads (see chapters 8b & 8e respectively of these guidelines) are the next most widely used messaging applications. Other clinical messaging, though now on the threshold of a major expansion, has been slow to develop.

Currently, all new messaging travels via the NHS Spine, for which accreditation to the demographics and other services is needed – but is not in place for many Trust systems. So

the recent work to develop the NHS Interoperability Toolkit[198](NHS ITK –sets standards based on web services for (any) systems to transmit data securely between themselves) will make communication between GP and Trust systems easier to establish. Through lowering the barriers to entry, it will also involve more systems as participants to the communications.

This diversity in messaging, allied to the increasing number of intermediate solutions being offered by document transfer systems (vide infra) and to the possibilities of remote login to Trust systems, brings both opportunity and threat. With the opportunity to participate in a communication that has long been desired (e.g. inpatient discharge summary) comes the threat of confusion from a variety of technical solutions and implementations.

The electronic transfer of documents (by NHSmail or by other means) and the transfer of data through web services has become sufficiently sophisticated that a clinician may not readily appreciate whether the data and text he or she is looking at is in the local or in a remote computer system, and is, or is not discoverable by a search of his/her system. This is likely not to matter for the immediate needs of the patient, but the clinician's responsibility for keeping adequate records does have implications for whether he/she: makes a local entry of data from a remote system that has been used for decision making; or makes a coded entry to allow later retrieval of data imported as text. It is particularly important to ensure that, when a patient record is transferred to a new general practice, information that is held on a remote system is not lost as a result.

8d.2.1 From this background, some guidance can be offered

- Clinicians have a responsibility to be trained in and to understand in broad terms the limitations of the clinical communication tools they use.
- For each new clinical messaging or communication facility offered to them, clinicians should ask some questions of the supplier, taking advice if necessary from their local support and through them from NHS CFH:
    - To what extent are data and information I am receiving to be incorporated into the local medical record and discoverable by searches on my system?
    - To what extent and in what form (coded or text) will data I am receiving be subsequently exported to the patient's next GP by a GP2GP record transfer?
    - For data which passes out of my clinical system, to whom will it go and what will it be used for?
    - Which are the standards governing the transfer, and are these all open or are any proprietary?
    - Does the transfer conform to NHS guidance on encryption & security[199]?
    - Has the NHS CFH clinical safety process been used to assure this development, and if not, what stands in its place?

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[198] http://www.connectingforhealth.nhs.uk/systemsandservices/interop

[199] http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/security

  o What training am I and any of my staff who are to use this software going to receive?

8d.3 Processes involved in handling clinical messaging data transfers

This section concentrates on incoming data handling. Outgoing data by messaging is less demanding and is covered by the guidance above.

All the incoming messaging applications to be discussed specifically below (Pathology, Radiology, OOH encounter, A/E or OPD attendance and I/P discharge) have common characteristics in the way they need to be handled. Some preparatory work needs to be done to confirm validity and to deliver them to the right person and they then need to be processed by a clinician and filed or archived away. The main steps in this process might be summarised as;

- An administrative process deals with corrupted or missing transmissions
- An administrative process matches manually those patients or clinicians identified in the message for whom an adequate machine match is not possible
- An administrative process assigns or reassigns messages to the work-stream for the clinician who is to attend to them
- A clinical process of examining and acting on the contents of the message occurs; this may involve coding or re-coding some of the message content
- An administrative process of filing the message content into the clinical record and clearing it from the work-stream occurs. This is often triggered by the clinician.

A large number of diverse communications converge on every practising clinician and these are gradually moving to be presented through the medium of the clinical records system. There is clear potential for failure if the handling mechanisms do not offer maximum utility and efficiency, and this is a prospective systems design issue.

Based upon this, some guidance can be offered:

- For every clinical communication stream, practices should appoint and train one or more members of staff (and at least one deputy to cover for sickness/leave) who is responsible for the administrative processes outlined above
- Practices should have a protocol for handling laboratory results and other clinical messages which are intended for a clinician's attention but which arrive during his or her absence

8d.4 Pathology messaging

The PMIP messages in widespread use were developed for use for Haematology, Biochemistry and Microbiology reports, and because of their success in this and the lack of development of other clinical messaging vehicles, they have since been used for wider purposes, including for cytology and radiology reports.

In 2005-6 new pathology messages were developed by NHS CFH[200]to extend the scope of use to requesting and the full range of report disciplines (supported by the Carter Report into Pathology[201]). A current NHS CFH project[202] is using the new report message to pilot the transmission of neonatal Blood Spot testing results in to departments of Child Health.

PMIP messages usually identify the investigations conducted by Read codes but also permit un-coded investigations. Systems have offered facilities to allow practices to encode these tests but this is to be deprecated because of the risk of not doing this as the laboratory would, had it been faced with the same code-list choices. This would not only have the potential to cause a later misapprehension, but also, in the age of GP2GP transfers, could cause tests not to be recognised as equivalent in the destination GP system.

As a result of the historical independence of pathology laboratories, there are many labs, which are conducting the same investigations, and reporting them using different units of measurement. Examples include the measurement of Haemoglobin concentration expressed in grammes per decilitre and grammes per litre. An initiative from within the Pathology[203] community is working to reduce these non-uniformities, but it will take many years before this is complete. Meantime, GP2GP record transfers and centrally-hosted GP systems with insufficient defences against these differences risk mixing these non-comparable data and leading to clinician confusion.

Based upon this, the following guidance may be offered;

- Practices and laboratories using PMIP report messages should avail themselves of the extensive implementation advice[204] available
- Practices should encourage their laboratories to use the National Message Assurance Service (NMAS[205]) for periodic checking of their message output and where problems arise in use
- Practices should be aware that where laboratory tests are not identified by Read codes, they will not be discovered by subsequent searches
- Practices should encourage their laboratories to use valid Read codes for identifying investigations, and where such codes do not exist, to apply for their inclusion in the Bounded Codelist[206]that constrains use of the PMIP messages and in the new National Catalogue for Laboratory Medicine[207]

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[200] http://www.connectingforhealth.nhs.uk/systemsandservices/pathology/modernising/projects/gp

[201] http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Pathology/DH_075531

[202]http://www.connectingforhealth.nhs.uk/systemsandservices/pathology/modernising/projects/newborn

[203] http://www.pathologyharmony.co.uk/

[204] http://www.connectingforhealth.nhs.uk/systemsandservices/pathology/edifact/pmip/guidance

[205] http://www.connectingforhealth.nhs.uk/systemsandservices/pathology/edifact/nmas

[206]http://www.connectingforhealth.nhs.uk/systemsandservices/pathology/edifact/technical/standards/bounded

[207] http://www.connectingforhealth.nhs.uk/systemsandservices/pathology/modernising/projects/nlmc

- Practices should exercise great caution in using facilities which may be provided to map uncoded investigations in laboratory reports to Read codes: it is in every way preferable for the laboratories themselves to do this mapping
- Practices should be aware of the limitations in aggregating report data (say into trend lines) caused by the changing of: codes used to identify investigations; laboratory methods; and laboratory reference ranges (the trend lines would not have the same basis for comparison)
- Practices should be aware that the import of laboratory results from a patient's previous practice via GP2GP transfer may bring together instances of the same investigation carried out in different laboratories, using different methods and reported using different units of measurement.

8d.5 Radiology messaging

As has been mentioned earlier, the PMIP report messages are being used in a number of places to convey reports for radiology, a subset of Diagnostic Imaging (DI) modalities. New HL7v3 radiology request and report message standards have been developed byNHS CFH. As yet, there are no smartcard-enabled PACS/RIS (radiology) systems, and until this is the case, these messages will not be able to travel via the spine to GPs. However the NHS ITK mentioned earlier offers hope of an earlier step towards using these messages (but does not negate the need for Smartcards).

8d.6 Out Of Hours (OOH) messaging

The dominant clinical systems supplier for OOH centres (Adastra) offers an electronic document transfer of details of an OOH encounter and there is widespread use of this. It is text-based and so practices will need to make their own decisions and to personally encode them if they wish to store clinically-coded information relating to these.

Practices receiving messages about OOH encounters should make decisions on clinical coding just as they would had the communication been received on paper

8d.7 A/E encounter, outpatients encounter, inpatients discharge

These three communications are grouped together because they share similar characteristics. Messages developed by NHS CFH are not now planned to be implemented as part of a future development of the Summary Care Record. While the path to developing the capability of GP systems to receive them is reasonably clear, the capacity of Trust systems to send them seems further off. Overall there seems little likelihood of centrally-driven clinical messages being implemented in the foreseeable future.

Meantime, a wide variety of initiatives may give GPs access to some of this information in varying degrees of structure, ranging from structured messages based upon a project in 2006

in Kettering, to unstructured document transfer (e.g. into the Docman add-on). In this environment, the precautions advised of in sections 8d.2 and 8d.6 above are also applicable.

Practices and PCOs may wish to consider the clinical safety, use of national standards, impact on record quality and inter-operability aspects of new initiatives, when deciding whether or not to participate in such schemes.

Chapter 8e- The Summary Care Record and the Emergency Care Summary

8e.1 Introduction

This chapter will provide advice and guidance on the Summary Care Record and the Emergency Care Summary under the following headings:

- Consent
- Data quality
- Smartcards
- Future guidance

The Summary Care Record (SCR)[208]in England and the Emergency Care Summary (ECS)[209] in Scotland are resources designed to assist in the care management of patients in urgent and emergency care settings (OOH/NHS24/A+E etc). Each resource is populated by selective extracts from the GP record. In both cases, the core extract consists of all current repeat medication, all allergies and adverse reactions identified in the source record. The SCR also includes recently discontinued repeat medication and any acute medication issued in the previous six months.

The SCR is capable of being added to with more coded data and associated free text, subject to the decisions of the patient and responsible clinician.

The ECS does not accept additional coded data in the summary itself but information relating to the gold standard for palliative care[210] may be uploaded if the patient gives prior consent.

Wales is deploying an Individual Health record, which has been implemented in Gwent and is now available to other Health Boards for rollout. Northern Ireland are also developing an Emergency Care Summary which should be rolled out to the Southern Trust during 2011.

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[208] http://www.connectingforhealth.nhs.uk/systemsandservices/scr

[209] http://www.ecs.scot.nhs.uk/

[210] http://www.gsfs.scot.nhs.uk/documents/GSFS%20palliative%20care%20OOH%20summary%20form.doc

8e.2 Consent

The consent models for the SCR[211] and ECS[212] are similar but differ in some details. For the SCR, a core extract is sent on the basis of implied consent. Access is allowed only if the patient gives explicit consent but that consent requirement may be overridden in the case of emergency (where, for instance, the patient is comatose). Each patient may opt not to have a Summary Care Record (and to have existing records deleted subject to a board review). If they opt to have a SCR, then they may decide to require to be asked each time it is accessed - or to give free access to those responsible for their care. The former option is the default one. For each patient his or her consent status is recorded on the local system using a flag or Read code. It is clearly important to record that status accurately so that, on the one hand, information is included in the SCR that should be, and on the other, that information is not sent when the patient has opted out.

Adding further codes/text to the record will only occur on the basis of a decision taken by the clinician and patient and requires explicit consent by the patient.

For the ECS, a core extract is sent on the basis of implied consent. Access is also determined by explicit consent except in the case of emergency as described above. No enrichment of the ECS record is currently possible except in the case of palliative care settings. In the latter case, explicit consent needs to be given before the upload of the agreed dataset.

8e.3 Data quality

The general requirements for data quality described elsewhere in this document apply (see also chapter 6 – High Quality Patient Records). Some specific considerations are detailed below:

8e.3.1 Medication
It should be recognised that the remote user of the SCR/ECS will not have access to the whole source record or, in most cases, familiarity with the patients concerned. In these circumstances, it is more than usually important to ensure the completeness and accuracy of the practice medication record by;

- Engaging in timely medication reviews
- Entering handwritten prescriptions in the electronic record
- Entering medication prescribed and dispensed in another care setting
- Entering regular OTC medication where possible.
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[211] www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/impguidpm/ig

[212] http://www.connectingforhealth.nhs.uk/crdb/boardpapers/agenda_item_11_2_ecs_report_200505.doc

8e.3.2 General clinical codes

Where it is decided to add codes and text to a summary care record beyond the core set, it is highly desirable that this should be done as consistently as possible so that the end clinical user of the record may have some confidence in the reliability of the information presented both in terms of what would be expected to be included and what would normally be excluded.

Clearly, there will be some differences in enriched records both because different platforms handle the summarisation of record content differently, and because different users will adopt different conventions of usage of their systems.

Having said that, the RCGP has produced a set of recommendations[213] for the enriched content of the GP Summary in the SCR which include the following general categories:

- Major diagnoses
- Conditions that may have a chronic or relapsing course
- Conditions for which the patient receives repeat medications
- Conditions that are persistent and serious contraindications for classes of medication
- Major operations
- Significant therapies & treatment plans
- Significant investigations
- Fractures
- Immunisations.

How this is achieved will, to some extent, be platform dependent. However, in order to reach this end, some general requirements will need to be present including:

- Practices will need to have a reliable and timely process for summarising the records of new patients
- Practices will need to have a comprehensive policy for capturing significant diagnoses and events made or occurring in primary care
- Practices will need to have a reliable process for coding significant diagnoses and events made or occurring in other care settings
- Practices will need to maintain the completeness, relevance and contemporaneousness of local problem lists

Finally, it is important to recognise that the ultimate responsibility for the completeness and accuracy of the content of the SCR/ECS will rest with the authors of the source (GP) record.

In addition to the need to include clinical codes consistently, there is a similar equivalent need to exclude sensitive data. An exclusion dataset has been defined for use by suppliers so that a range of codes relating to sexually transmitted diseases, HIV, human fertilisation/embryology,

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[213] http://www.scimp.scot.nhs.uk/documents/RCGPSummaryCareRecordGPSummaryFinal.pdf

abortion and gender recognition will be automatically excluded from any SCR upload. That dataset will be subject to ongoing review and it may be overridden by patient/clinician agreement if the patient decides to share items that otherwise would not be included in the SCR.

There may, of course, be information outside these areas, which might be deemed to be sensitive either generally or in individual circumstances. In such cases, responsible clinicians will need to flag such entries as "not for inclusion" in a Summary Care Record. The mechanism for doing this will vary from platform to platform. (See also Chapter 6 – High Quality Patient Records, Chapter 7 – Clinical Coding Schemes, Chapter 9 – A Pathway to Good Paperless Practice and Chapter 12 – Education and Training).

8e.3.3 Smartcards

As with all spine-enabled functions in England, access is determined by Smartcard usage and the role based access permissions associated with them (see also Chapter 4 – Records Governance). Record entries made when not logged on using a Smartcard or using the wrong role will not update the Summary Care Record. The consequence of this is that the summary will not be updated in line with the local record, resulting in potential clinical error if decisions are made on the basis of erroneous information. The consequence of this is that it is important to ensure that all clinical users including temporary staff have Smartcards with appropriate role based access when entering clinical data.

8e.4 Future guidance

These guidelines will be reviewed, revised and re-issued periodically, as the implementations of the SCR in England and the ECS in Scotland are deployed and developed. Implementations in Wales and Northern Ireland will also be included as and when they become available.

Chapter 8f - High Quality Medication Records and The Electronic Prescription Service

8f.1   Introduction

This chapter will provide guidance on good prescribing practice and the Electronic Prescription Service (EPS) covering the following areas:

- High Quality Medication Records
- Why is the EPS service being introduced?
- Different releases in EPS
- EPS Release 2
- Getting ready for EPS
- EPS consultation process
- EPS benefits for patients and carers
- EPS benefits for prescribers
- Smartcards
- Release 2 readiness
- Security and confidentiality
- Access control
- Unsupported prescriptions.

NHS Connecting for Health has developed the Electronic Prescription Service (EPS). This service enables GP practices to send an electronic prescription message to a central store (the 'Spine') from where it can be downloaded for dispensing at the patient's chosen pharmacy or appliance contractor. In the majority of cases this will happen without the need for a paper prescription. Walk-in centres and other NHS settings where dispensing takes place can also use EPS. There is less need for patients with repeat prescriptions to go to their GP practice just to collect their paper prescription.

Community pharmacies and dispensing appliance contractors will also be heavily involved in using EPS.

8f.2   High Quality Medication Records

High quality medication information is important for a number of reasons:
- It is clearly clinically important to be able to view a high quality prescribing record

- Most systems have automated decision support, which check such things as interactions, allergies, sensitivities and contraindication and can only do this insofar as they have a high quality computable medication record.
- Systems also provide a range of medicines management facilities and these too require a high quality computable medication record.

The quality of the medication record will depend on two things;

- How effectively the prescribing facilities in your system are used.
- How effectively the recording of medicines not prescribed by the practice is handled.

Users will automatically generate most of a typical GP medication record as they use the system to produce prescriptions, and these records should accurately reflect prescriptions produced by the system and subsequent actions in relation to prescriptions issued. However to ensure that this is the case users of systems should ensure that:

- No handwritten changes are made to computer-generated prescription including the manual addition or deletion of items. Always cancel the prescription and issue a new corrected prescription.
- Where a script is not subsequently issued to the patient or returned unused it should be destroyed and recorded as cancelled on the system.
- Where a pharmacy queries a prescription item and changes are agreed a new prescription should be issued to the pharmacy who should be asked to return the old prescription for cancellation as above. In the case of a script sent by EPS the prescription item should be returned to the Spine by the pharmacist, cancelled by the prescriber and a new script issued electronically.
- Handwritten prescriptions issued by the practice should be recorded on the system. All systems provide facilities to record a prescription without generating a new paper or electronic prescription.
- Where an item is discontinued for a reason which means that you would not wish to use that medicine with the patient in future (e.g. Intolerance or ineffective) the fact and reason for discontinuation should be recorded as some systems will warn the prescriber if they attempt to prescribe a medication previously discontinued in such circumstances.

It is also important that medicines not prescribed by the practice but which are of future clinical significance are recorded on the practice system. Discovering and recording all medication taken by the patient can be onerous and practices need to establish a policy, which defines the circumstances in which they consider it useful and practical to record such information, which might include;

- Medicines prescribed by other healthcare professionals.
- Over the counter and general sale (including those purchased online) medicines bought and taken by the patient.

- Herbal preparations bought and taken by the patient.

In general practices should seek to discover and record any medicines that patients are taking on a continuing basis. Some examples of situations where patients might be taking medicines not prescribed by the practice of particular clinical significance include;

- Psychiatric drugs being managed by mental health and home treatment teams including depot injections.
- Chemotherapy being managed by cancer treatment services
- Immunosuppressant drugs being managed in secondary care following transplant surgery or for the treatment of autoimmune diseases

How information is recorded will depend on the purpose to which the information will be put which falls into two categories:

- Medicines where the practice will be taking over ongoing prescribing (e.g. hospital outpatient of discharge medication where the GP has agreed to take over ongoing prescribing). In this case a new prescription should be issued from the agreed date of transfer of care with details of any current prescription issued elsewhere recorded as such.
- Medicines where the practice will not be taking over ongoing prescribing. In this case the medication should be recorded as being managed elsewhere such that prescriptions for the item cannot easily be accidentally produced by the practice system

Different systems handle the recording of prescriptions issued elsewhere in different ways and few systems fully support the recording of the partial data that might be all that is necessary or available when medicines are managed elsewhere. Ideally information should be recorded so that it appears on medication lists and is available in a computable form to prescribing decision support tools. Users should seek system specific advice from their supplier.

Where it is not possible to record medicines managed elsewhere in the medication record a note or alert should be placed elsewhere in the record such that prescribers will be warned of the existence of such prescribing. Again the best way to do this will depend on the system in use and users should seek system specific advice from their supplier.

8f.3   Why is the EPS service being introduced?

Once fully active, the Electronic Prescription Service will bring a range of benefits to patients, GPs and dispensing staff such as pharmacists.
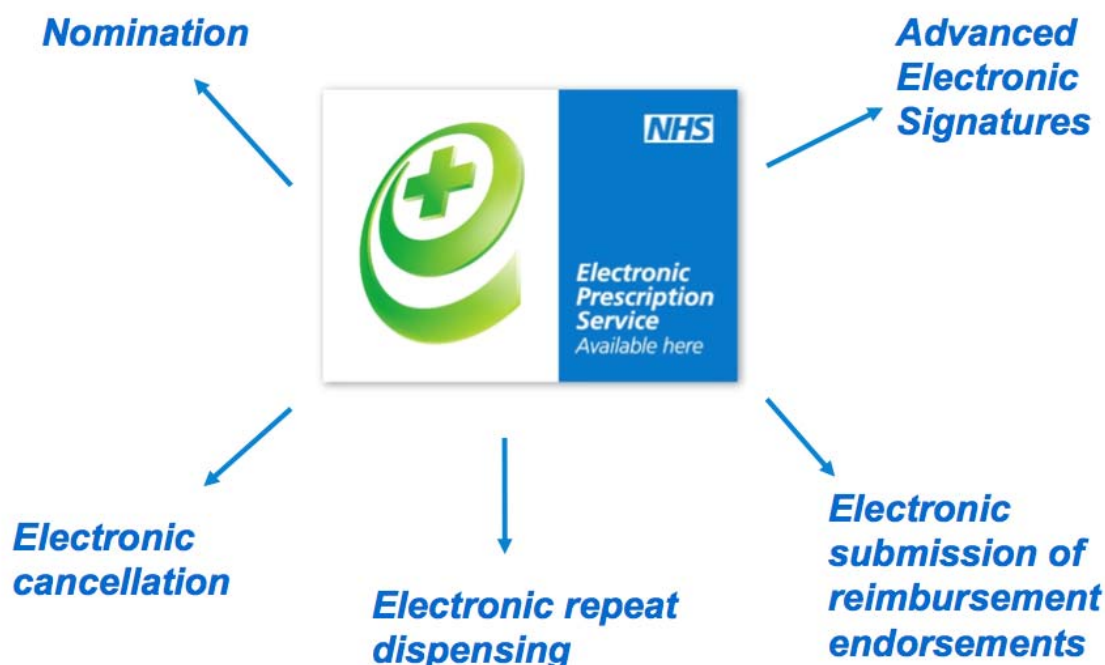
The Benefits Register[214]defines a core set of measurable, quantitative benefits directly related to the implementation of EPS Release 2 in general practice and community dispensaries and provides evidence of how these benefits support the delivery of NHS service objectives.

8f.4   Different Releases in EPS

Release 1 of EPS introduced the technical infrastructure to enable prescribers and dispensers to operate EPS. Release 1 will still print the prescription (which in itself is the legal entity) and it will have a barcode. Release 1 has also allowed robust testing of the infrastructure of EPS and Release 2 will help practices to reduce the administrative burden associated with generating large volumes of repeat prescriptions.

Release 2 allows the prescription containing the advanced electronic signature to be sent from the prescriber's clinical system to the NHS Spine ready to be drawn down by the patient's nominated pharmacy (explained below). It also allows electronic cancellation of prescriptions, which increases safety and the whole process is smoother if electronic repeat dispensing is used by the practice. EPS Release 2 also allows electronic submission of dispensing endorsements as part of the prescription reimbursement process.

Figure 8f.4- EPS Release 2 Functionality

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[214] http://www.connectingforhealth.nhs.uk/systemsandservices/eps/staff/benefits/benefitsregister/intro

8f.5   EPS Release 2

8f.5.1.

If a patient chooses to nominate a pharmacy, prescribers will no longer need to generate a paper token (unless they want to or are asked to do so by the patient). This will not only reduce the prescriber's workload, but also the workload of administrative staff who usually issue and sort repeat prescriptions for patients (and pharmacy collection services).

8f.5.2.

Release 2 makes it easier to administer repeat dispensing regimes. This reduces the administrative burden associated with patients requesting regular repeat prescriptions. Where a repeat dispensing regime is administered, the prescriber will need to print a single prescription token as opposed to a number of paper batch issues. Prescribers are also able to cancel a single item or the whole electronic prescription making it possible for them to maintain an element of control over the repeat dispensing regime.

EPS does not limit patient access to their medications. If a patient wishes they can choose not to send a prescription electronically. They can request a paper prescription to be printed and they can take that away with them to a pharmacy of their choice for dispensing.

8f.5.3 Prescribing Tokens

A practice can issue paper tokens at any time (see Figure below). They must also be issued in the following situations;

- At the start of a repeat dispensing regime
- Where clinical information needs to be communicated to the patient (i.e. on the 'right hand side' of the prescription)
- At a patients request
- If the prescriber deems it necessary to do so.

Figure 8f.5 – EPS Release 2 Prescription Token with barcode

A digitally signed electronic prescription sent via the EPS cannot include hand written amendments on the prescription token. The token is not hand signed therefore it is not a legal prescription, so any amendment would be ignored by the dispenser.

If an error is identified within the electronic prescription then this can be corrected using cancellation, see section 8f 5.5.

8f.5.4 Nomination

A patient can nominate up to three different types of dispensers – one in each field;

- Community pharmacy of their choice
- Dispensing GP practice – if they are classed as a dispensing patient
- Dispensing Appliance Contractor if they receive such items

Patients can change their nomination by asking their pharmacist to do this for them or patients can ask their GP practice to do this.

8f.5.5 Acute and Repeat Medication

All prescriptions, whether for acute or repeat medication are submitted to the Spine in real time. The EPS makes a distinction between 'routine' and 'immediate' prescriptions so that the millions of prescriptions submitted daily can be efficiently processed. By default, prescribing

systems send acute prescriptions as 'immediate' and repeat as 'routine'. Prescribers may choose to mark a repeat as 'immediate' for the next issue if patient circumstances require this.

8f.5.6 Advanced Electronic Signatures

An electronic signature is unique to the prescriber and the prescription and is applied by using their Smartcard and pass-code. It is the application of the advanced electronic signature to the electronic message that turns it into a legal prescription.

8f.5.7 Electronic Repeat Dispensing

Patients do not have to go to the same dispenser every time to get their repeat prescription fulfilled. If a patient wishes to have more than one issue dispensed at the same time (e.g. if they are going on holiday etc.) then they can request this.

Existing agreements in place for paper based repeat dispensing can be used for electronic repeat dispensing. If a patient can be transferred manually from paper based repeat dispensing to electronic repeat dispensing the prescribing system will notify the prescriber. A patient will always receive a prescription token when they receive a repeatable prescription and the patient can use this token to get medication dispensed from any EPS Release 2 dispenser.

When a patient changes their nominated dispenser, all repeat prescriptions issued but not downloaded will transfer to the new nominated dispenser. However, all items on a repeatable prescription issue must be processed (dispensed or not dispensed) before the next issue can be released.

8f.5.8 Electronic Cancellation

A prescriber (or an authorised member of staff with the necessary activity added to their smartcard) can cancel an electronic prescription at any point prior to it being downloaded from the 'Spine' by a pharmacist for dispensing. GP clinical systems allow cancellation of either the whole prescription or individual items on that prescription. The reason for cancellation should also be added to the record.

Prescriptions cannot be amended once sent – they must be cancelled and regenerated.

8f.5.9 Controlled Drugs

Initially, arrangements for dispensing schedule 1, 2 and 3 controlled drugs will remain the same and they will continue to be prescribed using paper prescriptions. They will not be transferred electronically. Work is being undertaken to ensure that all controlled drugs will be part of the electronic message as soon as possible.

8f.5.10 Mapping of Drugs

Every drug has an electronic code, which is sent to the Spine. There are a small percentage of common drugs that have not got the necessary coding structure to allow the message to be sent. If this is the case then that drug will be printed on a prescription to be handed to the

patient. If there are other items on the prescription that can be sent to the Spine because they have the correct coding then they will be processed without being printed out. (This is system dependant).

Further work is being undertaken to ensure that most of the remaining unmapped drugs will have the correct coding structure.

8f.6   Getting Ready for EPS

In order for a practice to be ready for when EPS Release 2 is implemented they should ensure they work closely with their PCT (or successor organisation) during the transition to EPS R2 to make sure;

- Prescribing and dispensing processes are safe and effective
- Practices and dispensers work in partnership.

GP practices can change their clinical processes by reviewing how:

- Prescribers can take advantage of enabling repeat dispensing
- Practice staff can manage the repeat dispensing process along with medication review and reauthorisation processes using protocols designed by the clinical staff.

The GP software system suppliers are working with NHS Connecting for Health (NHS CFH) to enable EPS Release 2. Some are at different stages of preparation and up to date information is published on the NHS CFH website[215].

8f.7   EPS Consultation process

In order to deliver a robust and fit for purpose system, NHS CFH has actively sought input from key stakeholders and user groups throughout the design and development of the Electronic Prescription Service.

8f.8   Benefits for Patients and Carers

Some of the major benefits will be to patients who will find it much easier to order and collect their prescriptions. They should also find;

- Reduction in the need to contact the GP practice to reorder and collect prescriptions, particularly once they use an electronic repeat dispensing regime.
- Greater freedom of choice, making it simpler to use a pharmacist convenient to them.

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[215] http://www.connectingforhealth.nhs.uk/systemsandservices/eps/staff/roadmap

- Potential to reduce waiting times as the pharmacist can prepare medication items in advance of the patient arriving.
- Improved patient safety with electronic cancellation increasing the ability to ensure patients do not receive medication they should not be taking. It also allows prescribers to make any immediate changes in medication that are necessary after prescribing.

8f.9   Benefits for Prescribers

Prescribers benefit from:

- Reduction in workload for staff at GP practices generated by patients collecting individual prescriptions from the GP surgery as collection from the GP practice is no longer required
- A more streamlined process for the issuing of prescriptions
- The ability to sign prescriptions electronically will be more efficient for GPs
- The ability for GPs to electronically cancel prescriptions at any point until they are downloaded prior to being dispensed
- With repeat dispensing regimes in place in a practice the prescriber has more control over drugs prescribed for a patient
- In time, it will remove the need for pharmacy staff to collect prescriptions where they offer a prescription collection service.

EPS will support new ways of working. It could allow further enhancement of the telephone consultation and enable prescribers to send an electronic message to the patients nominated pharmacy for medicines that the prescriber deems necessary.

8f.10 Smartcards

In order to ensure that only authorised personnel are able to use the Electronic Prescription Service, access is controlled using Smartcards.

The Smartcard grants users different levels of access depending on their function within the prescribing and dispensing process. Essentially only people with the appropriate level of access to the system will only see details of the prescription. This makes EPS safer both for patients and clinicians.

8f.11 Release 2 Readiness (& figure 8f.11)
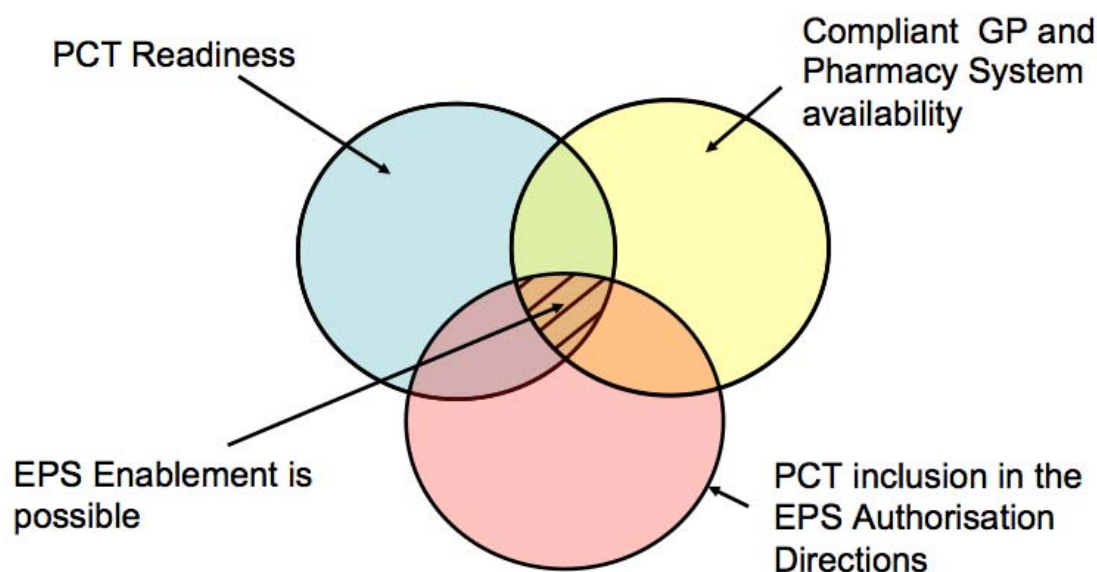
PCTs must be ready to implement Release 2 in their area before they can move forward. A PCT must be included in the EPS Authorisation Directions before prescribers in that PCT can apply an electronic signature to prescriptions. This requires approval by the Department of Health and a notice period of 3 months. There is no restriction on any pharmacy wishing to implement an accredited EPS Release 2 dispensing system.

8f.12 Security & confidentiality

The strongest security measures are in place and patients can choose whether to have their health information shared[216].

Although the new systems and services are changing the way in which patients' health information is stored and shared, they will not change the duty or commitment of the NHS to keep patients' health information safe, secure and confidential[217].

The NHS Care Record Guarantee[218]sets out the rules that govern information held in the NHS Care Records Service[219]. It 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,

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[216] http://www.connectingforhealth.nhs.uk/systemsandservices/eps/staff/faq/6

[217] GMC Confidentiality http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

[218] http://www.nigb.nhs.uk/guarantee

[219] http://www.nhscarerecords.nhs.uk/about/

access in an emergency, and what happens when someone cannot make decisions for themselves.

8f.13 Access control

All NHS staff using spine enabled systems and services must register to be an authorised user and be issued with an NHS Smartcard[220].

Even then, authorised staff can only see a patient's information if they have a 'legitimate relationship' with them, which means they are involved in that patients' care[221]. They only see the information they need to do their job.

Users should ensure that they take reasonable precautions to maintain patient privacy and confidentiality in the workplace (e.g. logging-out when leaving a terminal and ensuring screens cannot be viewed by unauthorised individuals).

An audit trail noting when, where and by whom patient records are accessed, will help to assure confidentiality.

8f.14 EPS Unsupported prescriptions

The following prescribing models are not supported at present and, therefore, still require a hand-signed FP10 paper prescription:

- Scenarios where the prescriber does not have access to the EPS (for example home visits and out of hours)
- Personal administration of medication
- Private prescriptions
- Bulk prescriptions (Drug Tariff Part VIII note 9) for a school or institution
- Controlled drugs - Schedule 1, 2 or 3 of the Misuse of Drugs Regulations
- When the patient chooses not to have an electronic prescription
- In the initial stages of the EPS where a patient has not nominated a dispensing contractor an EPS Release1 prescription (FP10) can be produced
- Where the prescription contains one of the very limited number of items that are not directly mapped using the NHS Dictionary of Medicines and Devices (DM+D).

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[220] http://www.connectingforhealth.nhs.uk/systemsandservices/rasmartcards

[221] http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/impguidpm/ig/legitrelate#type

Chapter 9 – A pathway to good paperless practice

9.1   Introduction

This chapter will provide guidance for practices on how they can change their business processes towards "paperless" working under the following main areas:

- From paper to paper-free
- Pre-requisites
- Benefits and risks
- Data quality recording standards
- Moving practice business to paper-light
- System user groups
- Accreditation of paperless practice

We will include discussion of the phases and requirements for paperless working as an outline pathway for change, and explore the risks and benefits of this method of working. The chapter will have safety and governance at its core; ensuring practices are supplied with the information they need to achieve these changes safely and without compromising continuity. Practical advice will include how to create and maintain a high quality electronic record; guidance for clinicians on how to consult using computerised records; how to record encounters; how to manage scanning of documents, both current and historical; document retention and shredding; standards for achieving and maintaining approval from governing bodies; practical aspects of messaging to and from the clinical information systems; business continuity; and where to obtain further support and assistance. The chapter will conclude with the recommended process for practices to gain and maintain their paperless accreditation status.

9.2   About this chapter

The term 'Paperless Practice' is widely used to refer to various grades of working with electronic records instead of paper. At its simplest this means 'working without paper notes', where 'paper notes' refers to the Lloyd George or A4 clinical cards traditionally used to record narratives of patient encounters. The term 'Note-less' is used for practices that record the day-to-day encounters on the computer record system (and not on paper), but may still be using a paper repository of correspondence. Similarly, the term 'Paper-light' describes practices, which, in addition to working note-less, also employ a scanning, or "Document Management System" (DMS) to handle paper correspondence and other files associated with patients' records.

Inevitably all practices will have to continue to manage paper documents at some level, both received by and sent from the practice, thus working entirely without paper is impossible[222]. There are, however, areas of general practice business historically reliant on paper workflows that can be operated more usefully, efficiently and safely by employing information technologies. Practices planning to move to 'Paperless' working must decide which functions of their practice business they wish to change and why, and consider the impact of these changes on other areas of the practice and upon the people who work for it.

In common with all business changes supported by or dependent on information technologies, the biggest challenges will arise from managing the change for your practice team and supporting them in these new ways of working.

9.3   From paper to paper-free

It is today very rare for a UK general practice to operate without any clinical information system (Clinical Computer System). The introduction of the Quality and Outcomes Framework (QOF) in 2004[223] has resulted in the vast majority of practices using their clinical information systems to capture some clinical data in a structured way. As a consequence of this, and other business requirements, all practices working for the NHS should have a clinical information system containing at least demographic data and basic electronic clinical records as required to meet QOF reporting.

Many practices that have partially evolved their use of computers for managing clinical data will find themselves in a mixed economy of paper and electronic records. This change has not been without difficulty and may not always have been approached systematically or with care. Some practices may only be using the minimum required functions of their clinical information system to support the demands of the contract, whilst others may have systematically moved towards paper-light working.

9.4   Pre-requisites

9.4.1 Motivation

Practices should consider the reasons they wish to move to paper-light working, the challenges involved and how these will affect individuals in the organisation. Having the support of the whole practice team is ideal, but most organisations will find people who are reluctant to change to new ways of working. Consensus amongst the management team of the practice and a clear statement of intent can assist with this. Describing the benefits to your team may also help, as well as an awareness of where there will be difficulty and recognition that some staff will require more hand holding and support than others.

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[222] Persistent Paper: The Myth of "Going Paperless", Richard H. Dykstra et al, AMIA Annu Symp Proc. 2009; 2009: 158–162.

[223] Quality and Outcomes Framework Guidance, 2004
    http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4088693.pdf

In order to work paper-light *all* practice staff must be prepared to change. Clinicians may find their consultation style and methods of managing their work changes substantially. Uncertainty about skills capability, perceived threats to roles and autonomy can lead to resistance to change as well as attempts to disrupt it. A stepwise approach in an achievable time frame to adapting consulting techniques and learning new computer skills can help alleviate concerns and build confidence. Consider how the technology will change roles and responsibilities for practice staff, and how this may impact upon the relationships and existing structures in the practice.

Practices may wish to reflect good information practice in their practice training material, induction packs for locums, GPRs and other temporary staff and even in their partnership agreements and employment contracts.

Practices should be cautious about moving to paper-light working as a mechanism to fix a dysfunctional system in their practice. Information technology can be used as a tool to support a business process, but if that process is already suboptimal then it is less likely that computerising it will result in success – do not computerise a problem.

9.4.2 Infrastructure, Hardware and Software

A review of the practice's hardware, software and network infrastructure should be undertaken to establish requirements for improvements needed to allow the practice to work paper-light. Your PCO will be responsible for ensuring your computer systems meet the minimum requirements to allow you to manage practice business. Practices should contact their PCO IM&T department for support in this regard.

Figure 9.4.2a Hardware

Your PCO will supply standard equipment only, to a minimum recommended specification for the applications the practice intends to run. Negotiation of changes or improvements to these specifications is a matter for individual practices.	
Workstations	Aim for one per consulting room; adequate numbers in administrative and patient facing areas; meeting rooms; laptops to support remote working
Printers	Dual bins in consulting rooms, also useful in administrative areas
Monitors	Larger monitors allow for more information to be shown; a rotating base and inbuilt speakers or USB hubs are also useful
Input Devices	Keyboards, mice, and other devices such as trackballs are a matter of individual choice. Providing specific pieces of hardware in this regard can ease the transition for members of the team who may be struggling

Software

General Practices should always check the constraints for local software installation with their PCO as policies may restrict or even forbid the installation of software to servers or workstations by practices.

Users working in remote desktop environments will similarly find that their ability to install specific software tools will be constrained. Depending on the hosting service, and the clinical system in use, an approved list of third party applications may be available.
Approved NHS GP systems in England are listed on the NHS CfH website[224].

Figure 9.4.2b Software

Clinical Information System	All NHS approved GP systems are able to support paper-light working. Changing your clinical system should not be undertaken lightly and only where there will be clear functional or practical advantage.
Document Management System	For scanning correspondence and other documents, an essential component of paper-light.
Office Software	Word processor and spread sheet programs, often with other applications included as a suite. Microsoft Office is commonly installed on workstations in the NHS.
Other Software	Practices may wish to use specific software packages for a variety of purposes, but care should be taken when installing other software. Check with your PCO IM&T department.

Figure 9.4.2c Network Infrastructure

Network Access Points	Ensure adequate numbers in locations suitably positioned to avoid running cables over floors and desks. Consider also for power outlets.
Branch Sites	If the practice has a branch site then a solution must be found to link all the sites to the clinical database.
Remote Working	Working from home or from other locations, if required, then a method of access must be supplied and configured by the PCO or system supplier.
Bandwidth	Adequate bandwidth into and out of the practice will be needed as the practice starts to use more NHS online services.

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[224] http://www.connectingforhealth.nhs.uk/systemsandservices/gpsupport/gpsoc/systems/suppliers

9.4.3   Continuity Planning

'Continuity planning' refers to the procedures and actions you employ to reduce the risks associated with loss of access to your computer systems.

As you move practice functions to the clinical information system it becomes increasingly difficult to manage the practice without them. Events such as fire, flood, theft, power cuts and technical problems can all result in at least temporary loss of access to the system and occasionally loss of data.

It is also a Data Protection Act requirement to store records safely (see also Chapter 4.2.4 – Records Governance).

9.4.3.1   Backups

Backup is essential for all practices that store any important business data locally. Practices working on centrally hosted desktops should have their clinical data, and any other data they store there, backed up by the service provider. This will be part of the service level agreement (SLA) that your PCO holds with the system supplier.

Where practices have locally stored data they must establish a backup schedule, and periodically have that backup verified to ensure data could be restored in the event of loss of the original. Remember any data not stored on servers such as any personal files on the local workstation. Users should be encouraged to store critical business data on backed up drives and be warned that locally stored files are at risk.

The costs of data loss include:

- The cost of continuing without the data
- The cost of recreating the data
- The cost of notifying users in the event of a compromise.

Practices have a responsibility for data governance commensurate with their role as custodians of confidential medical records. It would be hard to defend against losing patients' medical records through negligence or omission.

9.4.3.1.1   Backup Media

Your PCO IM&T department will be able to advise on the best backup medium for your circumstances.

Tape Backups	Commonly employed, large capacity, cheap, re-usable, established practices and software.
Optical backup	DVD, limited capacity, rarely suitable for full data backups, BluRay not widely employed.
Removable Drives	Large capacity removable hard drives can be used effectively for backup, more economical in recent years.
Network backup	Online backup services are not yet approved for NHS use due to encryption, storage location and bandwidth.

Whatever medium is used for backup the data must be encrypted if the backups will be taken off site.

9.4.3.1.2 Backup Schedule

A rotating back up schedule is typically used, normally with a nightly backup stored on site, and a weekly backup, suitably encrypted, taken off site. An alternative to off-site backups is to use a fireproof safe, but this is unreliable and may not protect your data in a severe fire or flood and, of course, could be stolen.

Practices should include the responsibility for the management and checking of system backups in the job description of a member of staff, often the practice manager. It should be made clear that failure to do this task will be a disciplinary matter, potentially resulting in dismissal.

9.4.3.1.3 'Live' local copies

Some clinical systems allow for a local copy of the system and data to be hosted on a workstation, which may then allow for limited access to the data in an emergency.

9.4.3.2 Working without the computer

9.4.3.2.1 Planned downtime

Most systems and networks require upgrading and maintenance, which will occasionally result in temporary loss of access to your system. These events can be planned for, and may be able to be completed outside of normal business hours.

Where downtime is required during the working week, practices should schedule it for quieter periods of the day and re-schedule tasks that make intensive use of the computers to a different time.

9.4.3.2.2 Unplanned downtime

- **Single machine**

Practices should create a checklist for use if a single workstation or printer in the practice stops functioning as expected. This will enable non-technical staff to work through a troubleshooting process. Such checklists should always include the contact details for IT support. A checklist need not be overly complicated and can, of course, only be as comprehensive as the technical expertise in the practice will allow.

For example:

> Is the power lead plugged in and the machine switched on?
> Try turning the computer off, and then back on again.
> Contact Tracy on ext 2134
> If Tracy is not in phone IT Support on 01236789876

Where the problem cannot be rapidly fixed, it may be useful to have a 'swap out' machine – a workstation that is functional but not in use, that can be substituted at short notice if needed.

- **All machines**

Where the network fails, or the server develops problems, you may find your practice abruptly and unexpectedly without access to the clinical system. This is never an easy scenario to manage and how you do so will depend on the practice's own circumstances.

Consider the following:

- Delegate the task of contacting IT support and have this done immediately
- Have staff trained and aware of how to handle patient requests and contacts without the computer system – a temporary paper system backup.
- It may not be unreasonable to move to 'emergencies only' working until the systems are returned to normal. It is potentially unsafe to do routine consulting without access to the clinical record.
- Inform patients in the waiting room of delays and the reasons for them.
- Consider how manually collected data handwritten during periods of downtime will be retrospectively entered onto the system.

9.4.3.3 Fire, flood and theft

Major data loss disasters, which may also result in damage or destruction of the practice infrastructure, are thankfully rare. In the event of such an occurrence you will rely on the latest data backup to restore your practice system, but repair of premises and other material damage is outside the scope of this document. Contact your PCO and system supplier as soon as possible; use their advice and help. Paper-light practices can be reassured that their patient

data should be able to be restored from backup, once systems are operational again. Practices that remain reliant on paper notes will perhaps not be so fortunate.

9.4.4 Training

This document assumes that the practice has in place an approved clinical information system and, consequently, that a level of skill and knowledge of use of the system already exists within the practice. Nevertheless, assessment of individual and team training needs should be undertaken and a plan drawn up for addressing these needs. Readers should refer to Chapter 12 (Education and Training) of these guidelines.

9.5   Benefits and risks

It is important to recognise that whilst there are many positive gains to paper-light working there may also be some dis-benefits. For example, loss of 'coffee time' chats, where clinicians traditionally meet to read and discuss incoming mail can change the dynamic of communication in the practice. Similarly, someone whose role was to maintain a paper appointment book may find a substantial part of his or her job changed or even removed from them.

9.5.1 Benefits

The biggest gains of paper-light arise from having a large volume of high quality data. High quality data will support the practice and the NHS by providing better information with which to treat patients and plan services. The main benefits can include:

- Patient records available from any workstation
- Patient records backed up
- Improved legibility
- Flexibility in presentation of clinical information
- Computerised Clinical Decision Support for prescribing and disease management
- Computer generated reporting for audit and analysis
- Computerised appointments
- Support for contractual requirements such as QOF target areas
- Templates and protocols for disease management to improve care
- Access to NHS services such as electronic prescribing
- Provision of shared records for unscheduled care
- On-line access by patients to practice services, including records access.

9.5.2 Risks

The main risks may include:

- Changing staff roles can be threatening, and there may be a risk of redundancy
- Risks of non co-operation or sabotage by practice personnel
- Loss of informal communication space

- Abstraction of record to computer may change meaning
- Working outside the practice requires a technical solution
- Changes to consulting style can be challenging
- Requires significant learning and sometimes re-learning of previously familiar tasks
- Risks to confidentiality require an increased knowledge of records governance across the practice
- Risk of duplication of recording onto computer and paper during transitions
- Risk of missed information due to not referring to appropriate resource during periods of concurrent systems.

9.6 Data quality recording standards

Much of the value of paper-light working comes from good data. It is therefore important that all members of the practice team understand how to record data on the system correctly.

Data quality means capturing information from interactions with the patient as accurately as possible in a way that is usefully computable. How much 'computability' you require, or can achieve, will depend on individual practice requirements and the clinical information system in use.

Although the primary purpose of the record is for patient care, other uses such as clinical and process audit, research, education, service planning and contract delivery are also important.

PRIMIS[225] and GPRD[226] have been instrumental in defining standards and procedures for improving data quality in Primary Care in the UK. Chapter6 (High Quality Patient Records) of these guidelines provides detailed advice on high quality records.

9.6.1 Recording Data
To support paper-light and note-less consulting data recorded should be:

- Complete
- Accurate
- Relevant
- Accessible
- Timely/Current

Chapter 6 (High Quality Patient Records) considers this in more detail.

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[225] http://www.primis.nhs.uk/

[226] http://www.gprd.com/

9.6.2 Processes for data capture

Data capture cannot be left to any one individual person in a practice – it is a job for the whole practice team.

Support Patient Care - The primary purpose of the medical record is to support the care of the patient. Consequently everyone in the practice has a responsibility to ensure the record is complete, accurate, legible, comprehensible and maintained at the time.

Every one participates - All clinicians must take part in recording data to ensure the whole practice population is covered. It is not acceptable for some clinicians to record electronically whilst others continue to record only onto paper notes. Such duplicate systems run the risk of disparate records, which can confuse patient care, increase the risk of error and be medico-legally indefensible.

Every encounter- Procedures must be in place to ensure that every clinical encounter is recorded on the computer system. This includes encounters in the practice and those that may occur outside on home visits as well as encounters with temporary staff such as locum GPs, GP registrars and temporary attached staff.

All prescriptions- A complete, chronological medication record is essential for paper-light working. All medication records must be added to the computer system, and all deletions, cancellations and amendments also recorded by updating the computer record. Prescriptions that may have been handwritten will need to be added back to the computer as handwritten on return to the practice. Similarly, where it is known that a patient has taken OTC medication this should be added to the computer system and where it is known that a patient has been issued medication from another organisation, e.g. as part of a discharge, this should also be added to the computer. Most GP systems allow these other types of medication issue to be recorded alongside that issued by the practice and having all of a patient's medication history can prove to be extremely useful. It may be prudent when visiting patients, if possible, to delay issuing prescriptions until return to the surgery when the prescribing can be completed using the computer system. This ensures decision support and avoids transcription errors and, with the introduction of the Electronic Prescription Service (EPS), may not inconvenience the patient or carer.

Agree coding standards - Every practice and every clinical information system is different, and the requirements of how granular the coding level is within a practice will depend on what the practice wants and, within the constraints of the clinical system, what is possible. Practices should agree which data is recorded in a structured way, which codes or groups of codes will be employed and how that data may be best entered. The requirements will be based on variables such as contractual necessities; practice population; special interests of the practice; secondary uses of the records; competence with the systems; requirements for audit and research and clinical safety.

Use templates and coding lists- Practices can encourage standardisation of coding within their local organisation by using clinical system provided code subsets, formularies or 'favourites'. For specific disease management and contract areas bespoke or centrally distributed data entry and review screens can be employed that mandate structured data entry to an agreed code list (e.g. picking lists or synonym lists).

Review and Audit- Policies for data entry must not be static – they need to be flexible to adapt to changed requirements, to respond to errors or refinements. Practices should be able to audit and review their data entry using reporting tools from the clinical system, or external analysis from organisations such as GPRD.

9.6.3   Coding systems

Computer systems have great difficulty in analysing freely typed narrative for significant meaning. As computers are very good at processing numbers, for clinical data entry to be useful the data we enter must conform to some type of numbering, or clinical coding schema. This attaches 'codes' to clinical terms – terms are textual descriptions of clinical concepts such as symptoms or diseases. Chapter 6 (High Quality Patient Records) and Chapter 7 (Clinical Coding Schemes) of these guidelines provide more information.

GP clinical systems will conform to a coding system approved for NHS use and allow users to enter a coded item in a variety of ways. Commonly a coded clinical term is added with an attached 'free text' comment. Subsets of the codes from a terminology may constrain the immediately available terms to the user depending on the context of the task, or their role or organisation. By reducing the number of available terms this can make it easier for a user to find an appropriate code.

In practice the conversion of clinical encounters to structured coded data can be quite difficult, especially for non-technical users used to working with handwritten narratives. Systems try and make the task of finding clinical terms easier using a variety of user interface and functional techniques and it is rare with today's systems for users to have to enter data using the clinical code directly, most systems are able to locate appropriate terms using text searches. Because any coding system is an abstraction of real clinical practice there will always be occasional difficulties finding a clinical term that exactly captures the clinician's meaning. New users can find this frustrating and unless provided with guidance and strategies may find workarounds that hinder data quality.

9.6.3.1   What is a Structured Record?

Clinical information systems aim to provide clinicians with a place to record clinical data. To do this they must apply a model of clinical practice into language that the computer systems can utilise.

When users write a clinical note they also apply 'structure' to it: they note the date of the encounter, the type of the encounter and who they are. Within the clinical narrative users

make use of clinical shorthand and convention to denote, for example a blood pressure reading. A blood pressure reading has values such as Systolic and Diastolic. If a user records these as free text then the computer will have no way of identifying that the user has entered a blood pressure, nor what the respective values for the readings are. To address this problem clinical modellers create a representation of a blood pressure in the computer record. This will have a place to record the Systolic value and the Diastolic value and a label, perhaps a clinical term, which identifies it to the system as a blood pressure reading. In other words, it is stored as a 'structured record'.

Clinical information systems all differ in their clinical models, the extent and scope of the models and how the users access and use them.

9.6.3.2   What should users be taught?

It is helpful for clinical users in particular to be given a basic understanding of the clinical terminology in use and the logic behind the system's clinical model and structure. Whilst this sounds complicated, it will generally be covered in training sessions from your PCO or supplier, and need not be very detailed. If users do not understand why the clinical system makes them record data in a particular way, nor the various levels or meanings of clinical terms, they will struggle to record data accurately or perhaps at all. (See also Chapter 12 – Education and Training).

9.7   Moving practice business to paper-light

Many practices have adopted computer use in a piecemeal fashion and may be operating a mixed economy of paper and electronic records. There are significant risks associated with this type of working as well as inherent inefficiencies and risks.

Finding information	By operating two or more repositories of patient information clinicians may miss important information by not knowing where to look, or that the information was there.
Loss of records	Paper records risk being lost and mislaid
Mixed prescribing records	Running two prescribing recording systems is inherently dangerous.
Legibility	Typed records are normally more legible. In mixed record systems it may not be clear which written entry corresponds to which computer record.
Duplication	Dual recording of information from the same encounter on paper and computer is not only inefficient, but risks the creation of conflicting records.
Efficiency	It is inevitably more efficient to use a single record system, and the always on, networked nature of the computer system favours it in this regard.

The practice should plan to move their core business functions to the computer system. Functional areas to consider include:

Demographic / Registration data	A patient Age / Sex register (e.g. information captured from GMS1 registration form)
Scheduling and Appointments	Appointment books for clinics and surgeries, as well as general practice calendaring and scheduling.
Prescribing	Moving to entirely computer based prescribing, with or without electronic transmission of prescriptions.
Clinical Data	Recording 'significant' medical history provides useful summaries, but the aim should be to record all encounters electronically.
Test results	Transcription or direct import of test results to the computer.
Document Management	Use of scanning software to store all incoming and outgoing paper transactions.
Referrals and Discharges	Ensuring all referrals and outcomes are captured on the computer system.
Transfers	Managing patient transfers to and from the practice.
Remote working	Working with patient records from outside the practice.

9.7.1   Demographic / registration data

Demographic data provides the base for managing a paperless practice. Without this data, comprising items such as names, dates of birth, addresses and NHS identification numbers, the practice cannot begin to use its clinical system. To use the system to manage patients, you must be able to clearly match the record you are working with to a unique patient.

In all parts of the UK, health authorities now hold registration data centrally. Most practice computer systems synchronise locally held demographic data with centrally held data. In England the Personal Demographics Service (PDS) requires checks on the synchronicity of the locally held data before allowing access to national services such as Choose and Book (See Chapter 8a – The Personal Demographics Service).

Practices are required to continue to manage registrations and transfers using their local systems, and to ensure the data they hold is accurate and fit for purpose. Some general rules to maintaining this data include:

Avoid abbreviations	For example, abbreviating 'Road' to 'Rd' or 'Rd.'
Use full postcodes	Some systems provide a post code / address lookup service
Include phone numbers with area codes	Collect different types of phone number and ensure they are correctly labelled, e.g. 'Mobile' and 'Work' etc
Include e-mail addresses	
Employ 'Known as' and 'Sounds like' fields	For short names and pronunciation.
Train staff on consequences of mismatched records	Can slow or prevent access to national services.
Use NHS Numbers	Single unique NHS Ids such as NHS Number (England) or CHI Number (Scotland) are essential for safe delivery of care
Always create a medical record for every patient	Even for single encounters, and always before the patient receives clinical care.
Family and Household linkage	If your clinical system supports it, this can be useful to maintain making address changes easier and identification of household members possible.
Do not operate two registers	For example, for private and NHS patients. Clinical systems normally have methods of identifying patients with different registration purposes without having to create a separate list.

9.7.2 Scheduling and Appointments

Electronic appointment systems offer huge efficiencies in general practice. There may be a large overhead in work in setting up an electronic system in the first instance, and at least one member of staff should be trained and competent to do this. Migration of large numbers of paper based appointment books and forward filling the electronic system with future appointments may take several days, depending on the size of the practice. An incremental approach can be useful, but should be time limited with a clear endpoint for becoming fully electronic.

Advantages include search and audit tools, multiple appointment types, accessibility from all workstations, clinical staff able to manage own schedules, patient remote booking by phone or internet and enabling self service check in terminals in waiting rooms.

9.7.3 Prescribing

Prescribing is more efficiently and safely managed by an appropriate computerised system, and was one of the first functions of early general practice computing that was widely accepted (See Chapter 8f – High Quality Medication Records and the Electronic Prescription Service).

Moving from paper to computer prescribing is normally beneficial for a practice, and can encourage reluctant clinicians to start using their computers. Advantages include:

* Legibility
* Standardisation of drug names, packs and formulations
* Decision support for adverse reactions, contra-indications, interactions and duplicate therapy
* Specific controls on high risk medication such as Methotrexate and controlled drugs
* Medication costs provided
* Generic and brand switching, with prompts for appropriateness
* Standard settings for commonly prescribed items.

However, there are risks associated with electronic prescribing (e.g. errors caused by incorrect use of drop-down menus, picking lists or predictive text) and care must be taken to ensure proper training and use of these systems.

Prescribing systems in the NHS in England must now conform to the Dictionary of Medicines and Devices (DM+D), a terminology for therapeutics[227]. This change has been to support the Electronic Prescription Service (EPS) and aims to standardise drug descriptions across systems and improve interoperability.

9.7.3.1 Electronic Transmission of Prescriptions

ETP in the UK is different in all four home nations, but all use the same premise of sending or providing an electronic version of the prescription to the pharmacy, either with or without a bar-coded printed prescription (See Chapter 8f - High Quality Medication Records &the Electronic Prescription Service).

New models of prescribing are also being introduced which are intended to improve the efficiency of repeated prescribing. The 'Electronic Repeat Dispensing' prescription model in England aims to provide the patient with a prescription, which may be dispensed over a period of up to 12 months, with dispensing instances handled by the pharmacist without a further prescription from the GP. The Electronic Chronic Medication Service (eCMS) in Scotland is similar, but includes a schedule of review messages and dispensing information for the prescriber. Use of these new prescribing services should be safer and more efficient for general practices, but to obtain the benefit all prescribers in the practice must be using the computer system.

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[227] http://www.dmd.nhs.uk/,

Figure 9.7.3.1 - What is required for paper-light prescribing?

Access rights	All prescribers must have logon rights to the prescribing functionality of the system and, for EPS, credentials to allow logon to NHS services.
Competence with prescribing functions	Prescribers must know how to access, search for and select items from the system's drug dictionary
Prescribing models	Prescribers must understand how and when to use the system's different prescribing models
Review prescribing history	Users must be able to view past and current medications
Know how to stop, cancel and delete items	To maintain an accurate, chronological record
Know how to 're-print' an item	Where printing fails for technical reasons, without creating a new prescription
Understand decision support warnings	These can be complicated and some training is required, users must know how to respond to them appropriately.
Printer problems	Some training in troubleshooting simple printer problems, such as re-loading paper or fixing jams.
All prescribing is computer based	All handwritten or amendments to computer prescriptions must be captured on the computer system
All staff aware	All staff must understand that all prescribing is now computer based.
Capture third part prescriptions	Decide a policy on capturing prescribing by other organisations, such as Out of Hours, to maintain a more complete prescribing record.
Record indications	A QOF requirement, practices must decide how they will identify an indication for Repeat Prescriptions
Drug Formulary	Who will maintain this, and how will users access it. Can they prescribe 'off formulary'?

9.7.4   Retrospective Data Capture and Clinical Summaries

Under the 2004 GP contract one of the quality measures is that clinical case notes are 'summarised', based in part on the advice of the GPC / RCGP document 'Good Medical Practice for General Practitioners (2008)'[228].

If your practice has no clinical summaries then this is a large volume of work that needs to be addressed. More commonly today, in light of the 2004 contract, practices have a substantial number of their records summarised, processes in place for updating these as new events occur, and for refreshing or creating summaries for new patients as they transfer in to the practice.

9.7.4.1 Decide what you want to code

Practices should consider coding only 'significant' conditions when doing retrospective data entry. What a 'significant condition' is will necessarily vary from practice to practice, as each summary is written primarily for local use to support decision-making and clinical care. Consideration should also be given to other purposes that a general practice summary may be used for. For example, the Summary Care Record in England uses items from the GP record for unscheduled care use, and the patient may also access summaries via HealthSpace[229].

SCIMP provides guidance on clinical summaries and a recommended code list for Read Version 2, 5 byte[230]. PRIMIS advice is also useful in this regard.

Items practices should consider recording include:

- The reasons for admissions to hospital – the presenting symptom or, if available, diagnosis
- All chronic diseases
- All significant infections
- All operations
- Fractures and other serious injuries
- Important primary care conditions such as back pain, depression, hypertension and skin conditions
- Immunisations
- Adverse reactions and intolerances.
- Pregnancies and births
- Significant investigations and their outcomes, such as CT scans and endoscopies
- Last blood pressure, smoking, alcohol, height, weight
- Cervical cytology
- Occupation.

9.7.4.2 How to summarise records

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[228] http://www.rcgp.org.uk/PDF/PDS_Good_Medical_Practice_for_GPs_July_2008.pdf

[229] HealthSpace https://www.healthspace.nhs.uk/visitor/default.aspx

[230] http://www.scimp.scot.nhs.uk/coding_readcodes.html

A practice can approach this by engaging a 'clinical coder', someone who has been trained to use the clinical system and the terminology it uses and is able to identify the items the practice wishes to include in its summaries.

Alternatively practices may elect to have medical staff complete the summaries, but again they must be familiar with the terminology and protocols in place. A GP should be available to lead on this process, and for a clinical coder to consult for queries. Audit of the summaries is important to ensure the standard required is being met.

Summaries are generally established by reviewing paper records for the patient, which may be the original NHS records including correspondence and results, or could be a printout from another practice.

If the practice has card based disease registers then the data from these can be transcribed to the computer system.

When there is an electronic prescribing record, running searches for drugs used in specific conditions can help identify patients who should have these conditions recorded.

Ensure that 'Event Dates' are used correctly when entering historical data. Consider using a Problem based recording for 'Active' and 'Inactive' conditions if your system supports this, or using a marker for importance of the condition such as 'High', 'Medium or 'Low'.

Estimate the time required for this process by averaging the time taken for a sample number of summaries, and multiplying by the number of records you need to summarise. This can assist in planning the number and type of personnel who need to be involved in the task.

Simply summarising a paper medical record does not mean that the original can be safely destroyed. This should only be considered after a document has been securely scanned to a robust document management system. (See also chapter 10 - Electronic Document Attachments).

9.7.5   Processes for Prospective Data Capture
This has two main facets: Coding of new clinical data received from third parties, such as hospital correspondence; and secondly, coding of consultations and encounters at the time.

9.7.5.1   Capturing data from correspondence
Practices must have in place processes for maintaining clinical summaries by capturing new or changed data received in correspondence from other agencies, such as hospitals. Clinicians may use a system of highlighting text on letters that can then be added by coding staff, or elect to do the coding themselves. With experience and training, clinical coding staff can identify relevant information from correspondence independently and enter this into the patient record without a clinician's prior review.

As a minimum, coding of significant morbidity and investigations from hospital correspondence is recommended, but letters frequently contain other data that can be usefully captured. Where this capture is automated via a document management system, practices must ensure that the process correctly identifies patients and accurately maps code translations.

9.7.5.2   Recording at consultations

Practices must have in place procedures to ensure every clinical patient contact is recorded. Data is commonly recorded during and immediately after the consultation. The cardinal rule is to write it up at the time, before moving onto the next encounter.

The content of the EPR should be *at least as complete* as the equivalent written record and must record the history as relayed by the patient, the nature and extent of examination, questions asked and responses (see also Chapter 6 section 6.3.1 - Coding, structuring and free text and Chapter 7 section 7.4.3 Codes or Text?)

Clinicians should be encouraged to add at least one clinical code per encounter. The clinical system will normally capture the Clinician, the Date and Time of the encounter and perhaps the Type of encounter, such as a Clinic or Routine appointment, thus providing some structure to the encounter record. It is dependent on the clinician to provide the clinical context and code relevant data.

In general the chosen clinical term should represent the main purpose of the consultation event. If there is more than one, then a clinical term should be added for each. This may be a presenting complaint, a diagnosis, procedure or administrative term. Users must understand the basic structure of the clinical terminology in use in order to make an appropriate choice, or the system must be explicit about the intended context for the clinical term. In general practice most encounters are managing chronic diseases, thus using symptom, examination or monitoring codes is often more appropriate than trying to enter a diagnosis.

Clinicians would normally then qualify any clinical term with narrative free text that places the coded information within the context of the patient's story.

This basic method has different implementations in different systems. For example, some systems will accept pure narrative without any additional coded terms, whilst others will try and identify code-able information from the free text narrative. Others mandate the selection of at least one clinical term before any free text can be added (See also Chapter 6 – High Quality Patient Records and Chapter 7 – Clinical Coding).

9.7.5.3   Contractual Requirements

The QOF requires that certain data items are captured and recorded to demonstrate the practice's achievements in clinical areas. Clinicians should record contract codes and values

as they capture them during consultations. Clinical systems provide templates and guidance to assist with this process.

9.7.5.4   Indirect Data Capture

It is always preferable to have anyone using the system and seeing patients add their own clinical record. On occasion, however, temporary staff or visiting clinical staff may not be in the practice for long enough to become competent and familiar with the practice processes. Practices need to consider how to handle these circumstances depending on their own requirements. Use of paper capture forms and subsequent manual transcription by staff may be the only viable solution in some instances, but practices should consider the safety issues of allowing staff not competent to examine the electronic record, to manage their patients. It is always preferable to supply a minimum training for data view and entry, even for unplanned visiting clinicians. The use of simple printed guidance, computer templates and protocols can help with this.

9.7.5.5   Data Linkage – Problem oriented records

Some systems allow clinicians to use a Problem Oriented approach to recording or viewing clinical data.

This is the provision of functionality to allow the creation of 'Problems' in the record, normally a label or clinical code for a condition that is then used as the header for all associated data. For example, a patient may have an 'Asthma' problem. The practice would record all encounters and data related to Asthma linked to the 'Asthma' problem, making it easier to filter and view the data together. Problems commonly have attributes of 'Active' or 'Inactive', implying whether a problem is current, resolved or in remission. This allows for a further structural level of 'episodes of care'. For example, 'Back Pain' as a problem may be active or inactive many times during a patient's life.

Problem orientation requires the practice to actively maintain the problem lists and associated data over time to maintain data quality and utility. Consequently while this may represent an additional overhead on data maintenance and training for the practice, it is likely to significantly improve the quality and utility of the patient records.

9.7.6   Diagnosis refinement and amendment and deletion

Practices need to be able to handle diagnostic amendments to ensure that patient records are accurate.

There is a difference between a diagnosis that is refined over time as it becomes clearer, and a diagnosis that is recorded inaccurately or subsequently found to be incorrect. They should be handled as follows;

- *Diagnostic improvement. In this case, a patient presents on several occasions and the diagnosis is refined over time. New morbidity codes would be added over time as the diagnosis 'emerged' but there would be no need to amend the initial diagnosis, as it was not factually incorrect.*
- *Amendment. There is no ethical difficulty with removing or correcting inaccurate or misleading information, or making a clear addition to incomplete information. It is important that records do not contain information, which may mislead another health professional using them. Indeed, the Data Protection Act 1998 gives patients a right to have inaccurate records amended. It is inadvisable to remove medically relevant information from patient records. It is important that notes provide a contemporaneous record of consultations and information gained about patients. Removing relevant medical information may give the impression that the notes have been tampered with, and may make later treatment and care decisions seem unsupported. It follows that doctors should take care to ensure that the records show all significant aspects of care, and clearly identify any decisions that were later found to have been inappropriate so that in the future carers do not misinterpret the patient's medical history.*

If there is dispute about the accuracy of information, for example that was recorded in the past by a previous GP, doctors should take reasonable steps to ascertain the accuracy of information in the records. If this is not possible, a note explaining the patients' views should be appended to the records. This allows health professionals using the records in the future to be wary of placing undue weight on disputed information.

Practices must be able to change or remove data in a medical record when appropriate to do so.

9.7.6.1 Data is incorrect
Where a record is known to be incorrect it should be deleted or changed. A record should be made of who changed it, why, what the original record was and when the change was made. Where data has been entered into the wrong patient's record, this data should be removed in line with the guidance above and should be copied to the correct patient's record. Care should be taken to protect the confidentiality of both patients by ensuring no identifiers are retained or transferred between the two records unless there are clear clinical reasons to do so.

9.7.6.2 Data is misleading, or has changed over time
In the course of managing a patient's care the diagnosis may change as more information becomes available. This may mean that an originally recorded diagnosis is now known to be wrong, and in this instance it should be changed or removed as above.

Expressing an 'opinion' is different from recording a 'diagnosis'. Opinions represent clinical formulations based on knowledge at the time, and are thus normally correct in context. They also inform management plans, and thus subsequent actions. In general where an opinion is subsequently found to be incorrect it should not be altered or removed if it was correct at the

time of recording. In electronic records one should distinguish between opinion and diagnosis based not just on the free text but on the Clinical Code or Term used for the record. An incorrect Code may be associated with free text that is opinion, for example:

E23..00 Alcohol dependence syndrome: "I suspect drinking to excess but denies it."

This is opinion but the effect of the Clinical Term used is to give the patient this diagnosis. Care should be taken to use appropriate codes when expressing opinions, for example symptom or examination codes rather than those for conditions. In the example above, assuming the patient did not have the condition, it would be appropriate to change the clinical code but retain the free text .

On occasion there may be differing clinical opinions regarding a diagnosis. Electronic records can handle this by qualification, attribution and linkage of data. That is: by adding free text explaining the difference of opinion; by ensuring the attributes of any diagnostic data make it clear who made the diagnosis and when, by expressing any appropriate qualifiers regarding certainty that may be available in the terminology; and by linking diagnosis to any associated clinical data (as occurs in a problem orientated record) so the diagnosis may be viewed in context. Where the patient disagrees with the diagnosis (or opinion) it would be appropriate to record this.

9.7.6.3   Requests for data to be removed or altered
This may occur where there is a dispute about the content of a record by a patient or third party. If the record is known to be incorrect, then it should be changed or deleted as above. Otherwise, changing or removing data from the record is not recommended as it will obfuscate the subsequent actions of health care workers who have since used the record.

Completely removing data from an electronic medical record is not possible for end users. All approved clinical information systems in the UK have an 'audit trail' which will record all changes to a record, saving the original data so that it may be used for medico-legal purposes if required. Where patients request removal of data from the record and this is agreed they must be made aware that the changes will be stored in the audit trail.

More guidance on these topics is available from the National Information Governance Board[231]

9.7.7   Consulting with Computers
Many clinicians find the change to working paper-light challenging. As well as the learning curve required to become familiar with the clinical information system, they also have to learn how to interact with the computer in the consulting room, in effect adding a new participant to their consultation (see also Chapter 12 – Education and Training).

9.7.7.1   Keyboard Skills

[231] NIGB http://www.nigb.nhs.uk/about/guidance/amendrecords

At present all GP clinical systems rely on keyboards and mice for navigation and input. Although voice control can be implemented for some systems, it is not immediately useful, requires training of the computer and the user and cannot replace the requirement for typing skills. Using voice for data entry or navigation may not be appropriate during a consultation.

Clinicians do need to learn keyboard skills to use computers. Methods of learning include internet-based or computer-assisted programmes, as well as specific face-to-face classes. Users should learn keyboard skills, not just typing, as being able to use the shortcuts and functions of a computer keyboard will aid their navigation and use of systems. Touch-typing is not a necessity, although can be an advantage.

9.7.7.2 How to sit

As the computer becomes more important to the clinical interaction, and the primary source of information about the patient, it is important that it is accessible to the clinician without requiring them to turn away from the patient. Placement of the computer monitor, keyboard, mouse and printer should take this into account.

Placing the patient-doctor-computer in a triangular formation is considered the most appropriate configuration – this is called 'triadic consulting'[232].
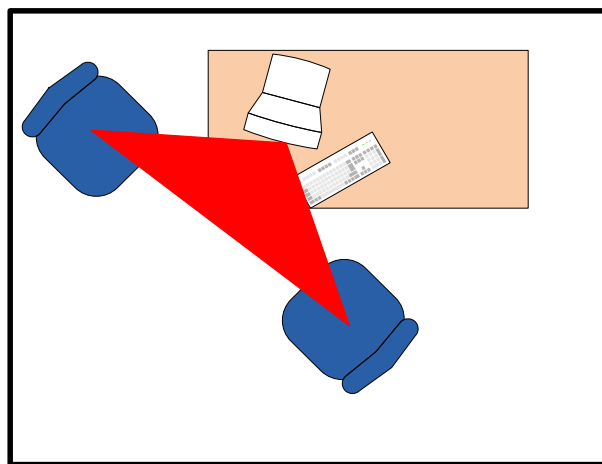
This allows the GP to refer to the screen without turning away from the patient, and also facilitates shared screens, where the computer display may be shown to the patient.

Care should also be taken to ensure the screen is not viewable by third parties attending with the patient, unless it is with the patient's consent. Similarly, care must be taken to ensure the record shown on the screen relates only to the patient and no others. For example, appointment books and reports from aggregated records may include names of other patients.

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[232] Information in the Consulting Room, final report 2002; Nick Booth, Judy Kohannejad, Paul Robinson; SCHIN, University of Newcastle

The configuration of some consulting rooms, the distribution of network access points and power points is not always conducive to this type of arrangement, but attempts should be made using extensions and replacement of access points to try and move towards this. Configurations where the computer monitor is behind the doctor should always be avoided.

9.7.7.3 Multi-tasking

In general it is not possible to try and talk to or examine a patient at the same time as trying to enter or even read data from the computer. Clinicians should keep their attention on the patient, or the computer but not both together.

9.7.7.4 Transfer Attention

Techniques to indicate to the patient that the clinician is now looking at the record are useful in managing the consultation.

- **Signposting** - The clinician says to the patient that they now need to look at the record. "I'll just have a look at your last blood pressure reading".
- **Informal chatter** - The clinician continues to chat to the patient to maintain rapport whilst referring to the record, but not about any specific clinical issue.
- **Re-direct attention** - If the patient is speaking, turning away from the computer and directing attention back to the patient to maintain rapport.

9.7.7.5 Shared Screens

It is useful to be able to share the information on the screen with the patient. This may be to confirm the information is correct, to reinforce a piece of advice or to provide explanations and advice. This is a learned skill, and not all clinicians are immediately comfortable with showing parts of the record to the patient. Providing specific 'patient friendly' displays of clinical data, such as blood pressures, can make this easier.

9.7.7.6 26 weeks to computers

A staged, iterative approach to educating clinicians on using their computers can be effective. No clinician should feel they must be able to do every task from the first day of using their computer system. Any learning and adapting of new skills requires time, and this must be accommodated into the working day.

For example, SCIMP publish a guide titled '26 weeks to Using Computers in the Consultation'[233]. This can be adapted to suit specific systems and clinician's needs.

9.7.8 Results

The management of the receipt of results in the paper-light practice has three main solutions:

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[233] http://www.scimp.scot.nhs.uk/documents/appendix%205.doc

- **Transcription with paper review** - Where clerical staff manually enter a subset of results to the computer record. This may only be for abnormal or significant results as identified by the clinical staff, or results required for contractual purposes. The paper result is filed to the paper notes and remains the definitive record used for processing purposes.
- **Scanning with transcription** - Where clerical staff manually enter a subset of results as above, but the paper result is scanned to the DMS and associated with the patient record. The scanned document is then the definitive record, and is used for processing via the DMS and clinical system.
- **Electronic Data Transfer or 'Pathology Links'** - Where the results data is received electronically by the practice's clinical information system and filed directly to the patient record using appropriate clinical terms and data areas. The clinical system will have results handling functions to manage clinical workflow.

The latter process is generally the preferred scenario. Transcription of results increases the risk of data entry errors. Provided the result used for processing is the original record, transcribing the results from paper can be a useful interim measure on the pathway to paper-light.

Pathology links can be enabled with the agreement of your system supplier, PCO and local laboratory service. Training should be provided for administrative and clinical staff and the practice needs to consider how to fit the new processes safely into the practice workflow.

Results from other tests such as spirometry and ECGs can sometimes be integrated into the clinical system directly via software that links the device making the measurement with the clinical information system. There is no standard solution, and each clinical system tends to provide integration with various third party suppliers.

Whatever the approach adopted, practices must have a robust system in place for taking appropriate action on incoming results and reports.

9.7.8.1   Test Ordering
In some parts of the UK it is now also possible to request tests from laboratories using an electronic service integrated with GP systems.

9.7.9   Document Management
An essential part of paper-light working requires the practice to utilise a Document Management System (DMS) to handle correspondence. This is often referred to as 'Document Scanning' and will consist of a document scanner and associated software, which stores the scanned images and allows them to be viewed on the computer monitor.

Once backed up, the original documents may then be shredded, within some safety and legal constraints, saving space and removing the need to file the paper into a patient record. There are two main types of document scanning: concurrent scanning, where documents are

scanned to the record as they arrive thus, over time, reducing the need to refer to archived paper correspondence in the paper notes; and archive scanning, or 'back scanning', where the paper notes are scanned to the DMS to make the full historical paper record available from the computer.

9.7.9.1   Preparing for Scanning

Commonly, scanning of incoming and outgoing correspondence is a stage undertaken after practices have moved to note-less recording. Practices must have in place methods for summarising notes and up to date summaries recorded on the clinical system. The practice should consult with their PCO and the system supplier to assess which DMS is available for them to employ.

The PCO and the DMS supplier will be able to assist with a site survey, and recommend a particular hardware and software implementation. Even small practices should consider having more than one scanning device to cope with technical faults in their main scanner. Larger practices may require several scanning locations and devices through their sites. DMS providers should also provide training in use of the software, and appropriate filing procedures.

Practices should ensure that all staff and clinicians who need access to documents and correspondence in the practice are provided with logon credentials for the system; are able to view, navigate and workflow documents; and are aware of the practice's new policies.

9.7.9.2   Document Workflow

'Workflow' in this context refers to the processing of incoming and outgoing correspondence. The movement of paper around practices is complex and widely varied as practices all work to systems suited to their own requirements. Moving to scanning documents will constrain some of this workflow within the functionality available from the DMS.

Practices should at least ensure that:

- Documents are uniquely filed against the patient to whom they apply
- All people who need to view and read a document can and will do so
- Documents can be marked as read
- Actions required from documents are achieved and confirmed. For example:
    - Appointments made
    - Results communicated to patients
    - Prescriptions provided or changed
    - Clinical codes and data is captured
- Exceptions are managed safely. For example:
    - Staff absence – planned and unplanned
    - Who will manage an absent users documents?
    - How will a user returning from absence manage a backlog of documents?

- How will documents that cannot be scanned be handled?
- A process for managing misfiled items.

Practices moving from a paper based mail management system to an electronic one must consider how they will workflow the documents. A DMS will provide workflow and routing functions. Practices should investigate these prior to accepting the deployment to ensure the functions provided will allow for a safe and workable system in their organisation.

The practice may have a social function associated with reading the mail, and this will perhaps change. Consideration should be given as to how informal communication between clinical staff can be maintained.

9.7.9.3 Scanning Processes

Normally the practice will train and engage clerical staff for this process. Clerical staff must be aware of the importance of filing documents accurately and chronologically, and complying with any folder structure. Staff must review scanned documents at the time to ensure they are legible and complete. Where a document has failed to scan, practices must have a policy for handling this.

Practices normally scan documents in Black and White or Greyscale. Where a document is in colour and the colour is important to its meaning staff should know how to change the default scanning process to create a colour scan.

Optical Character Recognition is a process whereby a scanned document image is analysed to extract the text. This text can then be used for other purposes, such as indexing and searching. This can be a useful function to employ, but has implications for storage and speed of processing.

9.7.9.4 Data recording

A method of capturing data from correspondence is required as simply scanning the document is not adequate from a data quality perspective; clinical codes and data should still be recorded from documents.

In general, a scanned document associated with a patient will be recorded in the DMS but should also be linked to the clinical system's patient record either directly by the systems or indirectly via a text description of the location of the file. An appropriate clinical term should be entered into the system to indicate that correspondence has been attached to the record.

9.7.9.5 Other practice documents and attachments

Practices may consider scanning other received mail to the DMS, for example guidelines and protocols, local service information and so forth.

Files other than scanned documents may be attached to the DMS. For example, clinical photographs, PDF files, word processed documents and web pages. (See Chapter 10 – Electronic Document Attachments, of these guidelines for more information).

9.7.9.6   Scanning Historical Records – "back-scanning"

This process has been undertaken by some practices that wish to have the entire historical primary care record stored on their DMS. This may be of value where the practice wishes to be able to archive the paper records, perhaps returning them to the Health Authority, thus freeing up space in the practice. It can help with paper-light working by removing the requirement to refer to the paper records for old correspondence. It may improve clinical safety, by making the records more accessible, and in some instances may be cheaper than establishing a paper records filing store.

Practices should examine the business advantages to this process against the financial cost. Various companies offer this process as a service, and practices should examine what is offered and consider if the methods used will increase the utility of the record. In general it is good practice to scan archived documents into the DMS using some type of filing structure, to distinguish between the various sections of the medical record. Scanning the entire record to a single, multipage image file may risk losing some of the inherent structure and utility of the paper notes and should be avoided (See also 9.7.5.1 above).

Comprehensive advice on scanning historical records is available from the SCIMP website[234].

9.7.9.7 Shredding

Paper-light practices employing scanning should establish safe processes for the subsequent destruction of the original documents (see also Chapter 10 – Electronic Document Attachments). In general this applies to documents attached to the record rather than the original record itself (e.g. Lloyd George envelope contents).

Documents can be shredded after they have been scanned, confirmed as legible, backed up, and that backup has been verified (confirmed local tape read-back). Practices should ideally employ a crosscut shredder, although there is no NHS required standard. In some areas PCOs provide a secure document destruction service, and commercial operators also exist.

9.7.10   Referrals and Discharges

9.7.10.1   Referrals

Moving referral systems to an electronic interface has become increasingly common in recent years with the advent of online referral services from the NHS such as Choose and Book in

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[234] http://www.scimp.scot.nhs.uk/documents/BackScanningSCIMP2009_Final.doc

England and SCI Gateway in Scotland, which is expected to be adapted for use in Wales and Northern Ireland.

These systems have been integrated with GP systems such that the referral process and correspondence this generates is captured into the patient record. Much of the content of the referral will be automatically generated by merging data from the patient's clinical record:
From Choose & Book guidance:

> *"The electronic referral letter will automatically be populated with Problems, Consultation, Medication, Allergies, Family History, Investigations, Values and Social information from the patient's record."*

The accuracy and relevance of the merged information will rely on the quality of the practice's summaries and merged referral data should always be checked by the author to ensure that the data is correct and appropriate. This may include the need to remove inappropriate sensitive patient information or other information the patient wishes to be withheld.
Other facilities may also be available such as the ability to attach external documents (see Chapter 9 – A Pathway to Good Paperless Practice), or to request information and guidance alone, short of a formal referral.

The referral is then sent electronically to the hospital and the appointment may be arranged directly by the GP Practice, organised by the medical records department or in some cases booked directly by the patient.

The increasing complexity of these systems makes it advisable for the GP practice to have at least one member of staff and clinician who is properly trained in their operation. It is particularly important that any workflow features of the system are safely integrated into the wider context of practice communications handling. For example, checking for unsent referrals, ensuring interim messages back from providers are actioned, and that the system is not disrupted during spells of absence by clinical or administrative staff.

9.7.10.2 Further guidance
Available from the following sources:

Choose and Book
- Chose and Book website[235]
- BMA website[236]

SCI-Gateway
- SCI website[237]

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[235] http://www.chooseandbook.nhs.uk/staff/training/materials

[236] http://www.bma.org.uk/ethics/health_records/connecting_for_health/Chooseandbookguide.jsp - book

[237] http://www.sci.scot.nhs.uk/products/gateway/user_guides.htm

9.7.10.3   Mail Merge

If a practice does not have access to an online referral service, the practice should still consider using their clinical system to generate referral letters. Clinical systems normally have the functions to generate mail merged letters and to save these linked to the patient record. In some situations it may be required to create paper letters and then scan these back into the DMS, although such workflows are usually transitional workarounds for practices en route to paper-light.

9.7.10.4   Discharges

Receipt of discharge details from hospitals electronically returned to practices is now available in a few locations. This can take the form of a document that contains 'metadata' about the discharge, allowing identification of the patient, the event and clinical data. It may allow direct import of the document into the DMS with appropriate attribution as well as provide mechanisms to file clinical data to the patient record.

9.7.11   Patient transfers

9.7.11.1   Transfers from the practice

When patients transfer out of the practice the practice needs to prepare the record for forwarding to the patient's next practice. In paper-light practices there are various methods for achieving this. The principle requirement is that the full medical record is transferred, thus the practice must ensure that the clinical record from the clinical information system and the document record from the document management system is sent (see Chapter 8b – GP2GP Electronic Record Transfer and Chapter 10 – Electronic Document Attachments).

Clinical information systems contain functions to allow reporting on the full medical record in a structured and readable way for sending. The practice should familiarise itself with these functions, and ensure staff responsible for registration management in the practice are able to use them. All clinical documents should also be printed from the document management system.

In some areas of the UK, GP2GP allows for electronic transmission of the patient's record in the clinical information system to the receiving practice when the patient registers at a new practice. This also allows for attachments to the record to be sent, with some constraints of numbers and file size. It will not necessarily send the documents from the DMS, and because of different methods of naming documents, it may not be immediately clear to the receiving system what the document is, requiring it to be re-filed. It may, therefore, be necessary to print the documents from the DMS and send as paper copies.

In Scotland the DMS in use (PCTI Docman), has a function to allow electronic document interchange between practices on transfer, thus a receiving practice will receive all the previous practice's documents for that patient with their original filing attributes. A process by

which the patient's clinical record is printed to a file, which is then attached to the Docman record, is used to provide a readable version of the clinical record with the Docman transfer (see Chapter 8 – GP2GP Electronic Record Transfer for more information).

A process for sending the records to the receiving practice using data downloaded to a CD is in use in some parts of England.(See Chapter 10 – Electronic Document Attachments of these guidelines.)

9.7.11.2   Transfers into the practice
Practices receiving only paper printouts or records for a new patient must decide how much of the information they wish to integrate to their electronic systems, and in what way. Processes will be in place to review paper records and ensure the medical history is summarised. A decision should be made on which parts of the record, if any, are scanned to the practice's document management system.

Practices are required to review incoming records from GP2GP transfers to validate the data, and to 're-shape' it to fit into the practice's clinical system. Practices may find that some data from the sending practice is converted to free text comments, this is the result of the data on the sending system having no similar container on the receiving system.

Critical to this process is validation and authorisation of medication records, and care should be taken to ensure safety and accuracy.

9.7.12   Remote Working
Practices have requirements to be able to work with patients or their records and practice data outside of the practice premises. This requirement arises through clinical staff visiting patients at home, carrying out 'ward rounds' in care homes, and taking administrative work home. With internet technologies and telephony the prospect of being able to conduct telephone or tele-health surgeries from locations other than the practice is becoming more realistic.

9.7.12.1   Asynchronous Remote Access
The use of portable computing devices (Pocket PCs, Laptops) in conjunction with specific software applications can allow a clinician to carry a version of the practice's electronic records with them outside the practice. Typically these devices carry only a subset of the data from the practice system, and will not provide the full functionality available in the main system. On return to the practice the device is then synchronised with the practice's clinical system.

In some instances it is possible to copy the practice data to a standalone computer, which can run the clinical application. As with all removable data, this requires strong encryption. In this scenario, the data is for 'read only' purposes, and any changes will not be written back to the practice's main data.

9.7.12.2   Synchronous Remote Access

In this scenario the clinician accesses the practice data live, remotely from another workstation external to the practice's local area network. Commercial companies do provide this service for the general public (e.g. 'logmein.com'), but the use of such services for the NHS is subject to approval from your PCO. Risks of using a non-accredited commercial company include potentially inadequate encryption and the location of servers, which may be outside of the UK. Such services normally require a computer in the practice remains switched on and is used for the remote worker.

The approved methods of obtaining access remotely to the practice system varies in different PCO areas, some provide an electronic 'token' to access the practice network through the national NHS network (N3) with a home computer, others require a specifically configured and purchased PC to be used. As the security risks are real and the configuration of remote access systems is complex, practices should not consider using a bespoke implementation for this task.

Accessing the practice data live and remotely from the patient's bedside remains experimental at present in all but a few cases, but the technology (such as high bandwidth connections using cellular telephony 3G) does exist to enable this. The use of wirelessly networked smart pens, combined with data entry forms, has been employed in some areas for specific care functions.

9.7.12.3   Printouts

Using reports from the clinical information system, clinicians should be able to carry a summary of patient data on paper for the purpose of home working or home visits. This is not always satisfactory as the data may be incomplete but is often a pragmatic solution when no electronic option is available. Care must be taken, of course, when carrying records outside of the practice.

9.7.12.4   Data downloads

Exporting patient data to a mobile storage device may provide another method of using the data remotely. Practices must check with their PCO with respect to the encryption requirements for this to be approved. No electronic patient data should be removed from the practice premises unless it has been securely encrypted.

9.8   System user groups

GP computer systems often have user groups, which can help and advise from other practice's experiences of using the system for paper-light working.

CSC SystmOne	http://www.tppusergroup.co.uk/
EMIS LV and PCS	http://www.emisnug.org.uk/
ACS Crosscare	No information
INPS Vision 3	http://www.nvug.org

iSoft Synergy and Premiere	http://www.isug.co.uk/
Microtest	No information

9.9   Accreditation of paperless practices

9.9.1 Introduction

In October 2000, the then NHS Executive changed GPs' terms of service to allow them to maintain part or all of their patient medical records on a computer system if they so wished. The change in regulations covers GPs working under both GMS and PMS contracts. Advice and guidance was issued to health authorities (working with their local medical committees) to develop mechanisms to allow the efficient discharge of their responsibility to approve requests to introduce electronic record keeping. With effect from 1st Oct 2002 and in accordance with Schedule 5 of the NHS Reform and Healthcare Professions Act 2002, this function was transferred to Primary Care Organisations.

9.9.2 National guidance

The changes to GPs' terms of service are permissive, allowing practices to keep computerised patient records instead of paper records. PCO approval is required when practices plan to keep computerised patient records in whole or in part. The legislation also applies to practices that were paperless before 1st October 2000.

Practices need to apply for paperless status when they propose to keep some or all of their records in electronic format only. Approval is permissive (practices maintaining EPRs can still maintain paper records if they so wish) but a practice may only maintain wholly electronic records if approved. Keeping duplicate paper and electronic records introduces the potential risk of the two record systems losing synchrony, information held on one not always being transferred to the other.

There are no mechanisms for penalising practices that are "paperless" but not approved although this would not be a wise position for a practice to find itself in. GPs who maintain EPRs must be able to generate a paper printout of the entire patient's records (including any scanned or linked documents) to be forwarded to their PCO on request.

Although the PCO cannot make any determination as to the content or adequacy of the record, it has an obvious duty to satisfy itself that any EPRs are being properly maintained and held securely.

GPs and PCOs should try to ensure that clinical systems are fit for purpose within the overall NHS strategic direction outlined in Chapter 1 of these Guidelines. That is to say, those systems that are approved under the GP Systems of Choice (GPSoC) framework[238].

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[238] GPSoC http://www.connectingforhealth.nhs.uk/systemsandservices/gpsupport/gpsoc

9.9.3   Implementation – PCOs and LMCs

Existing guidance to PCOs makes clear that "individual practices will decide how to implement electronic record keeping locally". PCOs have a key role in satisfying themselves that practices are ready to safely maintain EPRs, but there is no requirement for them to use any pre-determined process before giving consent. Indeed, PCOs are strongly advised to agree suitable processes locally with their LMCs. PCOs do not have any requirement to monitor ongoing standards of record keeping in practices but they can withdraw consent in exceptional circumstances. Once again, a procedure for dealing with this situation should be agreed between the PCO and the LMC. The PCO's main role is to approve appropriate applications and to ensure that practices receive the support they require to safely make the transition from paper to electronic records. Experience to date strongly supports the development of a joint approach to practice approval by PCOs and LMCs.

9.9.4   Generic schema for the approval process

The following generic scheme is continued from the last version of these guidelines and recommended for paperless practice approval

- The PCO (or its successor organisation) to implement, in consultation with their LMC, the mechanisms to provide written approval in response to requests to introduce or continue electronic record keeping in general practices
- The PCO to implement, in consultation with the LMC, the procedures that will operate should they wish to remove their approval to allow a GP(s) to maintain electronic records
- The PCO to identify a senior officer who will have responsibility for approving requests to maintain electronic records
- The practice makes a formal written request to the health authority to be paperless All the GP partners (PMS and GMS) should sign the first application. The lead IT partner should sign subsequent requests to maintain paperless accreditation
- The designated person at the health authority reviews the application
- Where there is no doubt as to the readiness of the practice to become or remain paperless, based upon the information known to the PCO, approval should be granted.
- This acceptance is then formally acknowledged by the practice that must also agree to inform the PCO of any future changes that could affect the approval
- Where the PCO has any doubt as to the readiness of the practice to be paperless, based upon the information about the practice known to them, they should consult the LMC
- If, after input from the LMC, there is no doubt as to the readiness of the practice to be paperless, approval should be granted as above
- If, after input from the LMC, doubt remains as to the readiness of the practice to become paperless, an accreditation visit should be arranged. The purpose of such a visit is to address any concerns the PCO may have
- If the LMC and PCO are satisfied, following the accreditation visit, approval should be granted as above

- If the LMC and PCO are not satisfied following the accreditation visit, the PCO should work with the practice to make any necessary changes to enable it to seek approval at a later date
- If at anytime after approval has been granted the PCO has reasonable concerns as to the practices' ability to maintain adequate EPRs, the PCO should notify the practice and the LMC immediately, that it is reviewing approval and provide details of any concerns to the practice and the LMC. The PCO should bear in mind that withdrawal of approval is appropriate only as an extreme course of action.

9.9.5 Implementation – practices

Practices need to understand that the decision to become (and remain) paperless must be supported by the whole practice team and that all clinical team members will require access to the practice clinical system and appropriate education and training.
Practices will need to carefully consider and plan for the transition from paper-based to electronic patient records as outlined in this chapter.

Practices should continue to provide the full patient record to their PCO as now, with the existing Lloyd George envelope and a printout of any electronic records that make up the totality of the patient record if requested to do so by the PCT. This requirement will be reviewed in the light of technical developments.

Chapter 10 - Electronic Document Attachments

10.1 Introduction

This chapter offers guidance on the principles of safe, consistent handling of attached electronic documents, common document formats, consistent document identification and the secure transfer of attachments between practices. Attached documents include letters, reports and other documents incorporated into the electronic patient record.

The advice and guidance given here will be discussed under the following headings:

- Attached electronic documents
- Format of attachments
- Storage of attachments
- Attachment identification and coding
- Transferring attachments
- E-referral attachments
- Other documents

10.2 Attached electronic documents

A normal requirement in GP clinical record systems is to be able to attach an external electronic clinical document to an individual patient record. A wide range of attached document types and technical formats may be encountered and the handling of attachments varies somewhat between GP clinical systems.

'Document attachments' should be distinguished from GP2GP messages, lab results, and other structured 'clinical messages', which contain coded and other computer processable information, and whose contents can be directly imported into the patient record. 'Clinical messages' are discussed in Chapter 8 - Data transfer and inter-operability.

Some clinical communications such as hospital discharge letters, which are currently delivered to practices as word processed documents, and handled as attachments, may in the near future be delivered as structured, processable clinical messages. GP system suppliers would normally adapt their systems to facilitate the appropriate handling process, advising practices of any need to change procedures.

Common examples of attached documents include:

- Clinical photographs e.g. skin lesions / retinal scans
- Scanned images from paper
- Images from diagnostic equipment
- ECG, Ultrasound scanners
- Clinical communications (e.g. discharge letters, outpatient clinic letters)
- Word-processed Documents, Email
- External hyperlinks – where the document is not stored locally
- Numeric results e.g. PEFR reports.

10.2.1 Legal status

Any attachment to an electronic clinical record should be regarded as having equal medico-legal weight as a note made within the system and should be accorded the same stringencies around audit trail and backup (see Chapter 4 - Records Governance). It should also be possible to extract these attachments and send them to the requesting practice either electronically or as a printout.

Before making use of attachment facilities, a practice should satisfy itself that the system does meet these requirements. Wherever possible all attached data should be stored on the clinical server and not on a separate server. If a separate server is used to store attached data, the practice must ensure adequate and appropriate backup provision to ensure seamless continuity should failure occur on either the clinical or attachment server.

10.3 Format of attachments

Potentially a very wide range of document types and formats may be received or used. Although almost any type of file is viewable with the correct software, when scanning, practices should generally adhere to a smaller subset of standard document types as suggested in Table 10.3.1. This avoids the difficulty of viewing unusual or proprietary formats if the appropriate software becomes unavailable, particularly where the records are transferred to another practice.

Key principles of attachment handling include:

- Following attachment, any changes made to an editable document must be logged in the clinical system's audit trail.
- Care must be taken that the document can be faithfully viewed after attachment, particularly when documents are scanned. Unusual or proprietary formats should be avoided when scanning.
- Where a document with an unusual format is delivered to the practice, the practice must ensure that appropriate viewing software is available and that the type of software required is documented within the patient record.

- Picture, image files and especially video files can take up considerable storage space which should be considered when deciding if some types of attachment should be stored in the patient record.
- Some formats, particularly JPEG, may result in the loss of image detail and should be avoided where the image needs to be of diagnostic quality. This may become a particular issue if the image is opened and re-saved repeatedly.
- When paper documents are scanned, practices should take care to make and save a close copy of the original document, retaining colour information where it is important to do so (e.g. highlighted information in a letter). Some image formats such as JPEG, compress the data, losing some image quality in the process, so that the scanned image may not be an adequate copy. Image formats such as TIFF and PNG, which do not 'lose information' in this way are generally preferable for scanned images.
- When scanning a multi-page document, which it is important to maintain as a single entity for medico-legal purposes, the TIFF format is generally preferred. TIFF can store a number of images/pages in a single file whereas JPEG, in its standard form, can only store a single image per file and, therefore, a multi-page document stored in JPEG format will consist of a number of separate files.
- Optical Character Recognition (OCR), which attempts to convert images of type-written text to word-processable formats, is becoming increasingly accurate, sometimes allowing additional semi-automatic processing of document headers. However the accuracy of OCR remains variable and results of the conversion should be checked carefully. Safest practice is always to retain an accurate scanned copy of the original document.
- It is possible to password protect some documents, such that the document cannot be viewed without the password. Whilst this may seem an attractive means of adding a layer of privacy to particularly sensitive documents, in practice it can be very difficult to ensure that knowledge of the password can be transferred safely and correctly between practitioners. This can result in documents being 'locked' if the password has become lost through changes of staff personnel or transfer to another practice. In general the use of per-document passwords should be discouraged and other means should be identified for protecting sensitive attachments. Use of native GP system or document management system security and privacy facilities may be helpful, though this may itself cause problems when transferring records to another practice, and ultimately the simplest solution may be to retain highly sensitive documents in a traditional paper 'sealed envelope'.
- When making referrals in England through Choose and Book, PDF file format for all written text is recommended, where practically possible.

Table 10.3.1

Attachment	File formats	Notes
Word-processed documents	Microsoft Word 97 -2010 (DOC, DOCX)	These are editable documents -any changes made after attachment must be represented in the clinical system's audit trail.
	Open Office (ODT)	Less common alternatives to the MS Word formats. Audit trail comments as above

Attachment	File formats	Notes
	Adobe Acrobat 4 or higher (PDF)	Audit trail comments as above. Use of the ability to lock the document, control comments and printing should be considered.
	Rich Text Format Version 1.5 and above (RTF)	Audit trail comments as above. For compatibility with non-Microsoft viewers images and graphics should not be embedded. Complex layouts may also not be retained
Clinical Photography	Tag Image File Format v6 (TIFF) http://partners.adobe.com/public/developer/tiff/index.html	This is an old but well tested and legally admissible file format that will handle colour and black and white images. It is difficult to edit but still must be covered by the audit trail of the clinical system. Care should be taken if the TIFF file is compressed as not all viewers will handle compression. Audit trail comments as above
	Joint Photographic Experts Group (JPEG, JPG)	A popular standard supported by the web. The format specifies compression and a loss of original data quality. It works well with natural pictures and less well with line drawings Audit trail comments as above
	Portable Network Graphics (PNG) http://www.w3.org/TR/PNG/	A relatively new standard supported by the web. The format specifies a compression method but which avoids a loss of original data quality
Scanned Images	Tag Image File Format v6(TIFF), PNG or JPEG Resolution of 150x150dpi is suitable for document archiving but not for diagnostic images.	For documents for which monochrome representation is sufficient, use TIFF with compression scheme 4 (COMPRESSION_CCITTFAX4) at a minimum resolution of 150x150dpi. For documents that need to be rendered with the original colour information, JPEG is recommended with a minimum resolution of 150x150dpi and a compression quality >=50% Audit trail comments as above. Data loss comments due to compression as above.
Images from diagnostic equipment	Proprietary	Wherever possible proprietary formats should be avoided for reasons of future legibility. Where this is not possible, clear directions and reasons for recording in this way should be retained along with a CD containing the viewing

Attachment	File formats	Notes
		software.
	JPEG, PNG, TIFF	Still image – As above for clinical photography
	High Quality Diagnostic images	Most modern X-ray and Ultrasound devices will produce high diagnostic quality (still or moving) images. They are generally out of the scope of this document but potential users in General Practice should satisfy themselves that the system's storage conforms to the clinical system's audit trail requirements as well as published standards such as DICOM (http://medical.nema.org)
	AVI, QuickTime, MPEG2, MP4	Moving images These are all popular methods of delivering moving information. Both may involve significant compression and data loss and should be used for thumbnail and aide-memoire purposes. They should not be generally used for diagnostic purposes.
Email	Plain text	Preferred over HTML
	HTML	Should not include external references, hyperlinks, backgrounds or fonts which may not be available on other systems
External hyperlinks	http://<resource URL> ftp://<resource URL>	The resource should be available to all potential users of the clinical record and should not link to resources only available at the practice. Commitment to the continued maintenance and backup of these resources must be assured.

10.4 Storage of attachments

GP systems store attached documents in a variety of ways, and generally provide guidance and user training material on best practise for storing attachments. These instructions should be understood and carefully complied with by practice staff.

In some cases, attachments are simply saved to a specific area on the practice network; in others the attachments are stored directly within the patient record database. A 'document

management package' may be used along with either of the previous options, generally adding more sophisticated handling or 'workflow', of incoming documents, along with detailed document categorisation and labelling facilities. Most Scottish practices now use the NHS Scotland approved 'Docman' package.

Whatever combination of approaches is employed, the practice must ensure that the attachments are treated exactly as other patient records, are backed up securely, are available for transfer to another practice, and are accessible to patients under terms of the Data Protection Act.

10.5 Attachment identification and coding

When attaching a clinical document, it is important to name or categorise the document within the local GP system so that its source and clinical significance is readily apparent when the patient record is subsequently viewed, without needing to open the document itself. The attachment should also be correctly attributed and coded to facilitate querying.

10.5.1 Attribution
As with any clinical record it is vital that the attribution of the attachment is captured so that date, time and where appropriate clinician or operator are available as well as the date and time and operator making the attachment.

10.5.2 Codingof numerical contents
Where a document includes significant numeric data and several values are derived together (Lung Function testing may derive Peak Flow, FEV1, FVC etc.), each value should be stored against an appropriately coded entry to facilitate system functionality and subsequent retrieval.

10.5.3 Attachment identification
If an attachment needs to be subsequently identified or 'labelled' within a patient record, a meaningful description such as **'Discharge letter Cardiology Western Infirmary Anytown'** is clearly more informative to the viewing clinician than a bland label such as **'File Attachment'**, and which would require the document to be opened to ascertain its contents.
Work is progressing at UK level to define standard ways of labelling clinical documents across a wide range of care settings, but at present no such standard has been agreed, other than for Scottish GP practices, which store attached documents within a common set of 'Docman' folders, primarily based on speciality type[239]:

A UK-wide clinical document identification standard is likely to include the following elements which offer a minimal but effective way of communicating the contents of a clinical document (see table 10.5.3)

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[239] http://www.scimp.scot.nhs.uk/.../Procedures%20%20DocMan%20Document%20Folders%20v2.3.doc.

Table 10.5.3

Label element	Examples
Document type	"Clinic letter", "Discharge document"
Speciality	"Occupational therapy", "General medicine"

This approach, coupled with the use of standard lists of document types and speciality names may, in time, lead to the majority of NHS clinical documents being labelled 'at source', substantially reducing the need to do so within GP practices or any other document recipient.

The method of applying a label or category to the attached document will depend on the GP system used and whether a document management package or other formal categorisation facility is available. Use of such formal categorisation is the recommended approach, wherever possible. Most document management packages allow attached documents to be categorised in a variety of ways, which it would normally be possible to adapt to use the recommended Document type and Speciality categories.

Where formal document categorisation facilities are not available, it may be helpful to use the suggested elements to construct a single label or description for the attachment

e.g. "***Discharge document General Medicine***"

If the system does not allow a description to be recorded for an attachment, it may be helpful to construct the saved file name in a similar fashion.

e.g. ***"Discharge document General Medicine.doc"***

When creating file names, it is generally best to avoid using any punctuation marks other than the dot character, as these may not be uniformly acceptable across all computer operating systems.

Choose and Book referral attachment names

Choose and Book guidance suggests naming attachments with recognisable filenames such as:

Surname, forename, date of birth e.g. *smithjohn23061966* as a basis for ensuring files are easily recognisable and associated with specific patient records.

10.6 Transferring attachments

A common issue arises when patients leave a practice and their records are required to be transferred to the new practice or other agency.

10.6.1 Legal issues

When a patient moves to a different practice, it is legally incumbent upon the original practice to respond to a request to transfer the patient's whole medical record. The legal requirement is that either party may insist on the records being transferred as paper printouts, and of course, in many practices, significant parts of the clinical record will still be available only in paper format. However, when some or all of the clinical record is held in electronic form, the use of some means of electronic transfer of the record is much less time-consuming for both practices, particularly for attached documents which otherwise have to be printed out by the original practice, then re-scanned by the recipient practice (see Chapter 9 - A Pathway to Good Paperless Practice).

10.6.2 Modes of transfer

Within the UK four nations, there are currently significant differences in approaches to the electronic transfer of GP clinical records, including the transfer of attached documents:

10.6.2.1 NHS England

10.6.2.1.1   GP2GP records transfer

Where available, the NHS Connecting for Health GP2GP project offers the most safe and practical means of effecting electronic transfer of records between practices. It incorporates the transfer of electronic attachments (with the limitation of a maximum of 100 attachments and a 5MB limit per patient record), generating an attachment file-manifest, which associates attachments with a patient record irrespective of the filename. (See Chapter 8b – GP2GP Electronic Record Transfer, for guidance on GP2GP record transfers).

10.6.2.1.2   CD-ROM based attachment transfer

Although GP2GP rollout continues to progress in England (and is the professionally preferred method of electronic record exchange) it is not yet available for all GP systems. As an interim step, an alternative means of transferring attached documents via CD-ROM disc has been developed by an IM&T Committee consisting of members of the Beds and Herts. Local Medical Committee, GPs, practice staff and PCT staff, working in cooperation with several GP system suppliers.

Detailed guidance on operating this CD-based transfer, including advice from individual GP system suppliers, is available from the project website[240].

The protocol has been operating successfully in a number of PCTs, to the benefit of both sending and receiving practices but the following principles and caveats should be noted;

- Formal permission should be sought from the Sending practice's PCO to allow CD-based transfer.

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[240] http://www.starpace.co.uk/page.asp?pageID=97

- The process should not be carried out until administrative staff have received training in the necessary procedures, as documented at the project website, both to create the outgoing CD and to import attachments from the received CD.
- The procedures advised by the appropriate GP system supplier should be closely followed to prevent potential loss of information in the transfer process.
- The recipient practice retains the right to receive the record and attachments in paper format if they so desire, but must request this from the sending practice in a timely fashion.
- Only non-rewriteable CD-based transfers are acceptable. Other media such as DVD, floppy discs and USB memory sticks have significant risks and drawbacks in comparison.
- After importing and checking the data, the CD received must be shredded or destroyed by cutting – the project website gives further instructions.

10.6.2.1.3   CD encryption issues

Department of Health information governance guidance suggests that where clinical documents are electronically transferred outside the practice, patient privacy should be protected by the use of encryption and passwords, in case of inadvertent loss or interception of the document in transit.

> *"David Nicholson, NHS Chief Executive, has directed that there should be no transfers of unencrypted person identifiable data held in electronic format across the NHS. This is the default position to ensure that patient and staff personal data are protected. Any data stored on a PC or other removable device in a non secure area or on a portable device such as a laptop, PDA or mobile phone should also be encrypted. This is also now a requirement across all public sector organisations set by the Cabinet Secretary.*
>
> *It is recognised however that this may take some time to achieve in the NHS where patient care is our highest priority. NHS bodies will need to make a local judgement on the balance of risk to patient care against risk to personal data security in determining whether use of unencrypted devices should continue as an interim measure. Where it is felt that continued reliance upon unencrypted data is necessary for the benefit of patients, the outcome of the risk assessment must be reported to the organisation's Board, so that the Board is appropriately accountable for the decision to accept data vulnerability or to curtail working practices in the interests of data security."*[241]

This is one rationale for the use of approved NHS mail and messaging facilities such as the Spine and SCI-Gateway, which provide such security automatically for emailed attachments and clinical messages such as electronic referrals and GP2GP record transfers.

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[241] http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/security/encryptionguide.pdf

To comply fully with the DH directive, a CD used for attached document transfer should be encrypted, but this considerably complicates the transfer process, requiring agreement on the encryption method, availability of the appropriate encryption/decryption software in both practices and communication of the associated password in a secure and timely fashion. If not handled correctly, it may also interfere with patient rights to access records under the Data Protection Act.

In view of such added complexity, the Beds and Herts. CD transfer project team judged that within this very specific context, encryption adds little to patient privacy protection, given that the CD-ROM is physically transferred via a secure courier service alongside a set of unencrypted paper printouts of other aspects of the clinical record.

Whilst generally acceptable to participating practices, PCOs and suppliers, this advice has not been formally endorsed by practitioner representative bodies, NHS, or medical defence advisers. It remains likely that in due course formal guidance will be introduced, jointly with the Department of Health, on standard methods of encryption of CD-based document transfers and associated operating procedures.

Until such time, where encryption is not used, practices should make an individual assessment of the risk of a privacy breach and agree the approach with their PCO.
Full Department of Health Information Security Guidance may be found on their website[242]

10.6.2.2 NHS Scotland

10.6.2.2.1 Docman Transfer
Almost all Scottish GP practices now use the 'Docman' document management package and associated standardised folder structure. The NHS Scotland Practitioner Services 'Docman Transfer' facility allows the automated transfer of attached documents between practices without the need for the documents to be re-filed in the recipient practice. In addition, an export of the entire GP system patient record to an electronic document may be made, imported to Docman and transferred electronically with the other attachments.

At publication, the 'Docman Transfer' facility was available to 95% of Scottish practices and for these practices represents the simplest and safest approach to attached document transfer. Details of the 'Docman Transfer' process are available online[243]

10.6.2.2.2 CD-ROM based attachment transfer
The use of compact discs (CDs) to exchange attachments or other electronic records is not currently formally supported by the NHS in Scotland. Any such arrangement would be strongly discouraged where 'Docman Transfer' is available but if necessary it should be agreed on a

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[242]http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_074141.pdf

[243] http://www.psd.scot.nhs.uk/professionals/medical/DocmanTransfer.html

per-case basis between sending and receiving practices. The protocol used within NHS England for CD-ROM attachment transfer (see above) may be regarded as a robust model on which to base any local arrangement.

10.6.2.2.3   GP2GP records transfer

NHS Scotland is examining the possibility of making GP2GP records transfer available. In these circumstances, GP2GP is likely to offer the most safe and effective means of electronic transfer of records, including attached documents.

10.6.2.3 NHS Wales

10.6.2.3.1   GP2GP records transfer

NHS Wales has indicated that GP2GP records transfer will be made available led by the NHS Wales Informatics Service (GMS IM&T Programme). When it becomes available, it will offer, to Welsh practices, the most safe and practical means of effecting electronic transfer of records (including attached documents).

10.6.2.3.2   CD-ROM based attachment transfer

The use of compact discs (CDs) to exchange attachments or other electronic records is not currently formally supported by the NHS Wales. Any CD based transfer would have to be agreed on a per-case basis between sending and receiving practices and seeking prior clearance from a PCO. CDs must be encrypted and transferred via the all Wales secure courier service. The protocol used within NHS England for CD-ROM attachment transfer (see above) could be adapted to provide a robust model on which to base any local arrangement.

10.6.2.4 HSC N. Ireland

10.6.2.4.1   GP2GP records transfer

At the time of writing (December 2010) we have no information on GP2GP records transfer in Northern Ireland.

10.6.2.4.2   CD-ROM based attachment transfer

The use of compact discs (CDs) to exchange attachments or other electronic records is not currently formally supported by the Health and Social Care organisations in Northern Ireland. Any CD based transfer would have to be agreed on a per-case basis by the Health and Social Care organisations and between sending and receiving practices. The protocol used within NHS England for CD-ROM attachment transfer (see above) may be regarded as a robust model on which to base any local arrangement.

10.7   e-referral attachments

Chapter 9 - A Pathway to Good Paperless Practice, outlines the use of e-Referral systems (section 9.7.10). Both of the main e-referral packages in use, Choose and Book (England) and

SCI Gateway (Scotland), allow the upload of attachments along with the referral e.g. a scanned document or clinical image. Most of the common file formats listed in Table 10.3.1 are supported but there may be some minor limitations along with restrictions on numbers of attachments and attachment size per referral. These limitations are unlikely to be significant in usual practice and relevant system documentation should be consulted for specific guidance.

10.7.1 Choose and Book attachment limitations

It is not possible to add notes or letters from a GP system directly into a Choose and Book 'Advice and Guidance' request. Instead you should copy and paste from a practice system into the body of the advice request or save the additional information in a document outside of the practice system and then add it as an attachment.

10.8 Other documents

Practices maintain many different forms and documents about patients that are essential to their day-to-day operations. Some of these do not form part of the patients' records but carry information about patients, carers and others. Below, we give some examples of these documents and advice about their retention and disposal;

- Notification of infectious disease – no need to retain counterfoil providing there is an appropriate entry in the relevant EPR. In NHS Scotland, notifications are performed electronically via SCI Gateway.
- Message books/logs – ensure any action taken (e.g. phone call/consultation/visit) is recorded in the EPR. It is advisable to retain written message books/logs in line with general medico-legal guidance.
- Ambulance request logs – ensure any action taken is recorded (as above)
- X-ray films. These should be retained in line with the Department of Health guidance.

Most of the above are "process" forms but may be important medico-legally. If practices are in any doubt about retaining a document we recommend that they scan and store an image of the document in an appropriate format (see Table 10.3.1) and then shred the original document. However, where any records relate to patients where there are known medico-legal issues (complaints, civil or criminal law) then practices should keep all relevant records pending further advice from their medical defence organisation, PCO or LMC.

Chapter 11 - Working in an e-business environment

11.1 Introduction

General practices do not work in isolation from the rest of the world, and the business culture in the UK and internationally is becoming increasingly dependent on the internet and internet technologies. This chapter will discuss where the business of General Practice fits in the broader electronic world and how the use of computerised and internet based tools and services can enhance patient care and improve efficiency.

We will include advice on;

- NHS Internet connectivity and NHS Net based services
- Practice web-sites and internet accessible practice services for patients
- Non-practice internet services for patients e.g. patient owned records
- Online services for clinicians; peer support, reference and education
- Supporting the management of the practice with computers
- Remote working and communicating with patients electronically
- Maintaining and improving internal practice communications
- Guidance on assessing the validity and quality of health information from the internet
- Protecting your privacy and security online

11.2 Working in an e-business environment

11.2.1 Wired World

When an earlier version of the Good Practice Guidelines was published in 2003, only 47% of UK households had access to the internet. In 2009 this figure was 70%. Today broadband connections account for over 95% of all domestic connections, compared to only 11% in 2003. High bandwidth connectivity to NHS services via N3 is now ubiquitous in general practice in England and Scotland, and Wales and Northern Ireland have similar high bandwidth private networks.

In 2009, analysis over a three month period showed that 76% of the UK population accessed the internet with 73% using it every day. Whilst communication in the form of email or social

networking use comprised the majority of accesses, 42% used the internet for health information purposes[244].

General practice information systems and the users of these systems do not sit in isolation from the changes that the information technologies are making at every level of our society. In this chapter we discuss managing your practice, its records and electronic systems in the wider world of an online society.

11.3 NHS connectivity

11.3.1 The NHS National Network (N3)

The NHS National Network (N3) is a broadband, virtual private network serving around 1.3 million users in the NHS in England and Scotland[245]. This network is contracted for by the NHS and for General Practices the connection is provided at no cost.

Access to N3 from the internet is controlled via a 'gateway' that allows users on N3 to access the internet and, with appropriate controls, may allow a user on an external network such as the internet to access N3 services. Gateways are also provided between NHS networks in Wales and Northern Ireland.

To receive an N3 service, practices must comply with the "Information Governance Statement of Compliance"[246].

This is a set of rules and guidance around security of and appropriate use of the N3 network.

N3 is used to support NHS online services such as Choose and Book, the Electronic Prescription Service (EPS), NHS Mail and the NHS 'Spine' in England. In addition, N3 can be used to support other network dependent services such as telemedicine and voice communicating over the internet (VOIP).

In Wales, Informing Health Care[247] has provided the Public Sector Broadband Aggregation Network (PSBA Network), which provides a single communications network for health, education, local government and other local services.

11.3.2 The NHS 'Spine'

This is a core part of the national NHS IT infrastructure to support the NHS in England. While commonly referred to as the 'Spine' it may also be usefully thought of as a set of national services that underpin other NHS electronic functions. The Spine provides, for example, the

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[244] Office for National Statistics, Internet Connectivity December 2008
http://www.statistics.gov.uk/pdfdir/intc0209.pdf

[245] http://www.n3.nhs.uk/

[246] http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/igsoc/general/

[247] http://wales.nhs.uk/ihc/

Patient Demographics Service (PDS), which is used as a source of patient demographic information such as name, address, date of birth. To access other NHS services such as Choose and Book, practices in England must use PDS details either directly or via a synchronisation process with local systems.

The Spine also provides directory services – lists of NHS organisations – and, at a more technical level, services for managing messaging transactions between NHS organisations for purposes such as GP2GP and EPS.

11.3.2.1 Smart Cards
NHS England access to Spine services requires a role based logon supported by a Smartcard and a user pass code or PIN. This identifies the user to the Spine as having particular roles which, in turn, determines the level of access to functions and data that the user is allowed.

11.3.2.2 Choose and Book
Choose and Book is an online service in England that enables practices to refer patients to specialist care and book them an appointment from the GP surgery.

11.3.2.3 Electronic Prescription Service
The Electronic Prescription Service in England is supported by the Spine, which acts as the message broker for the exchange of electronic prescription messages, and uses the directory service to identify community pharmacies eligible for the service.

11.3.3 Scottish Care Information (SCI)
SCI[248] provides two main services for practices in Scotland – SCI Store and SCI Gateway.

11.3.3.1 SCI Store
SCI Store is an information repository primarily used for pathology results and radiology. Clinicians are able to log on to this service via a N3 connected web browser and view results for patients with whom their organisation has had a care relationship.

Interfaces with SCI store are used to provide laboratory messaging into GP systems in Scotland. However, where agreed locally (e.g. Grampian region) laboratory reports are sent by structured (EDIFACT) message using a bounded set of Read-codes, so the results may be filed directly into the patient's EPR (as for EDI in England, see Chapter 8d - Clinical Messaging).

11.3.3.2 SCI Gateway
SCI Gateway is an implementation of an electronic referrals service although on-line booking of the appointment is not routinely available. It provides directories, referral forms and protocols for local NHS services and, via integration with primary care information systems, allows merged data from the GP record to be used in generating the referral letter.

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[248] http://www.sci.scot.nhs.uk/

Implementations may also allow for the generated referral letter to be stored as an attachment to the patient's GP record.

SCI Gateway technology is also being adopted in Wales and Northern Ireland.

11.3.4   NHS Mail

NHS Mail[249] is a secure email and directory service for NHS users in England and Scotland. This has been approved for sending confidential patient information, but users should be aware that confidentiality is only maintained when sending emails between two 'nhs.net' addresses.

NHS Mail also provides NHS Directory services using a standard protocol (LDAP) compliant with most email clients. NHS Mail works with a variety of clients and platforms, including most mobile devices.

11.4   Practice websites and on-line services

11.4.1   Websites

Although there is no contractual obligation for practices to provide a website many practices use a website to inform patients and others about practice services.

Methods of creating a website for your practice range from 'do it yourself', which requires some technical competencies, to contracting with a specialist website company for a bespoke site. There are companies that specialise in providing GP websites, many of which use a design template with common content structure for all practices, such as 'Practice Team' and 'Opening Hours' that can be customised to meet individual customer's needs.

Practices should consider which information they wish the website to provide; what the web-site address or 'domain' will be and how to protect their domain names; how to maintain and update the site; whether the site will contain advertising and if so, how this will be regulated.

Maintenance of content should be possible in-house unless you can guarantee the responsiveness of your website provider to update changes. Normally this will require at least one member of staff trained in using the website content management system.

Websites have become increasingly interactive and practices may wish to think about how the site can be more than a simple information repository. For example, provision of an electronic subscription to a practice newsletter or by allowing email inquiries to the practice manager.

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[249] http://www.connectingforhealth.nhs.uk/systemsandservices/nhsmail/

11.4.1.1   Registering a domain

Whilst it may be possible to use the inclusive web space often provided with domestic internet accounts or perhaps a free web hosting service for this purpose, practices should consider registering an internet domain name for their practice and contracting with a commercial provider for website hosting. This should provide better reliability, safer backups and makes it easier to transfer the domain hosting in the future if required.

When registering a domain name it is useful to register as many variations on the practice name as possible: consider abbreviated forms of the practice name, as well as more than one domain suffix. Practices should register the '.nhs' domain. To register a domain with the '.nhs' suffix refer to the NHS web registration website[250].

Registering a domain name with commercial companies is relatively easy and can be achieved using one of many providers, most of which also provide hosting.

If allowing a website design company to register domains for you, make sure ownership of the domain rests with the practice, and not the design company.

Some PCOs provide practice template websites hosted from their own websites. Ask your PCO if they provide this service.

11.4.1.2   Requirements for a General Practice website;

- **Accessible** - For users with partial sight or other disability, try to ensure the site is accessible. The Royal National Institute for the Blind (RNIB) has useful guidance on this subject[251].
- **Accurate** - Ensure the information provided is correct and up to date
- **Cross Platform** - Ensure the site works across all commonly used web browsers and also consider how the site will look to users using mobile devices such as smart phones.
- **Privacy Statement** - With respect to what data, if any, your practice will use from visitor statistics, and especially if any interactive services are provided
- **Contact Details** - Ensure a contact email, phone number and postal address is provided for queries concerning the website.
- **Not exclusive** - Information provided on-line should reasonably be able to be provided in another format for users without internet connections. Similarly, the delivery of contractual services to patients should never be exclusively provided via an online service.
- **Appropriate external links** - Links to external sites should be tested and considered appropriate by the practice, including any advertising. Practices may include a disclaimer to indicate the extent of their liability if referring patients to external sites.

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[250] http://www.connectingforhealth.nhs.uk/systemsandservices/addressing/webregistration

[251] http://www.rnib.org.uk/professionals/webaccessibility/

11.4.1.3   Online Appointments

Some GP system suppliers provide online booking services to practice appointment systems. This is most commonly achieved via a web interface linked to the practice's own website. Methods of implementation include practices reserving some appointments for web booking, or live booking of appointments in real time using the practice appointments software. Automated telephone booking of appointments is also provided by some companies.

11.4.1.4   Online Prescriptions

Repeat prescription ordering services can also be implemented using a practice website. Again, there are a variety of methods of implementation ranging from simple DIY services using email or 'form to email', to services integrated with the GP clinical systems.

11.4.1.5   Access to records (See also Chapter 5 – Shared Electronic Patient Records)

Some services provide for patients to access all or part of their GP record online. This is a complex area, and requires careful implementation by the practice with respect to data quality, consent, security controls and workflow safety.

11.4.1.6   Patient Confidentiality

Practices must be careful to ensure that online access to services for patients meets requirements for consent and confidentiality. Patients need to be provided with information about the risks associated with sending prescription requests by un-encrypted email, and similarly understand that they have responsibility to ensure their email accounts and logins are kept secure.

11.5 'Consumer' oriented Internet health services

By providing patients with easy access to health information the internet has changed the doctor patient relationship – patients are no longer solely reliant on their doctors to provide all advice and guidance about their health. Research shows that the majority of patients with internet access will use it to research their symptoms or conditions[252,253]yet the quality of health information on the internet is very variable, and patients often require some guidance in interpreting information they find.

Use of discussion forums and special interest sites for specific conditions can mean that patients are more abreast of current developments than their doctors, and the doctor's role becomes one of placing the patient's expectations and understanding in a context that is practical to currently available practice and services. Patients attending their GPs with

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[252] Using the Internet for Health-Related Activities: Findings From a National Probability Sample
Nancy L Atkinson et al
J Med Internet Res 2009;11(1):e4

[253]Family Medicine Patients' Use of the Internet for Health Information: A MetroNet Study
Kendra L. Schwartz et al
The Journal of the American Board of Family Medicine 19:39-45 (2006)

information from the internet are often a cause of anxiety for the clinician, challenging their knowledge and understanding of the condition, their role in managing care and leading to increased patient expectations.

Online personal health records provide a patient controlled store of their medical history, and may be useful for the patient when travelling or consulting with other care providers who may not have access to their general practice record.

11.5.1 What makes a good health website?

Evaluating the quality and usefulness of health websites for patients has been attempted formally, and we can identify a number of criteria to examine, which can help in assessing such sites. Some schemes for certification of consumer and professional websites have been made, such as the "Health on the Net Foundation (HON)"[254] and "The Information Standard Scheme"[255]. While reassuring when present, there is no legal requirement for sites to meet these standards.

11.5.1.1   Criteria to evaluate a website

Evaluating a consumer based health website is similar to evaluating one aimed at medical professionals, although the emphasis and language may necessarily differ.

Users should consider:

- **Domain** - The address of the website may be helpful in itself.   The URL should reflect that of the organisation publishing the site. '.uk' domains generally mean the site will be aimed at a UK audience. '.co.uk' and '.com' suffixes suggest a commercial site, whilst '.org' and '.org.uk' are normally used for non commercial purposes.
- **Ease of use** - Is the site easy to navigate and easy to read? Is the user in control of navigation through the site, or does the site open pages without warning, use misleading links or demand payment before allowing evaluation of any content?
- **Commercial purposes -** Many useful sites are commercial in nature, and others may be funded through advertising. Any adverts should be appropriate to the content of the site, inoffensive and, ideally, passive requiring the user to follow the link rather than forcing the user's attention through popup windows or misleading controls and buttons. The funding for the site, and its intended purposes, should be clearly stated.
- **Accessible** - Is the site accessible to all users? Are the colours, contrasts, fonts and images easy to read and view? Do they provide accessibility controls such as font changers or high contrast schemes? Providing the site in multiple languages may be appropriate where the intended audience may include non English speakers.

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[254] http://www.hon.ch

[255] http://theinformationstandard.org

- **Language** - The level of trust granted to a website will increase if the language, grammar and punctuation is largely correct, in keeping with the intended audience. Frequent miss-spellings or grammatical errors should give rise to caution in the reader.
- **Contact details** - Organisations providing health websites should always provide contact details, including a telephone number and postal address in addition to any email address.
- **References** - Information provided should be justified with direct or indirect references to the source of that information. Where references are not provided from the site, an inquiry to the contact address should result in the attribution of the information being provided.
- **Privacy** - Sites should state their privacy policy and, if they collect personal information, should advise users the purposes to which this will be put. Users should expect to have control over any account with the website, including how much personal information is collected, how it will be used and the ability to delete the account and associated data if desired.
- **Transparency** - No attempt should be made to conceal the ownership or authors of the site's content.
- **Complementary** - The site should provide information and support that works with the patient's other health care providers, and does not aim to replace them.
- **Useful** - Is the information the site provides of real and practical benefit?
- **Authoritative** - Is the providing organisation known to the user, and are they known to be a trustworthy source of information. For example, users would expect a site provided by the NHS to provide authoritative information, but information from an anonymous blog publisher would be treated with less trust.
- **Source** - Consider how the site was discovered? References from trusted sites would raise the trust level for the viewed site. Discovery through a search engine or via an unsolicited email should be treated with more caution.

HoN provides a list of certified websites, and sites that have passed HoN accreditation will display the 'HoNcode certification seal' – a small image that will link to the HoN site confirming the website's status.

The 'Information Standard' scheme is a certification scheme for health and social care information, currently funded by the Department of Health. Certified organisations can display the Information Standard's Quality Mark on their web pages or printed material.

11.5.2   Internet Based Personal Health Records

A 'Personal Health Record' (PHR) is a record used and maintained by the individual to whom it pertains, or by their nominated representative. The term PHR is not new, but in today's environment generally refers to an electronic, normally web based, repository for health information. This differs from the 'Electronic Health Record', a term commonly used to refer to health care professionals' records for a patient. The PHR is distinguished from an EHR by the focus of control for access and editing residing primarily with the patient, not the professional. This definition becomes less precise as records for patients increasingly become distributed

with the boundaries between EHRs and PHRs, and other forms of medical record, blurring and intersecting.

Several companies provide PHR services, most notably Google[256] and Microsoft[257]. These services are aimed at the US market, and some US health insurers now require the use of PHRs by patients as part of the policy. Such services are clearly commercial, with the providers using contracts with health insurance companies and health related products to profit from the venture. To do so they must retain the trust of their consumer market, and thus need to find a balance between health care requirements and commercial requirements that meets the market's needs. Health Vault (from Microsoft) is not available to UK users. Google health allows access to UK users, but the services it provides are largely US based.

In the UK the NHS in England provides a service called HealthSpace, available to anyone resident in England over 16 years of age[258]. Described as a 'free, secure online personal health organiser', HealthSpace can be used by patients to store important medical information, manage appointments and obtain advice on lifestyle issues in some parts of England. The service offers an 'Advanced Account' which will allow the user to view their 'Summary Care Record' details.

How these services will in the longer term impact upon general practitioners is unclear, although the change in culture that it may catalyse will again challenge the nature of the doctor patient relationship.

11.5.4 Support Groups and Forums

The internet has allowed the development of communities of users who may share a health interest or condition. Such forums or support groups are often accessed via health related websites[259]and similar rules to assessing their validity apply. Many patients may find using a condition specific health community a useful support to managing their condition, but there are also risks associated with this. Patients should ask if the forum they are using is 'moderated', that is: has an administrator who can edit or remove inappropriate or misleading messages and manage the forum's subscribers. It may not be easy to identify posters to a forum, and whilst this 'anonymity' is often part of the appeal it also makes it easier for those providing misleading information or products to target sometimes vulnerable people. Informal associations of people with similar health conditions or concerns can also be enabled on generic social networking sites such as Facebook.

11.5.5 The expert patient

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[256] https://health.google.com/

[257] http://www.healthvault.com/.

[258] https://www.healthspace.nhs.uk

[259] http://diabetes.org.uk/Get_involved/Online-communities/

This provision of health care information on the internet with peer support and health care communities can be very empowering for patients, but challenging for clinicians who may not have the same level of expertise in a specific condition, nor the time to acquire it. Similarly, this leads to conflicts between the scientific, clinical model of medicine, which underpins most medical training with the patient's health model, which may be significantly different. Organisations such as the Expert Patient Programme (EPP)[260], aim to assist patients to self manage their conditions, allow them to make informed choices and work in a complementary way with clinicians.

GPs may feel anxious when presented with a patient who presents information about their condition that they have found on the internet. Suggested reasons for this include fears of being seen as incompetent, of losing control of the consultation and of feeling devalued. [261] Adapting consulting styles to accommodate this, by respecting the patient's views and providing time to listen to their opinions, can be useful strategies but the emergence of the expert patient will prove challenging to conventional models of care delivery in primary care.

The internet provides opportunities for clinicians to direct patients to appropriate, trusted resources to encourage them to educate themselves on the management of their condition. An educated patient who is able and willing to work in partnership with a general practitioner should benefit the doctor patient relationship and improve care. It is perhaps part of a GP's role today to educate and inform patients on using health information from the internet.
Areas to consider and discuss with a patient who provides internet researched health information include;

- What was the source and how was it discovered?
- Is the information correct, accurate and scientifically valid?
- Is the information concise and readable within the time constraints of the professional?
- Is any recommended or requested treatment appropriate for the care context? That is: for primary care; for the contract of care; for the UK?
- Is the treatment licensed and available?
- What does the patient think of the information? Do they trust it?
- How does this information fit with the patient's health model?
- Where there is a previous doctor-patient relationship with the patient, how does this new information affect this and can it be used within it.
- Are there alternative sources of information that can contradict or support the provided views?
- Is the patient willing to listen to alternative viewpoints?
- The information provided may be new to the clinician, valid and appropriate. It is important to acknowledge when the patient is correct.

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[260] http://www.expertpatients.co.uk/

[261] Br J Gen Pract. 2010 Feb;60(571):88-94. 'A heartbeat moment': qualitative study of GP views of patients bringing health information from the internet to a consultation. Ahluwalia S, Murray E, Stevenson F, Kerr C, Burns J.

In many ways the challenges provided to doctors working with patients who have sourced information from elsewhere are not new, just more frequent. The opportunities that arise from being able to educate and inform patients through internet resources probably outweigh the disadvantages, but this does demand of clinicians that they accept their role as the elite custodians of health knowledge has been usurped and patients are rightly becoming more equal partners in their care.

11.6 Using the Internet for consulting

Internet technologies should provide new methods for patients to consult with their doctors. Email, video conferencing and instant messaging are all relatively new services for communication, which are now widely used in both business and by the public, but their penetration into health care service delivery in the UK has been limited.

11.6.1 Email consulting

Consulting with patients by email has not been widely adopted in UK general practice to date. The reasons for this are complex, and at first glance it would seem that email was well suited to the task of improving communication between patients and clinicians, but several significant barriers stand in the way of this.[262]

Practices that are considering using email to allow patients to communicate with the practice need to consider the risks and benefits this may incur. Potential benefits arise from the asynchronous nature of email – the sender does not require the receiver of the message to be online, nor would they expect an instant response; and the messages can be sent outside of normal working hours. Other proposed benefits include:

- Improving access to those who may be housebound or live in remote areas
- The opportunity to include additional information in replies, attachments or clickable links to supporting websites
- A more 'anonymous' medium that may make some patients more confident about addressing difficult issues
- Potential efficiencies in time.

The drawbacks arise from the lack of personal contact and cues. Clinicians are often experienced in consulting in real time using verbal and non verbal cues, but asynchronous consulting requires a new set of skills and carries a new set of risks; carries risks to privacy for patient and clinician; and may result in additional work rather than changed work.

Practices wishing to use email for patient communication may wish to consider using it only for clearly defined purposes of limited scope, such as repeat prescription ordering or the provision of a practice newsletter. Using email for clinical consulting will require the practice to address

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[262] INFORMATION IN PRACTICE: Josip Car and Aziz Sheikh. Email consultations in health care: 1—scope and effectiveness. BMJ, Aug 2004; 329: 435 - 438

patient authentication to ensure the email address used belongs to that patient; patient education to improve their understanding of the risks of sending confidential medical details unencrypted, and their responsibilities to ensure only they (or trusted others) have access to the messages. Practices will need to address how emails with patients will be integrated into their clinical record system, and when. Time must be made available to clinicians to respond to email queries, and practices must decide if this is to be an additional service to patients or will replace other methods of consulting to some degree.

A policy statement should be provided to patients explaining the limits of the service, such as 'not to be used for emergencies', and this can be re-iterated using auto-responses from the practice to incoming emails as well as in standard texts sent in replies. Incoming practice emails should be to a default practice email address rather than named individuals to cover leave and other absences. Patients should also be advised that they should be careful of their own privacy for email and other electronic communications they send and receive about health matters.

Practices should develop protocols for dealing with unsolicited email inquiries, which may be from patients or purport to be so. Remember unless a process has been used to confirm the ownership of an email address to a specific patient it is impossible to guarantee that the inquiry is indeed coming from the stated author. A judgement needs to be made depending on the specific circumstances as to how such inquiries may be dealt with, but where doubt exists or the information requested is potentially sensitive caution should be used.

Practices should be aware that all email communications pertaining to a patient, form part of the medical record and, as such, can be requested for release under the terms of the Data Protection Act.

At the time of writing (December 2010) HealthSpace in England is undertaking a pilot of a secure and verified email channel for patients to communicate with health professionals (HealthSpace Communicator), thus managing some of the risks associated with this medium.

11.6.2   Voice over Internet Protocol (VOIP) and Video Conferencing
VOIP supports internet telephony services such as Skype[263]. These services often also support video conferencing, provided both parties have webcams.

There is theoretically no reason why practices could not use VOIP services for telephone communications with patients, but practically it will be harder to manage and implement. Constraints in bandwidth of the N3 network would be unlikely to support large numbers of users of VOIP applications simultaneously, and would have to be negotiated with the support of a PCO and the N3 provider.

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[263] http://www.skype.com

The specific configuration of using VOIP services for practice telephony is beyond the scope of this document.

Using Video Conferencing technologies to communicate with patients presents interesting possibilities, but again actual implementations in the NHS primary care environment will, at this stage, be largely experimental and may require specific support for network configurations.

11.6.3   Text Messaging

It is possible to use SMS text messaging for some GP services, such as appointment reminders and results advice. NHS Mail includes an email to SMS text service and using either bespoke integration, where technical competencies are available in-house, or by purchasing commercial software it is possible to integrate practice demographic data to use the NHS Mail SMS gateway for such purposes.

11.7   Supporting general practice

11.7.1 Education

Revalidation, GP appraisal and re-licensing have increased the requirements for general practitioners to be able to plan, undertake and log their learning activities. Various services are available to support these processes, such as Scottish Online Appraisal Resource[264] the NHS England Appraisal Toolkit[265] and information services such as GP Notebook[266] provide tracking services to log learning activities.

11.7.2   Peer Support

A number of online communities for doctors exist in the UK, where electronic discussion can take place between clinicians. 'Doctors.net.uk' (DNUK) is one of the best known, and is a password secured site, which requires the user to have a GMC number and matching name to register. It provides online forums for discussion across a wide variety of topics, as well as educational material, job vacancies and an email service. DNUK is funded through commercial arrangements with groups and companies "who need to communicate with doctors" and as such it contains some commercial material such as advertising. Other mailing lists include 'GP-UK', an ostensibly academic list for GPs running since 1994[267], as well as specific mailing lists to support users of various clinical information systems.

11.7.3   Other Software applications

General practices can find benefit in using general commercial software packages for a variety of purposes in their organisation. Most commonly used include an 'office' suite, typically

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[264] http://www.scottishappraisal.scot.nhs.uk/

[265] https://www.appraisals.nhs.uk/

[266] http://www.gpnotebook.co.uk

[267] www.jiscmail.ac.uk/lists/gp-uk.html

Microsoft Office, which provides at least a word processer and spreadsheet application for document writing and data analysis respectively.

Accounts packages can simplify and ease managing the practice's accounts and specific GP accounting packages are available. Some accountants require the use of such a package, or will provide a discount to those practices that do.

11.7.4   Intranets

An Intranet is a local information service that uses internet technologies, such as a web browser and web pages, to provide information for the local organisation only. Some practices have created local intranets for storing local protocols and guidance, contact information, referral forms, calendars and so forth. The NHS provides a product called 'Digerati', which is an intranet management system that can be employed in practices at no licensing cost (as at December 2010)[268].

11.7.5   Messaging

Information technology can be used to support messaging internal to the practice; providing for group alerts, informal discussions, clinical discussions and notifications. Two principle methods are commonly used: email and instant messaging.

11.7.5.1   Email

Unless practices have the technical expertise to set up and maintain a local mail server, and ensure that it is secure within the practice network boundaries, the recommended approach is to use NHSMail for this purpose. NHSMail is available in Scotland and England. In Wales the NHS is rolling out a national email service based on local servers. This will in due course provide email addresses for NHS Wales staff and directory services. Plans are also in place to introduce an email to SMS gateway. Practices should consult with their PCO IM&T department for advice regarding using their email systems for confidential patient data prior to employing them for this purpose.

11.7.5.2   Instant Messaging

Popup or instant messaging is provided by a variety of companies, some of which specialise in the primary health care market. This type of messaging allows for 'chat' client software to receive messages in real time from other users, may provide an online status indication for that user and other functions such as emergency broadcast messages and message of the day. Functions to support scheduling, rotas and home visit management may also be provided.

The use of third party applications for instant messaging, such as MSN Messenger or Google Talk for internal practice communications carries risks with respect to confidentiality and the physical location of any stored data, which may be outside of the UK. Instant messages are commonly transmitted unencrypted and thus are at risk of 'snooping' attacks.

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[268] http://www.connectingforhealth.nhs.uk/systemsandservices/ssd/prodserv/digerati

11.7.5.3   Messages about patients

Every record about a patient in any format, including those used for messaging in the practice or between NHS organisations is considered part of the medical record. Practices should ensure that all such communications are linked to or recorded in the patient's main electronic record on the clinical information system. Messages and documents which refer to a patient are legally part of that patient's medical record and thus liable to disclosure if requested, even if the document was only intended for internal use or exists only in a draft format.

11.7.6 Teleconferencing

This can be very useful, especially in remote and rural settings for education CPD (Continuous Professional Development); sharing clinical situations, local practice/NHS business and case conferencing.

11.8   Privacy and security in the online world

11.8.1   Managing your privacy and protecting your identity

As clinicians increasingly work using electronic records and online tools and services they have a responsibility to understand how to manage their online security and identity.

11.8.1.1   Logins

Password and username policies vary with different applications and services. It is tempting to use a single password for all applications to which users need access, but this policy puts your data at greater risk if this password is compromised. Aim to have a number of passwords for different purposes, and a method of changing these when prompted. Forgetting your password is also a security risk, and for some services, where the data is of limited use and not patient related, keeping the password written down, or in a secured or encrypted file may not be unreasonable.

Do not share passwords with others, and always ensure when using any system that you log out of it when you are finished. Never use another person's login name and password for work, which should be attributable to you. Do not share Smartcards.

If leaving your computer terminal for a short period of time, users should 'lock' the screen and ensure a password is required to regain access.

11.8.1.2   Secure browsing

Modern web browsers have implemented tools to help keep users safe from fraud by making it clear when the site you are using is 'secure', by indicating when the site name may be misleading, by controlling software installation and preventing access to known scam sites. It is important, therefore, that your web browser is kept up to date and is, ideally, the most recent

version. Constraints on the technology and sometimes operational requirements have resulted in some desktops provided to practices by the NHS being restricted to older browsers, or preventing users installing the browser of their choice.

Users should be aware that they may not be receiving the same level of protection from fraudulent or deceptive sites at the surgery as they would normally have elsewhere, a degree of caution is therefore recommended.

Do not use the facilities on your web browser to store form data or passwords, especially on shared workstations or use a 'master password' facility in the browser, if one exists. Ensure you can identify when a secure connection has been established on the browser (typically the site will be prefixed with 'https://', but on its own this can be misleading) before entering any confidential details such as credit card numbers.

Never follow links in unsolicited emails (spam), nor open electronic attachments from unknown sources.

The PCO should ensure that your workstations are provided with anti-virus software, and that this is updated and maintained.

If you consider your machine may have been compromised in some way, turn it off and contact IT support.

11.8.1.3   Social networks

Care should be taken when using social networking sites. It is always inappropriate to use these to discuss identifiable patients and caution should be used when discussing clinical details in an open forum where the patient *could* be identified. Similarly, posts to social networks may be accessible to all and users should consider carefully if they are the best place to discuss system or operational issues, particularly if they relate to identifiable individuals. Inappropriate posts can result in disciplinary action by professional or contractual bodies and threaten careers. Although a social network site or peer support forum may appear to be a friendly place, always consider who else can read the messages and the implications this may have if taken out of context.

11.8.2   Protecting Electronic Information

Guidance is available from the NHS CFH website[269] on this topic.

11.8.3   Educate users on their responsibilities

The changed nature of the health record as it has migrated to electronic formats, with a number of different services providing some details about patients, has blurred the lines between what constitutes maintaining confidences for today's doctors. It is important when new electronic record services are introduced and made available to clinicians that they are educated in their rights of access to these services and the records they contain, their

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[269] http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/igsoc/general/Protecting.pdf

responsibilities to these records, the monitoring of compliance that will be employed and the consequences of failing to meet them.

Maintaining confidence for doctors twenty years ago could be summed up as 'Don't tell'. Today, given the exposure of records across internet services clinicians should also remember that 'Don't look' is of equal importance.

11.9 Data extracts

There are a number of services that use extracts from GP system records to support areas such as unscheduled care, shared care of conditions such as diabetes, medical and pharmaceutical research and health care planning (see also Chapter 4.8 – Records Governance).

11.9.2 What do they do?

Extracts from GP systems have some common features. Generally they all require some 'middleware', or an implementation that allows the GP clinical information system to extract the required data in a suitable format for the receiving service. Normally, they extract a subset of data on the system, rather than all data. The exact specification of the subset varies depending on the service and the structure of data in the GP system. They may have controls for the practice as a whole, and for individuals or groups of patients to consent, or otherwise, to the data extraction and for inclusion or exclusion of specific data items. Free text may be included or excluded. Extractions are often automated, and scheduled by the software to occur at particular times. The data extracts may be 'incremental' (sending only data which has changed or been added since the last upload), or 'full' (always sending the complete data set).

Once the data has left the practice it is no longer within the bounds of the practice's data controller to maintain it or control its subsequent usage. Practices must ensure they understand the uses the data will be put to, the consent model in use and the functional controls available in the practice. Practices must have reassurances in the contract or service agreement with the data extractor that the uses will always be appropriate to the intended purpose and that the data will be handled securely.

Some examples include;

- **General Practice Research Database (GPRD)**

GPRD[270] is a not-for-profit research database owned and operated by the Medicines & Healthcare products Regulatory Agency (MHRA). This uses 'anonymised' data from records extracted from GP systems for research by various public and commercial organisations.

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[270] http://www.gprd.com/

GPRD provides funding for practices to support the data extraction process, and material for informing patients of the processes and purposes to which the data is put. Practices receive data quality advice and reports from GPRD based on their analysis of the received practice data.

- **The Health Improvement Network (THIN)**

THIN[271]is similar to GPRD but only accepts data from users of INPS Vision. It is operated by a private company, Cegedim Strategic Data.

- **Practice Team Information (PTI)**

PTI[272] extracts GP Records from clinical systems in Scotland and specifically examines workload by analysing face-to-face consultations.

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[271] http://www.thin-uk.com/

[272] http://www.isdscotland.org/isd/1044.html

Chapter 12 - Education and training

12.1 Why education and training are important

The use of computers is becoming ever more prevalent in our daily lives. Their design is growing ever more intuitive and in many settings people are used to a 'just get on with it' approach to using a new machine or system. This approach is not appropriate for large-scale initiatives such as using electronic records in health care. This has been recognised for some time, as is shown in this quote from a literature review, commissioned by the NHS Leadership Centre, from the Henley Centre:

> *The main factors in the success or failure of the introduction of IT-led change initiatives are clearly shown by the evidence to be the human elements. It is not the technical aspects that cause major IT projects to fail but the 'people' aspects. Unless these are tackled from the outset, there is little likelihood that IT projects will be successful. This is true not only in health care systems but also in other public sector enterprises and the private sector, and not only in the UK but also internationally.*
> *- Williams (2004)*[273]

Similar points are made in UCL's independent evaluation of the SCR[274], particularly in sections 7.3. The SCR: 'Plug and play' technology or socio-technical change? and 7.4. The change model: 'Make it happen' or 'let it emerge'?

Sadie Williams and Trishia Greenhalgh are referring to 'engagement' and their comments are made in a political and social context. These themes, when expressed as motivation and learning climate, are familiar to educators.

Social and affective aspects of learning are at least as important to a curriculum as is content.

12.2 Learning needs

Aside from these 'hearts and minds' issues there are two particular aspects of electronic health records that demand attention and require specific education and training.

The first relates to the main theme of this version of GPG: i.e. interoperability. This is dealt with in detail in the report from the Shared Records Professional Guidance Project[275]. Records are

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[273] http://www.nursingleadership.org.uk/publications/LitRProfGps04%20(Henley).pdf

[274] http://eprints.ucl.ac.uk/6602/

[275] SRPG report http://www.rcgp.org.uk/health_informatics_group/srpg.aspx

no longer written primarily for the benefit of the clinician who writes them and his or her immediate colleagues. Elements of the shared record may be read, and relied upon, by clinicians in other teams in other locations and in other professional groups, often at considerable distance in each of these dimensions. They also may be read and relied upon by the patient. When care is shared in this way the record is a form of communication that does not merely impart data and information. The communication may also convey expectation. For instance, a clinician in a single contact with a patient may prescribe a medication (such as an ACE inhibitor), which requires subsequent monitoring. It is essential for patient safety that this expectation is passed on and understood. It's possible to design systems and care pathways so that the expectation and the need for subsequent clinical monitoring is clear to all users purely from the way the information is presented on the clinical computer system. More commonly, such transfers of responsibility are implicit in the ways of working of local teams: the clinical record is written in the context of this local knowledge and understanding. This requires the clinician to be able to make technically correct coded entries, while at the same time being aware of the contexts within which the record entry is written and later read.

The second imperative relates to the way that information, particularly coded information, is displayed by clinical computer systems. Even the youngest and most computer literate of clinicians have been brought up with paper documents. On paper, position on the page and the spatial relationship between different elements of text are part of the context that contributes to meaning. Clinical computer systems re-present items of information in different spatial relationships. As a consequence, things that appear to be clearly understandable on one screen view may not carry the same meaning so clearly when viewed on another screen view. This is particularly true of a coded entry that is qualified by free text. That qualification will not apply if the two items become physically separated. Making a good record does not merely require the correct choice of coded clinical term; it requires a contextual understanding of how the record will appear to the reader. This understanding includes the functionality of their individual clinical systems, as well as an understanding of the secondary uses that data can be put to.

In addition there are semantic issues to consider. Different professional groups, specialties and sub-specialties are examples of sub-cultures that use language in different ways. They all use language in ways that can be opaque to the general public, i.e. their patients. These issues are dealt with in more detail in the SRPG and Record Access reports (see Chapter 5 – Shared Electronic Patient Records). They all hinge on properly combining the technical accuracy of the coded clinical term and the context in which it is being used by the writer and the reader.

All clinicians need to know the technical aspects of which codes to use; they all need to understand how contextual factors shape the meanings of records; they all need to be able to use the electronic records as a safe, effective and reliable way of communicating with other health professionals, and their patients.

Similar statements of need can be written for other aspects of practice with electronic health records. In records governance, for instance, there are technical details of how to apply each guidance or statute. These have to be implemented in local and broader contexts. The person who is sending an extract from a patient's records to an outside organisation has the following learning needs: to be aware that information about third parties should not be disclosed (i.e. awareness of the principles of the NHS Code of Practice for confidentiality); to have the technical knowledge of what constitutes a third party reference that should be deleted or redacted and the specifics of how to do that; local contextual knowledge of who's responsibility it is to do the check for third party references and to ensure that the task is always done.

This is a recurring theme. Whatever the task undertaken, necessary technical accuracy is not sufficient without considering wide and local contexts. The relation between an understanding of the technical and of the contextual is a fundamental characteristic of health informatics.

12.3 Meeting these learning needs

12.3.1 Training and practice management

Especially in the case of records governance, but to some extent in all areas, some of the local and wide contextual factors may be embodied in practice policies and protocols. So that when the practice receives a request for an extract from records, it is clear that a check for, and deletion of, third party references is required. The practice policy will set out how this should be done; by whom, and how the checking should be confirmed before dispatch. In this example the practice and its systems are taking responsibility for the wider contexts. The employee needs to be trained to follow practice policy and in the technical detail of how to do the check. Equally, the practice managers who write the policies may need guidance with that task.

Up to a point a similar approach can be used with regard to clinical coding. Through the Quality and Outcomes Framework (QoF) clinicians and managers have come to appreciate the need for technical accuracy in coding and have learnt some of the costs of inaccuracy. The QoF contains a limited code set for the conditions it embraces. In other contexts, SCR and ECS for instance, restricted code sets can be agreed and used to limit ambiguity (see Chapter 8e – The Summary Care Record and Emergency Care Summary). Their preparation and implementation are matters of management and training.

However, large parts of the primary care repertoire are not so simple. Not all conditions are as well circumscribed as those in the QOF, we deal with many complaints that are not sorted into neat diagnoses while co-morbidity and social and psychological factors add to medical complexity. In these circumstances, business processes and structuring of the record can only contribute so much: the note-writing clinician must understand the communicative aspects of the record as well as being technically proficient in coding.

The important point here is that local ways of working (business processes in the practice, and the way that different local clinical teams work together) have an impact on education and

training needs. At the simpler end of the spectrum it is possible to build required understanding into business processes, so that the individual needs only to be trained to follow protocols. As things get more complex, or where business processes are less well developed, so the contextual understanding required of the individual increases.

This means that any learning needs assessment needs to take into account aspects of practice management as well as the competencies of the individual practitioner or staff member.

12.3.2 Context and communication

The intended outcome here is that the individual will understand how their use of a particular clinical records system or application impacts on other users and on patient care. This requires a different approach. While skills acquisition and learning how to do specific tasks lend themselves to a training approach that can be relatively didactic and put into packages that are cascaded through e-learning or other methods, matters of understanding often require a more discursive and individual approach.

The individual needs to be able to relate their work to the work of other members of their team, and also to understand how their team fits in with the bigger picture. The rich variety of sizes and types of General Practices, and other types of primary care provision, makes it very difficult to achieve this level of understanding by means of pre-prepared material whether delivered on line or in person. A one-size-fits-all approach is inappropriate. Group discussion that allows people to situate their experience in the wider context is much more likely to be successful.

In terms of learning about and coming to understand the use of the electronic record as a means of communicating with other professionals the most useful activity is likely to be meeting with and talking to the other professional groups involved. Much of this can be done within a practice, but as care of one patient is increasingly shared by different organisations so increases the benefit of people from those organisations meeting each other.

As will be shown in the next section, the NHS website offers e-learning support for developments such as Summary Care Record and Personal Demographics Service. While these are invaluable as guidance and expositions of content, they are not wholly sufficient in themselves. Clinicians and administrative staff need to be given the opportunity to apply the material to their own situation, to grasp the implications of using this technology in their work setting and in their communication with other professionals. This kind of work is best done in facilitated groups. This is relatively costly of resources. The cost is justified as these human elements are the key to success of IT-led change, as demonstrated in the quote from Sadie Williams at the start of this chapter.

12.3.3 Clinical and non-clinical staff

Information handling is part of the role of everyone who works in health care and so of everyone who works in an organisation such as a General Practice. The scenario of third-party references illustrates this. Informatics is beginning to be included in the undergraduate curriculum for doctors[276]and is being promoted for all clinicians in the e-ICE project (see Chapter 12.4 below). There is not the same structural support for admin and clerical staff. As mentioned above, this falls into the realm of practice management as an aspect of staff development and appraisal. Ways of working, practice protocols and staff development and appraisal should each complement the other.

Factual guidance and pre-prepared training materials need to be supplemented by facilitated inter-personal learning so that human elements of learning and change can be properly addressed.

12.4   Some learning resources

There are many useful resources available on the internet. The few examples listed below are NHS related and provided by NHS Connecting for Health and PRIMIS+ among others. They include general material as well as e-learning resources for specific items such as Summary Care Record, Patient Demographics Service and Information Governance, all of which are on the NHS CFH e-learning resources website below:

- NHS CFH ETD http://www.connectingforhealth.nhs.uk/systemsandservices/etd
- NHS CFH e-learning resources
  http://www.connectingforhealth.nhs.uk/systemsandservices/capability/phi/personal/elearning
- E-Learning for Healthcare http://www.e-lfh.org.uk/
- Health Learning and Skills http://hlas.careers-advice.org/NHS/courses/index.html
- e-ICE project (embedding informatics in clinical education) http://www.cfh.nhs.uk/eice
- PRIMIS+ http://www.primis.nhs.uk/
- PRIMIS+ - Find a facilitator http://www.primis.nhs.uk/index.php/about-us/find-facilitator

The following discussion boards are also a useful source of information and may go some way to addressing the need for interaction and social aspects of learning;

- Data Quality Guild http://www.ic.nhs.uk/services/the-data-quality-programme/news-and-developments/guildspace-goes-live!
- JISC
- PRIMIS+ http://forum.primis.nottingham.ac.uk/
- PHCSG Discussion board http://www.phcsg.org/index.php?p=discuss
- Clinical system supplier forums and clinical system user group forums are also available (see also Chapter 9.8 – A Pathway to Good Paperless Practice).

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[276] Tomorrow's Doctors http://www.gmc-uk.org/education/undergraduate/tomorrows_doctors.asp

GPGv4 - Glossary

DM+D	NHS electronic dictionary of medicines and devices
DMIP	The Data Migration Improvement Project (England)
Docman™	Commercial electronic document management and messaging system. Sometimes term "Docman" used to refer to generic document management systems
ECS	Emergency Care Summary (Scotland)
EPR	Electronic Patient Record
EPS	Electronic Prescription Service (England)
GP2GP	Electronic message transfer of copy of GP record between GP practices (England)
GPG(v.xx)	Good Practices Guidelines for GP electronic patient records (version)
Heterogenous (data transfer)	Data transfer between different clinical IT systems (with different information models supporting different data structures and possibly different coding systems (e.g. Emis LV to InPractice)
Homogenous (data transfer)	Data transfer between same systems (e.g. Emis LV to Emis LV)
Inter-operability	The facility to safely exchange electronic patient data between clinical IT systems
JGPITC	The Joint GP IT Committee (of the BMA GPC & RCGP)
PACS	Picture Archiving & Communications System (radiology imaging – England)
PDS	The Personal Demographics Service (England)
PMIP	Pathology Messaging Improvement Project (England)
SCI	Scottish Care Information (SCI Store & SCI Gateway services)
SCIMP	Scottish Clinical Information Management in Practice
SCR	Summary Care Record (England)
SEPR	Shared Electronic Patient Record (a single logical detailed patient record e.g. TPP SystmOne)

Appendix 1 - GPGv4 Contributors

The Good Practice Guidelines depend on the contribution of many individuals and organisations and is a genuinely collaborative effort between professional representative bodies, generously supported by NHS CFH and the Department of Health. The Joint GP IT Committee would like to thank all those involved in producing these guidelines. We acknowledge below most of the principal contributors but would also like to thank those many others who also supported and advised the authors.

- Dr Sebastian Alexander
- Dr Joanne Bailey
- Dr Nick Booth
- Ms Cheryl Cowley
- Dr Paul Cundy
- Mr Ewan Davis
- Dr Dai Evans
- Dr Leo Fogarty
- Dr Mary Hawking
- Dr Grant Ingrams
- Dr Ian McNicoll
- Dr Paul Miller
- Dr Bob Milne
- Dr Libby Morris
- Dr Stephen Pill
- Dr Manpreet Pujara
- Dr Paul Robinson
- Dr Jeremy Rogers
- Dr Peter Short
- Dr Ralph Sullivan
- Dr John Williams
- Dr David Wrigley

- Dr Alan Hassey (Editor)

Appendix 2 – GPGv4 List of organisations consulted

- The Royal College of General Practitioners
- The General Practitioner Committee of the BMA
- The Joint GP IT Committee (of the GPC & RCGP)
- The Department of Health
- The Scottish Government
- The Welsh Government
- The Northern Irish Government
- The General Medical Council
- NHS Connecting for Health
- The NHS Information Centre
- The UK Terminology Centre
- The Medical Protection Society (MPS)
- The Medical Defence Union (MDU)
- The Medical and Dental Defence Union of Scotland (MDDUS)
- The National Vision User Group
- The Emis National User Group
- The iSoft National User Group
- The TPP SystmOne National User Group
- The Primary Health Care Specialist Group of the British Computer Society