



Royal College of  
General Practitioners



Record Access Collaborative  
Patient Access to Medical Records

# Enabling Patients to Access Electronic Health Records Guidance for Health Professionals

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# Enabling patients to access electronic health records

Guidance for health professionals

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Royal College of  
General Practitioners

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# Preface

Patients have had the right to read their paper records since the 1990s. However, few ever choose to do so unless there is a problem or a complaint, perhaps in part due to procedural and physical constraints. With the widespread use of electronic records, it is now much more feasible for patients to access their own records directly. This presents new challenges and opportunities for health professionals.

This document has been created primarily by the doctors who pioneered the work to enable patients to access their own electronic health records. The doctors have explored the opportunities for people not just to read their records but also to enable them to better look after their own health, interacting positively with the healthcare system.

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

Record Access provides 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 professionals, the result can lead to improvements in their care.

Record Access is a new development and this guidance is intended to be a dynamic document that will evolve as more experience is gained.

Dr Libby Morris, Chair, RCGP Informatics Group  
Dr Bob Milne, Deputy Chair, RCGP Informatics Group  
1 September 2010

# Principles of Record Access

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)<sup>i</sup>

1. Patients should be given appropriate information and opportunities to exercise control over the healthcare decisions that affect them.<sup>ii</sup>
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.<sup>iii</sup>
4. Record Access for patients is likely to improve their care and their safety (see Section 2.1).
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 (see Section 3.1).
8. Health records are used by health professionals as a tool to provide care. 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 (see Section 3.1).
10. Computer systems suppliers should develop tools to provide patients with secure access to their records.

<sup>i</sup> The NHS Constitution for England, published January 2009, is available at: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093419](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093419). The NHS Care Record Guarantee is available at [www.nigb.nhs.uk/guarantee](http://www.nigb.nhs.uk/guarantee) [both accessed August 2010].

<sup>ii</sup> See the General Medical Council's 'Duties of a Doctor' at: [www.gmc-uk.org/guidance/good\\_medical\\_practice/duties\\_of\\_a\\_doctor.asp](http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp) [accessed August 2010].

<sup>iii</sup> This is consistent with the General Medical Council's 'Duties of a Doctor', and specifically the statement '[s]upport patients in caring for themselves to improve and maintain their health'.

## Acknowledgements and endorsements

This guidance was conceived by Drs Brian Fisher, Richard Fitton and Amir Hannan under the Record Access Collaborative, which pioneered the work to enable patients to access their own electronic health records. They developed the themes for good practice guidance and wrote the original document. In 2009 NHS Connecting for Health commissioned the Royal College of General Practitioners Informatics Group to quality-assure the guidance and ensure its suitability for all NHS health professionals. This was undertaken by an extensive consultation with stakeholders.

Many stakeholders, including professional bodies and patient groups, provided essential information and suggestions vital to the final document (see Appendix I). Special thanks are due to Rachel Merrett of the British Medical Association for her considerable efforts to improve the readability of the document. We would like to acknowledge the invaluable contributions of Marlene Winfield, Graeme Catto and Martin Severs, and the work of both the Steering and Project Groups. A full list of those involved in both groups appears in Appendix V.

The guidance has been developed with advice from the Information Commissioner's Office, the British Medical Association and the Medical Defence Union. The National Information Governance Board has reviewed and agreed the guidance. The Royal College of Obstetricians and Gynaecologists supports the guidance.

The following organisations endorse the guidance:

- Arrhythmia Alliance
- Atrial Fibrillation Association
- British Dietetic Association
- College of Occupational Therapists
- Department of Health
- Faculty of Dental Surgery, Royal College of Surgeons of England
- Gorlin Syndrome Group
- HPTH (Hypoparathyroidism) UK
- Institute of Health Records and Information Management
- Medical Protection Society
- Migraine Action
- Nursing and Midwifery Council
- Pelvic Pain Support Network
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Physicians
- Royal National Institute of Blind People
- Syncope Trust And Reflex anoxic Seizures (STARS).

The Project Team is grateful to all of the above organisations for their support.

Dr Libby Morris  
Dr Bob Milne  
1 September 2010

# 1 Introduction

Policy and law across the UK entitle people to access their health records, with specific exceptions, under the Data Protection Act (DPA) 1998. In England this has been enshrined as a right in the NHS Constitution (2009). Sharing relevant information with patients is also considered good practice in health care. Patients make the best decisions for their own care if they have access to all the information about them that they might reasonably need. Record Access goes beyond the legal rights of subject access requests by offering routine access to patient records, enabling a partnership to promote good health care.

This document aims to facilitate the implementation of Record Access in a variety of settings. It offers good practice guidance to help health professionals enable Record Access and support patients who wish to access their records. The guidance aims to address safety and legal concerns, maximise the benefits, minimise risks and demonstrate how to deal with some of the limitations.

Many health professionals have concerns about Record Access. These include 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. It is hoped that this document will address these concerns and provide health professionals with confidence in the process and ways of managing any risks.

This document was written for NHS health professionals and is based on over 35 years of experience in Record Access by three GPs who have pioneered this project in their own practices. However, the guidance is expected to be applicable across all care settings. There are excellent examples of access to hospital records in specific specialties and these are referenced in the document. It is intended that a separate document will be produced for patients. Access to social care records is outside the scope of this document.

The development of the guidance was sponsored by NHS Connecting for Health in England, but it is intended to be applicable to health professionals across the UK (although other UK countries may wish to modify it further for their own use).

A patient version of this guidance is being prepared.

## 2 Record Access

Record Access describes the process by which patients can routinely read their own health records. Record Access does not have to be electronic. However, this guidance document deals primarily with electronic Record Access.

Record Access can be achieved with paper access and even spoken presentation of the record contents in the consulting room or clinics, with touch screens in waiting rooms, or by logging on to an electronic system from home with a user name and password. Patients may choose to access their records in many environments, for example at home, with family or carers, or with someone who acts as an advocate, in community clinics, pharmacies, libraries or optometrists. There are many media through which patients in future may choose to view their records such as online, in a kiosk or via mobile phone, PDA, MP3 or iPod.

Most work on Record Access has been in primary care but some hospital-based specialties have enabled Record Access, for example in renal medicine where 'Renal Patient View'<sup>iv</sup> is widely used by renal clinics in the UK to allow patients, their families and GP (if they wish) direct access to their clinic letters and blood test results. Increasingly, people in England will have direct access to their Summary Care Records through a secure web service called HealthSpace. Midwives have been using patient hand-held records for many years. BabyLink<sup>v</sup> is a project in the Special Care Baby Unit of Edinburgh Royal Infirmary, which gives parents direct access to the electronic record of their baby. Parents using BabyLink can give access via password to anyone they choose. All EMIS practices (approximately 60% of the UK) can enable patient access to the full GP record.

The electronic GP record in the UK tends to be comprehensive, bringing together information from various care settings such as hospital, social care, insurance companies and housing. It includes notes of consultations, prescribed medications, past medical history, results, letters and information such as allergies and immunisations. In addition, a further important purpose of the GP record is to record details for administration and business needs of the practice and as a legal record of all transactions involving patients. Allowing patients access to this wealth of information may be a daunting prospect for health professionals.

Record Access can be considered as a staged process. Initially, in a general practice setting for example, there can be a gradual introduction of access to test results, clinic letters or repeat prescribing, depending on the knowledge of the patient and the clinical circumstances. This can be gradually extended to provide access to the complete clinical record, although health professionals may still decide that access to some parts of the record such as business information or *aides-mémoire* are not necessary or appropriate. A gradual approach will help health professionals adapt to this new way of working. They can develop confidence in patients accessing core information before opening up access to the fuller record. Health professionals will also be able to establish the impact Record Access has on their time.

Record Access is not just about information-sharing but encouraging patient involvement and awareness of the care provided. In the traditional arrangement, the patient can only access the record through the healthcare organisation.

iv [www.renalpatientview.org/index.do](http://www.renalpatientview.org/index.do) [accessed August 2010].

v [www.babylink.info/edinburgh/NeonatalUnit/Welcome1.aspx](http://www.babylink.info/edinburgh/NeonatalUnit/Welcome1.aspx) [accessed August 2010].



The new situation can be described like this: both patient and health professional have almost equal access to the record.



Record Access should enable patients to understand the information in their records and help them make use of that information. It should be linked with 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. 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. In addition to patient information leaflets, sources may include decision aids, videos and links to local agencies, NICE or SIGN, NHS Direct or NHS24. Information sources need to be accredited and regularly updated with minimal input from health professionals. This will give patients a broader understanding and patient organisations could support this process.

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.<sup>1</sup> Record Access is not compulsory. Some patients may not be able to, or may not wish to, access their records. However, some patients may choose to use it as a substitute for elements of care and this should not impact on the quality of care provided or the information supplied to them. All patients should be provided with relevant information to inform their care and decisions about their care.

## 2.1 The potential benefits of electronic Record Access for patients and health professionals

Evidence for the benefits of Record Access is accumulating for both patients and health professionals. In general, it seems clear that Record Access can improve care and safety.<sup>2-5</sup> Further studies are required as Record Access becomes more widespread.

Record Access has the potential to improve discussions between patients and health professionals, encouraging a more open and honest relationship.<sup>6</sup> If a patient feels that he or she does not understand something or that something has gone wrong, the patient has easy access to his or her data. There is no evidence of increased litigation.<sup>7,8</sup> Patients can share their record with family members or carers as they choose.

Access to the electronic record by the patient at any time encourages good-quality record keeping.

Experience has shown that patients can use Record Access to improve the accuracy of their record.<sup>2,9,10</sup>

Patients using Record Access can make their contacts with general practice and hospitals as efficient as possible. For example, reviewing the record at home after a consultation can assist memory<sup>11</sup> and concordance. So far, there is no evidence that patients attend more often or take longer for consultations.<sup>8,12</sup>

Access to medical records may be most beneficial when accompanied by information to improve patients' understanding of the data. There is some limited evidence that Record Access improves compliance and supports positive health behaviour such as smoking cessation.<sup>3,13,14</sup> In general, self-care and shared decision-making have been shown to improve outcomes and to reduce the use of health services. If patients are to maximise their involvement in their own health care, they need to understand their current care and management. Record Access can be a significant help for this.

Another way to give patients information is with an information prescription, which itself can be facilitated through Record Access. It may also be possible to link the record with other transactional services such as appointment reminders, patient decision support, targeted advice on health promotion and advice on taking medicines.

Providing electronic access to records can help health providers to comply with their duty to ensure equal access for patients with disabilities. Paper is not a suitable medium for many people with visual impairments, whereas electronic records are accessible to many of them by using computers with assistive-technology reading aids. People will benefit if they can easily access their records online using their own computer and reading aids, and may be less likely to need large-print, Braille and audio formats.

## 2.2 Record Access has a cultural dimension

Different cultures have different views about health professionals, being a patient, confidentiality and individuality. For instance, in some cultures, a husband and his family may feel that they have a right to access the records of the wife. This will require different solutions but in the UK the legal framework should be clear enough to offer guidance in particular situations, in particular to protect vulnerable individuals. The DPA sets out the rights of access applicable to all citizens.

Currently, there are no plans or facilities to translate health records into other languages. Experience shows that people have found others internal or external to the family to translate when necessary. This is unsatisfactory but applies to many situations in the NHS. It is good practice to offer an independent translator where possible.

## 3 Legal background and professional guidance

### 3.1 Legal background

In the UK, under the DPA<sup>vi</sup> and Access to Medical Reports Act 1988,<sup>vii</sup> patients (including ‘Gillick competent’ children), or anyone authorised by the patient, are entitled to access their records, including reports supplied by a medical practitioner for employment, insurance or other purposes. Parents, or those who have parental responsibility for children who are deemed not ‘Gillick competent’, are entitled to access a child’s medical records in the child’s best interests (see Section 6.6). There are provisions under the Mental Capacity Act 2005 for England and Wales for access to records of patients who lack capacity (see Section 6.5).

The Information Commissioner has made it clear that having online access to medical records does not replace formal rights of access under the 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:<sup>viii</sup>

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.<sup>ix</sup>

### 3.2 The meaning of serious harm

There is no formal definition of serious harm. The GMC has offered advice in the context of withholding information when seeking consent to treatment:<sup>x</sup>

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.

vi Available at: [www.opsi.gov.uk/Acts/Acts1998/ukpga\\_19980029\\_en\\_1](http://www.opsi.gov.uk/Acts/Acts1998/ukpga_19980029_en_1) [accessed August 2010].

vii Available at: [www.opsi.gov.uk/acts/acts1988/Ukpga\\_19880028\\_en\\_1.htm](http://www.opsi.gov.uk/acts/acts1988/Ukpga_19880028_en_1.htm) [accessed August 2010].

viii See paragraph 27 of ‘Confidentiality guidance: endnotes’, available at: [www.gmc-uk.org/guidance/ethical\\_guidance/confidentiality\\_endnotes.asp](http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_endnotes.asp) [accessed August 2010].

ix Available at:

[www.ico.gov.uk/upload/documents/library/data\\_protection/detailed\\_specialist\\_guides/dealing\\_with\\_subject\\_access\\_requests\\_involving\\_other\\_peoples\\_information.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/dealing_with_subject_access_requests_involving_other_peoples_information.pdf) [accessed August 2010].

x See paragraph 16 of ‘Confidentiality guidance: endnotes’, available at: [www.gmc-uk.org/guidance/ethical\\_guidance/confidentiality\\_endnotes.asp](http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_endnotes.asp) [accessed August 2010].

There is some evidence that doctors may be more likely to consider data to be damaging to a patient than the patient might him or herself.<sup>8,15,16</sup> 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 him or herself 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. He or she should consider consulting others who have contributed to the record for help in assessing the nature and extent of any risk.

### 3.3 Copying letters to patients

The Copying Letters to Patients initiative,<sup>xi</sup> 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.<sup>xii</sup> 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.

xi See: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4008765](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008765) [accessed August 2010].

xii Available at: [www.bma.org.uk/images/consultantscopyingletterstopatients\\_tcm41-190155.doc](http://www.bma.org.uk/images/consultantscopyingletterstopatients_tcm41-190155.doc) [accessed August 2010].

## 4 Preparing for Record Access

### 4.1 Security, registration and authentication

It is vital that patients are confident that the Record Access service is secure and that their privacy is protected. Security includes both technical controls, such as audit trails of accesses, and 'human' or 'process' elements, such as assigning responsibilities (which will depend on local circumstances). As data controllers, NHS organisations must take appropriate measures to secure, and control access to, the personal data in patient records, and deal with any security or confidentiality breaches. These responsibilities fall to both the organisation as a whole and to individuals such as health professionals who access these records. When providing Record Access to patients, an organisation must provide a computer and human systems environment that enables a patient to access his or her own personal data without providing access to confidential information about other people held in the patient's own record (see Section 6.3), or in the records of other patients.

Once patients have accessed their records, they may share that information as they wish. They must understand, however, that they bear the responsibility for their actions.

It is essential that the correct patient has access to the correct record. Robust assurance of identity is a prerequisite to registration for a Record Access service.<sup>xiii</sup> Until such time that a suitably robust online registration and authentication method is available, registration should include sight of photo-ID plus appropriate household bills and other documentation that between them confirm full name, residential address and date of birth. The extent of identity checks can be supplemented by, or combined with, the healthcare organisation's existing knowledge and relationship with the patient. Alternative arrangements may need to be found for people such as travellers, homeless people, and people with a disability.

It is recommended that two-factor authentication is used before enabling Record Access to provide an acceptable and stringent level of security that aligns with national standards. The two factors can be something known to the individual (PIN/password) and something they hold (card or token or mobile phone that generates random numbers). Shared secrets, using carefully pre-selected questions, can also be an acceptable method of authentication.

Different electronic systems have been developed for Record Access in the UK. It is important that access and authentication be not only to a high standard but also, to avoid confusion, the process should be similar, or preferably the same, in all systems. More detailed guidance on security is being developed as part of the Good Practice Guidelines for General Practice Electronic Patient Records version 4. For more information on the security of personal information, see the plain-English 'Good Practice Note' produced by the Office of the Information Commissioner.<sup>xiv</sup>

<sup>xiii</sup> Identity verification may present particular issues in some settings, such as community pharmacies where there will always be a proportion of patients who are not personally known to the pharmacist. Such organisations will need to ensure they have a robust procedure for checking patient identity.

<sup>xiv</sup> Available at:

[www.ico.gov.uk/upload/documents/library/data\\_protection/practical\\_application/security%20v%201.0\\_plain\\_english\\_web-site\\_version1.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/practical_application/security%20v%201.0_plain_english_web-site_version1.pdf) [accessed August 2010].

## 4.2 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, that it could include test results together with an explanation of results, if this information is available. Some of the issues outlined in this document 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 should also be a mechanism for patients to change their mind about having access, the parts they access or the access rights granted to others.

Patients may wish to share their records with family members or others by giving them direct access. Where that is the case, they should be made aware of the associated risks (see Section 6.2), and understand that they are responsible for any consequences arising from their decisions to share confidential information.

## 4.3 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.

Education and training in Record Access should be included in medical, nursing, pharmacy, allied health professional and healthcare scientist undergraduate and postgraduate training. Nurses are already being trained to see themselves as 'information brokers' for patients and this could be extended to record access.

Patients and the public may also benefit from advice on how to best make use of Record Access. With appropriate training, voluntary agencies could be a potential source of advice.

## 5 Making healthcare records accessible to patients

### 5.1 Language and interpretation

The record should be written as an accurate summary of each encounter for legal and professional purposes, and also so the reader (patient or health professional) understands what is happening to the patient and what should happen next. The clinical record is currently written primarily for the health professional and for communication between health professionals. It is important that Record Access does not reduce the effectiveness of these traditional functions, even if the record changes in future so it is jointly held by the patient and his or her health professional, and includes contributions from the patient.

Substantial parts of a health record and its meaning are subjective. Even measurements and test results can be interpreted in different ways within one clinical team. It is important that health professionals still feel able to enter subjective thoughts into the record and this should be explained to patients when enabling access.

The need for clinical accuracy for health professional communication may also involve highly technical information, which must not be made less informative simply for the patient's ease of understanding. On the other hand, if the record is to become useful for patients, the clearer and more straightforward the writing the better. These can appear to be competing claims, but in many situations there is no conflict. Clearer writing is helpful to both health professionals and patients; for example 'stroke' may be as clear as 'CVA'. Nevertheless, in some situations, information will have to remain technical and the patient will need to rely on any information linked to the record for explanation.

When writing care plans, there should be less need for technical terms, so these could be written using the patient's own words.

#### Advice for health professionals

- Write as accurately, clearly and honestly as possible.
- Always assume that the patient will have access to what you write. This applies whether the patient has electronic contemporaneous Record Access or not and is good clinical practice in any case.
- Avoid local abbreviations or jargon if possible, provided that this does not detract from the clinical message or the way the record is coded, or significantly extends the time taken to enter information into the record.
- Using the patient's own words may be useful, provided that they add meaning and do not affect the clinical quality of the record.
- If the record has to be technical, so be it. Where possible, there should be links to patient-friendly explanations.

Several professional bodies have issued guidance and standards on record-keeping,<sup>xv</sup> and these remain appropriate when providing Record Access.

Record Access means that patients can play an important role in highlighting any errors, confirming or refuting accuracy based on their own understanding. Health professionals should amend any errors or inconsistencies as a matter of good practice.

Various tools have been developed to help general practices and other health organisations to improve the quality of the data in their clinical systems and the opportunity to find out how they compare with similar organisations around the country.

## 5.2 Including speculation in the record

Speculation is an important part of medical records and is clinically essential in structuring diagnostic tests and treatments. Health professionals are sometimes concerned about patients seeing their thoughts and speculations about differential diagnoses. Speculative data added during a consultation process gives health professionals the opportunity to place information in context, and explain the likelihood and timescales. An example would be explaining 'it is more than likely that you have X but I need to record all possibilities in your record, so do not be alarmed that I have entered Y'.

Experience shows that Record Access does encourage honesty, which can lead to occasional uncomfortable conversations with patients. However, experience also confirms that many patients welcome and expect openness, and that health professionals are best advised to share these options and decisions with patients.<sup>17</sup>

### *Advice for health professionals*

- Include speculation in the record where relevant.
- If possible, share potential alternative diagnoses with patients, explaining likelihood and timescales.
- The record should make it clear when speculation is being expressed.

xv See, for example, the Essence of Care Benchmark for record keeping, which is widely accepted in nursing, and is available at: [http://collections.europarchive.org/tna/20081112112652/http://www.cgsupport.nhs.uk/downloads/Essence\\_of\\_Care/Record\\_Keeping.doc](http://collections.europarchive.org/tna/20081112112652/http://www.cgsupport.nhs.uk/downloads/Essence_of_Care/Record_Keeping.doc) [accessed August 2010].

## 6 Record Access use cases

### 6.1 Use case: test results

Enabling patient access to test results may safely reduce demand on healthcare organisation time. Test results should always be communicated promptly whatever medium is used. Patients may need explanation in order to understand most test results because the meaning and significance may be difficult for health professionals to decide. Also, normal and abnormal may not apply unless the context is known. For example, a normal result may imply that action needs to be taken, while an abnormal test might be insignificant.

Some patients such as renal patients have an understanding of frequently repeated blood tests and so may want to access their results without waiting for the health professional to read them first. Other results that are potentially frightening or difficult to interpret should normally be screened by a health professional. If the patient wants to read his or her results raw before the health professional has screened them, the health professional could enable this, having explained the potential risks. However, it is important that patients who have elected to see the 'raw' result have ready access to a health professional for explanation.

Results with serious implications (including results that could be falsely reassuring) should be communicated by the health professional before the patient can read the result through Record Access, unless formally agreed beforehand.

#### *Advice for health professionals*

- Decide with the patient whether results can be read by the patient first or not; in general, results must be accompanied by appropriate explanation.
- Try to ensure that appropriately trained clinical staff are available to interpret test results if there is any confusion.
- Make comments on test results as comprehensible as possible, for instance 'kidney function is stable, please repeat in 3 months', 'test is abnormal, but you are on the correct treatment', 'results improving', 'repeat test in 1 month'.
- If appropriate, link tests with specific targets, for example HbA1c results show improvements as they reduce. If the results are within a given range, no change in dose of medication is required. If the results are outside a certain range, make an appointment with your usual health professional.
- Ideally, the system should inform the patient that a result is available, for example by SMS or email, or using the organisation's usual communication methods.

### 6.2 Use case: the patient sharing the record with someone else

#### *6.2.1 Benefits and risks to patients of sharing the record with someone else*

Experience shows that patients sharing their records with others can be positive and can enable family members to support people more effectively. Patients should feel able to share their information with whomever they choose.

Experience shows that patients commonly share their records with their family. For instance, older people may give permission to younger members of the family to access their record in order to

monitor their progress and care. While many patients will feel it is natural to share passwords with members of the family who they trust, this is not good practice and patients should be advised that they must take full responsibility should there be any subsequent misuse of the confidential information by friends or family.

Health professionals need to make patients aware that there are risks to sharing records. Patients need to understand that if they share records with another person there is the potential for that person to read something the patient doesn't want known. Examples are a patient on contraception or a patient being in London when the patient said he or she was in Manchester. In addition, there is the possibility that someone could use information from their record to help steal their identity or even steal some aspects of data that are highly confidential and open to criminal use (e.g. coercion or blackmail). Patient leaflets and systems should include advice to patients on security, for example: ensuring passwords are confidential; what to do if they change their minds about the people with whom they share their record; and who to speak to if they are concerned about the security of their medical records.

Rather than providing full-record access by password sharing, it is less risky for patients to show key aspects of their record to family, friends, other health professionals, or someone who can act as advocate on their behalf. The latter is more common when patients are disabled, do not speak English well or are experiencing a mental health problem.

A possible alternative would be to enable a patient to give permission for friends or family to be given their own separate individual passwords to directly access the patient's record. Whilst this may be a more secure approach than password sharing, the processing of personal data to manage the allocation of passwords to any other additional users would bring with it significant data protection responsibilities for the particular health organisation or health professional responsible for the patient's own record. Under the terms of the DPA the health organisation would also become the data controller for all the personal data relating to the provision of passwords to these other additional users. It would also be responsible for ensuring that the processing of this additional personal data complied fully with all the requirements of the DPA. Furthermore, at the time of writing, most systems do not provide facilities for registration of such users.

Currently, there are no plans or facilities to translate the record into other languages, so patients who do not speak English well may find it helpful to allow family members access to translate when necessary. It is important that this is the patient's, rather than the family member's, decision. It is good practice to offer the alternative of an independent translator where possible.

Some patients may use Record Access to share their data with other professionals or carers and this can also bring benefits. For example, it may be possible for a patient in an A&E or out-patient setting to provide access to a paper or electronic copy of their Summary Care Record or general practice record to a consultation.

Patients might also use Record Access to question the completeness or appropriateness of care. In such circumstances, they should be helped to secure the necessary improvements in a constructive way. The GMC's guidance states:<sup>xvi</sup>

Work with colleagues in the ways that best serve patients' interests. ... Never abuse your patients' trust in you or the public's trust in the profession.

### 6.2.2 *Sharing under coercion*

Sharing under coercion could happen if the patient is a child (see p. 15) or an adult in an abusive relationship. Health professionals should be aware of the potential for coercion and be vigilant in its detection. If suspected, it should be discussed with the patient and Record Ac-

xvi See [www.gmc-uk.org/guidance/good\\_medical\\_practice/duties\\_of\\_a\\_doctor.asp](http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp) [accessed August 2010].

cess avoided altogether or stopped before any harm is done.

### 6.3 Use case: third-party data

It is recommended that health professionals should minimise the amount of information that is not shared with the patient. However, before enabling Record Access for a patient, care needs to be taken to ensure that the patient does not have inappropriate access to third-party information. When a patient submits a subject access request, time can be taken to examine and process the records for the management of third-party information. Instant access by the patient to the electronic record means that systems need to be in place to ensure that the information a patient can access is within the current legal framework.

In general, the patient should not read any confidential information about another person, or learn the identity of someone who has provided information about the patient in confidence. Information that identifies a health professional who has contributed to the health record or has been involved in the care of the patient is not considered to be third-party data. Similarly, information about a third party that was provided by the patient, or information that the patient already knows, need not be withheld.

When a patient requests Record Access, it is the responsibility of the health professional, seeking advice where required, to judge whether any parts of the patient's record should be withheld. Determining whether third-party information should be withheld can be difficult; if in doubt, see the Technical Guidance Note from the Information Commissioner's Office entitled 'Dealing with subject access requests involving other people's information'.<sup>xvii</sup>

Searching all patient records for third-party data is likely to be a very difficult task. To overcome this obstacle, some systems allow health professionals to provide access to all information from a specified date. Another option is for the patient to access all past coded data (coded past history, immunisation, allergy information and prescribing data) but with free text and clinical notes – where third-party data is usually found – only visible from the specified date.

Another option is gradually to build up access by allowing views of certain information such as prescribing, test results or letters. These options also provide a solution for speculative data, which has been included in the past without explanation. Health professionals should always write records on the assumption that patients will be able to read them.

#### 6.3.1 *A third party who gives information but does not want his or her identity disclosed*

Many of the principles relating to the disclosure of third-party information apply to all medical records and not just Record Access. When deciding whether disclosure is reasonable without the consent of a third party, the following need to be taken into account:

- the duty of confidentiality owed to the third party
- the steps taken to obtain his or her consent
- whether the third party is capable of giving consent
- any express refusal of consent by the third party.

Consider the situation where a patient's wife informs a health professional that her husband drinks heavily. She wishes the professional to act on the information but does not wish to talk to her husband directly about it or reveal her identity as the information source to her husband. Whilst the alleged alcoholism would be recorded in the medical record and could be revealed to the husband, it is important that the source of the information is withheld from the husband. In

<sup>xvii</sup> Available at: [www.ico.gov.uk/upload/documents/library/data\\_protection/detailed\\_specialist\\_guides/dealing\\_with\\_subject\\_access\\_requests\\_involving\\_other\\_peoples\\_information.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/dealing_with_subject_access_requests_involving_other_peoples_information.pdf) [accessed August 2010].

most cases it is usually sufficient to explain to the individual giving the information that the person to whom this information refers will be able to read it but the identity of the provider will be protected. In all cases, this protection of identity must be real and secure. Alternatively, it may be possible to encourage honest discussion between the provider of the information and the patient. There is always a possibility that information given by a third party, for example the patient's wife, may not necessarily be factual or accurate, or may even be malicious. A patient is entitled to challenge the validity of computerised and manual data, and to have errors corrected.

Letters coming into a healthcare organisation may contain information about the patient provided by a non-clinical person, such as a spouse. If the writer does not want to be identified or it is not clear whether permission for disclosure has been given, the organisation will need procedures to deal with this, such as making a note of the information rather than adding the letter itself to the record. Alternatively, the sender could be written to in order to gain permission for sharing (i.e. filing in the patient's record).

### 6.3.2 Organisational risk

It is a risk to the healthcare organisation and to patients if letters are made accessible through the clinical system without a health professional reading them first. This could result in patients with Record Access reading them before a health professional has checked the content and made them safe, for example by removing confidential references to third parties.

### 6.4 Use case: mental health data

There is evidence that patients with psychiatric problems are more likely to be upset by reading their records than most other patient groups. However, it appears that they still feel that Record Access is the right thing for them to do.<sup>18</sup>

Health professionals sometimes worry about allowing patients with serious mental illness access to their records, fearing litigation and distress. Records often contain confidential third-party information and may on occasions contain information that could cause serious harm. Nonetheless, patients with severe mental illness have as much right to read their record as anyone else. Discriminating against patients with mental health problems is likely to increase mental health stigma. In such cases, other health professionals should always approach the patient's mental health services to confirm whether Record Access is appropriate. Access to healthcare information may have therapeutic benefits and provide reassurance for patients. However, there may be times when access may provoke paranoia or aggression.<sup>xviii</sup> Those working in mental health services who are involved in the care of the patient may well be in the best position to advise.

### 6.5 Use case: patients who lack mental capacity

For patients who lack mental capacity it may be necessary to develop a formal process by which an individual (or individuals) can be authorised to access the record on the patient's behalf.

The guidance for England and Wales in the Mental Capacity Act 2005<sup>xix</sup> is that an Independent Mental Capacity Advocate, appointed to support and act on behalf of the patient with impaired capacity, will have access to relevant records under 35(6)(b) of the act to help make health-related decisions on the part of the patient.

Lasting Power of Attorney (LPA) may enable the holder to access a patient's record. It does not allow

xviii There is advice on this topic in the BMA's 'Defining best practice for copying letters to patients' guidance at: [www.bma.org.uk/ethics/confidentiality/consultantletterstopatients.jsp](http://www.bma.org.uk/ethics/confidentiality/consultantletterstopatients.jsp) [accessed August 2010].

xix See the Mental Capacity Act Code of Practice at: [www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf](http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf) [accessed August 2010].

unfettered access. Special arrangements may need to be made. Detailed advice is available at [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk). Scotland and Northern Ireland have different procedures in this regard.

### *Advice to health professionals*

- It may be helpful to ask of patients who are losing capacity what they would prefer to do about Record Access. Particular care should be taken with such patients to ensure they are capable of making decisions about Record Access.
- It may be helpful for each organisation whose records are being shared to have a named person – their current Caldicott Guardian or equivalent – to take responsibility for implementing good practice in record-sharing.

## 6.6 Use case: children

People with parental responsibility for younger children normally have an automatic right to access their children's records.<sup>xx</sup>

Once children are 'Gillick competent',<sup>xxi</sup> parental access is only acceptable with the child's permission. Competence depends on the decision being made, so there is no specific age at which it is achieved. There is a difference between giving a child access to his or her records and allowing the child the right to control others' access. Competence to exercise these rights might be reached at different ages.<sup>xxii</sup>

When a child becomes competent to make such decisions, parents should no longer be allowed access without their child's permission. This permission, in most cases, will be readily given. Where the competent child does not give permission, disclosure could be justified if the public interest justifies, or where required by law. It may be possible to agree with the child that limited information is provided to parents, for example the disclosure of information relating to a child's need to have some very complex surgery would be acceptable, while not giving access to the whole record. The GMC provides guidance on responding to emerging capacity as children grow.<sup>xxiii</sup>

Children mature at different rates. An individual assessment of a child's competence may not always be practicable. Possible approaches for Record Access<sup>xxiv</sup> include:

1. Begin with a policy of not allowing either parent or child access to a record if the child is below a certain age, say 16 years old
2. Do not allow formal Record Access to any child's record below a certain age, say 16 years old
3. Have the system prompt the health professional when the child reaches 12, so the health professional can consider competency<sup>xxv</sup>
4. Have the Record Access system automatically disconnect parental access when the child reaches 12 years old. This would stimulate discussion within the family about whether parental access should continue. If asked, the following kind of leaflet could then be given to the family:

xx For more information on who has parental responsibility, see Appendix 2 of *0–18 Years: guidance for all doctors* by the GMC, available at: [www.gmc-uk.org/guidance/ethical\\_guidance/children\\_guidance\\_index.asp](http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp) [accessed August 2010].

xxi Where a child has the maturity and understanding to make a decision for him or herself.

xxii Note also that specific provisions apply in Scotland. See Section 66 of the DPA at [www.opsi.gov.uk/acts/acts1998/ukpga\\_19980029\\_en\\_7#pt6-pb7-11g66](http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_7#pt6-pb7-11g66) [accessed August 2010].

xxiii [www.gmc-uk.org/guidance/ethical\\_guidance/children\\_guidance/index.asp](http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance/index.asp) [accessed August 2010].

xxiv Note that the approaches below relate only to Record Access, and not subject access rights under the DPA (which would for example give some young people under the age of 16 the right to a copy of their personal data).

xxv The Information Commissioner's guidance is that 'a person under 16 may exercise any right under the Act when he has a general understanding of what it means to exercise that right and that a person of 12 years or more shall be presumed to be of sufficient age and maturity to have such understanding'. See section 4.1.6 of the guidance, available at: [www.ico.gov.uk/upload/documents/library/data\\_protection/detailed\\_specialist\\_guides/data\\_protection\\_act\\_legal\\_guidance.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/data_protection_act_legal_guidance.pdf) [accessed August 2010].

Dear parent/carer of \_\_\_\_\_,

We hope you have found Record Access useful. You may want to continue it.

However, as children grow up, they can increasingly take responsibility for themselves. The Record Access system has automatically cut off parental access at 12 years old. This is designed to encourage your child and the family to consider how to proceed in the future. Your options include:

1. Only the child has access. The child holds the PINs and passwords, and he or she will now need to change these
2. Parents, carers and the child all have access to the child's record, with the child's agreement. The PINs and passwords are shared
3. Only the parents/carers have access and the child does not. This is not recommended, as it may, in unusual situations, disadvantage the child.

Please let reception know what you wish to do about Record Access now.

Yours faithfully,

\_\_\_\_\_

### 6.6.1 *Records of Child Protection Case conferences*

In this instance, we refer to 'case conferences' as meetings to consider child protection issues with a family. The aim is to assess progress and, if needed, to come to a decision about whether the child should be under special social work surveillance and/or protection. The minutes commonly include information from a wide variety of people, professional and lay, about the children concerned and the adults who have had dealings with them.

Unless data is likely to cause serious harm, divulge confidential third-party information, or disclosure would be against the child's best interests, then it should be provided to the parents if the child lacks competence. Similarly, it should go to the child if the child is competent; it would also normally go to the parents of the child in such a case unless the child objected.

Some children may not have been informed about the meeting or the process of child protection to which they were involved when younger. This information should still be available to the child when he or she grows up unless the data is likely to cause serious harm or divulge confidential third-party information. These principles should be applied to other multidisciplinary meeting records.

#### *Advice to health professionals*

In the UK, members of the family and carers sometimes receive minutes of the meeting, and those can be filed in the child's clinical record. Other relevant child protection information can also be stored in the child's record and in some cases a summary may be preferable. The child has the right to make a separate subject access request to read such information in the future, which will enable the organisation to scrutinise the record before handing the information to the child.

### 6.6.2 *Family disputes*

Fragmentation of families and family disputes increase the problem of parental access to child records. Where parents or those with parental responsibility for a child are in dispute over key issues concerning the child's health there are risks the child may be coerced by one or both parents. In this situation, Record Access might need to be halted for the whole family. This would need to be a decision for the organisation with advice from a medical defence organisation and/or the GMC.

## 6.7 Use case: responding to issues of accuracy and interpretation identified by the patient

There is good evidence that medical records can be inaccurate both with regard to demographics and health information.<sup>19</sup> Record Access can assist health professionals with improving the quality of the record, for which they have a legal responsibility.

The Good Practice Guidelines for General Practice Electronic Patient Records<sup>20</sup> states:  
Personal data shall be accurate and, where necessary, kept up-to-date.

[and]

It is important that records do not contain information which may mislead another health professional using them.

The National Information Governance Board has published guidance on this topic, which is essential reading for health professionals planning to implement Record Access.<sup>xxvi</sup> It may also be helpful to look at the Information Commissioner's Good Practice Note 'How does the Data Protection Act apply to recording and retaining professional opinions?'.<sup>xxvii</sup>

### Advice for health professionals

Amendments to data, particularly diagnostic data, held within electronic records are essential where the initial data is inaccurate or incorrect.

Where a patient and health professional disagree about accuracy, a note explaining the patient's views can be included in, or appended to, the records. This also allows health professionals using the records in the future to be wary of placing undue weight on disputed information.

If an entry is no longer accurate because the original diagnostic condition is now resolved, it should remain on the system because it is part of the patient's past medical history. However, an additional code should be added, for example 'Asthma resolved'.

If an entry is inaccurate primarily because of incomplete or misunderstood data, it should remain on the system but must be amended – i.e. it should be substituted with the revised code plus a free-text comment conveying the meaning of the original entry. An example would be 'Myocardial Infarction replaced by Chest Pain', which was originally recorded as 'Myocardial Infarction which was ruled out after investigation'.

If an entry is wrong, an administrative code should be used to explain why the code is being deleted from the patient's incorrect record. The healthcare organisation should refer to its clinical system guidance on deleting codes. The original entry should still be present on the clinical system audit trail but may not be visible on the screen, so a free-text comment such as 'added in error against wrong patient's notes' can be added when the code is deleted.

If a patient states that a particular event or piece of information is missing and the health professional has no means of validating this information, a note of this should be added to the record.

xxvi [www.nigb.nhs.uk/guidebooklet.pdf](http://www.nigb.nhs.uk/guidebooklet.pdf) [accessed August 2010].

xxvii Available at: [www.ico.gov.uk/upload/documents/library/data\\_protection/practical\\_application/gpn\\_recording\\_and\\_retaining\\_professional\\_opinions%20v1\\_290408.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/practical_application/gpn_recording_and_retaining_professional_opinions%20v1_290408.pdf) [accessed August 2010].

## 7 Future considerations

### 7.1 Patients contributing to the record themselves

It will soon be possible for patients to add their own data to the record. This might include blood pressure, peak flow, blood sugars and oxygen saturation measurements, and lifestyle information such as diet and exercise charts. It may also be possible for patients to complete questionnaires and to write their history before arriving for a consultation. This could be particularly helpful for people with communication difficulties or for people who wish to leave documents in the record, such as advance directives (sometimes called 'living wills'). Of course, this frequently happens in current practice, but patients usually provide their data on paper and may include treatment preferences, resuscitation and end-of-life care instructions.

Patient-added data will need to be treated with care. Health professionals should use it to supplement, not replace, their own clinical assessment. For example, it should not be assumed that patient-added data will be completely accurate in relation to self-monitoring, although over time the health professional will be able to gauge the accuracy of a particular patient's data entry.

At times, information entered by patients and their guardians/carers may be contradictory, but that is no different in principle to them writing letters that would be scanned into the record.

It must be made clear to patients that adding details to the record is not an appropriate way to communicate urgent information. However, once patients start adding non-urgent information, health professionals could find themselves in a vulnerable position if they failed to act upon it and the patient came to harm. Health professionals could also be held accountable if a patient came to harm if they relied on patient-added information without making their own clinical assessment and judgements. This will be complicated by shared records and is explored in more detail in the Royal College of General Practitioners' 'Shared Electronic Patient Record (SEPR) systems in primary care'.<sup>xxviii</sup> Medical defence organisations may offer further advice.

#### *Implications for health professionals*

Unsolicited additions may need to be treated with caution and should not be accepted as a proxy for medical assessment. If patients add data of their own, it will be necessary for the source of the information to be clearly indicated in the clinical record. Workload and process issues will need to be investigated before implementation, for instance procedures to support timely review and appropriate decision-making in response to patient entries. Health professionals should consider whether they need to read the information before filing it in the record in case action needs to be taken in response to the data. This is particularly complex in the case of patient-entered data in a shared electronic record.

### 7.2 Other professionals writing in the record

As care becomes more of a team process, so will the record. Many patients' records already contain entries by health personnel from multiple organisations. This is likely to be extended to staff from social care. Such staff will also need training in order to understand the implications

<sup>xxviii</sup> Available at: [www.rcgp.org.uk/get\\_involved/rcgp\\_standing\\_groups/informatics\\_group/shared\\_record\\_professional\\_gui.aspx](http://www.rcgp.org.uk/get_involved/rcgp_standing_groups/informatics_group/shared_record_professional_gui.aspx) [accessed August 2010].

of Record Access and this guidance will also apply to them.

### *Implications for health professionals*

The implications of shared records extend beyond Record Access and therefore are not described in detail in this document. Health professionals should refer to the Royal College of General Practitioners' guidelines on shared records, which cover the governance, medico-legal and patient safety consequences of Shared Electronic Patient Record (SEPR) systems in primary care.<sup>xxix</sup>

xxix Available at: [www.rcgp.org.uk/news\\_and\\_events/news\\_room/news\\_2009/rcgp\\_shared\\_record\\_professiona.aspx](http://www.rcgp.org.uk/news_and_events/news_room/news_2009/rcgp_shared_record_professiona.aspx) [accessed August 2010].

## 8 Summary and conclusions

The emerging evidence is that health records can be safely shared with patients for the improvement of their care. Sharing records with patients has significant potential benefits for professionals and patients: for relationships, for understanding, for health outcomes and for safety. At an early stage in the development of this approach to care, uncertainties are understandably widespread amongst health professionals and there is a need to learn from good practice.

The intention of this document is to address these concerns, to make it easier for healthcare organisations and health professionals to provide contemporaneous electronic Record Access to patients and to highlight some of the benefits of enabling this interaction, as well as some of the risks and concerns about sharing.

Further research will be carried out to explore the potential risks and benefits in more detail, and this guidance will be regularly reviewed to reflect experience.

In time, Record Access is likely to become the norm, and lead to a new level of mutual trust between patients and health professionals, based on an improved understanding of each other's perspective.

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## Appendix I: organisations providing feedback

The authors would like to thank people from the following organisations who kindly reviewed and provided comments on draft versions of this guidance:

- Action for Blind People
- Addison's Disease Self-Help Group
- Allied Health Professionals Federation
- Arrhythmia Alliance
- Arthritis Care
- Asthma UK
- Atrial Fibrillation Association
- Behçet's Syndrome Society
- Breast Cancer Care
- British Dietetic Association
- British Medical Association
- The British Society for Rheumatology
- Cancer Research UK
- Clinical Leads
- Community Practitioners' and Health Visitors' Association/Unite
- Consumers' Association
- Department of Health
- Diabetes UK
- Faculty of Dental Surgery, Royal College of Surgeons of England
- General Medical Council
- Gorlin Syndrome Group
- Herpes Viruses Association
- HPTH (Hypoparathyroidism) UK
- Insulin Dependent Diabetes Trust
- Joint GP IT Committee
- Medical Defence Union
- Medical Protection Society
- Migraine Action
- Mind
- National Clinical Reference Panel
- National Information Governance Board
- Nursing and Midwifery Council
- Information Commissioner's Office
- Pelvic Pain Support Network
- Public Health Nurse
- Rotherham General Hospital Foundation Trust Patient Panel
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Obstetricians and Gynaecologists
- Royal College of Paediatrics and Child Health
- Royal College of Physicians

- Royal National Institute of Blind People
- Royal Pharmaceutical Society of Great Britain
- Skin Care Campaign
- Syncope Trust and Reflex anoxic Seizures
- Terrence Higgins Trust
- Torbay IBD Panel
- Tuberous Sclerosis Association
- *Which?*

## Appendix II: literature review

### What do we know about Record Access? An overview of research

Although opportunities for patients to view their medical records have increased over the past 20 years, uptake is low, with many patients placing trust in their clinicians to provide face-to-face information.<sup>1-3</sup> There is also little known about what happens when patients do access their records.<sup>2,4</sup> This section reviews the small number of studies exploring patient access to both paper and electronic records. It highlights the perceived benefits of Record Access as well as concerns about confidentiality and clinicians' views about patient access.

### Patients' experiences of paper-based Record Access

Early research focused on patients' attitudes towards accessing paper-based records in a variety of settings. Research on the provision of records to psychiatric patients has generally shown a positive response, with patients finding access to healthcare records helpful.<sup>5-11</sup> However, psychiatric patients have also been the group most likely to experience difficulties when seeing information about themselves that they have found difficult to accept.<sup>12</sup> Patient hand-held records have also been used successfully in obstetric, paediatric and cancer care to improve communication and promote patient involvement in their own care.<sup>13-16</sup> Similarly, the provision of records to patients in general practice settings, including the provision of hand-held pregnancy records, has also met with a positive response. One study looking at the effect of a computer-generated patient-held medical record summary, combined with written personal health records, found that they enhanced health promotion activities such as making lifestyle changes.<sup>17</sup> Studies have also shown that Record Access is perceived to be helpful, reassuring and advantageous, with a positive effect on communication without increasing anxiety.<sup>1,12,18,19</sup> A comprehensive review of the literature on access to paper-based records reported that the most consistent finding across studies is that patient-accessible medical records enhance doctor-patient communication.<sup>20</sup>

### Electronic access – public views of potential benefits and patients' experiences of access

Current research in the area of Record Access focuses both on patients' views about computerised and online electronic Record Access to medical records.

In the UK, an NHS-commissioned report recently published qualitative and quantitative findings from a study examining patients' views about the concept of NHS Care Records Service (CRS) and its potential impact. Findings indicated that, overall, patients had a positive reaction, believing that it would provide benefits both to healthcare professionals and themselves in terms of a better-managed healthcare service. The idea of access was welcomed by the majority in a survey of the general population:<sup>21</sup>

The ability to see recent test results, ability to look at medical history at any time and the facility for a GP to book appointments at hospitals and clinics during the appointment was felt to be important by the greatest proportion of respondents (63%, 60% and 60% respectively).

Patients also welcomed the opportunity of adding to their records and being able to ask for repeat

prescriptions and make online GP appointments. There were concerns about confidentiality and with patients wanting access to records to be restricted to those within the NHS. Patients also wanted to control the amount and type of information available to other healthcare professionals such as ambulance and paramedic staff.<sup>21</sup>

Similarly, another study looked at the potential impacts of patient access to their electronic care records in general practice. This study showed that patients were positive about the possibility of accessing their records electronically. They felt that it would improve their relationship with their clinician and, whilst anticipating that there would be some mistakes in their records, they welcomed the idea of adding to their records. Although patients also had some concerns about accessing their records over the internet, security issues were not a significant concern.<sup>3</sup>

However, unlike previous studies with paper records, these studies did not address the patients' actual experiences of accessing electronic records in practice. Instead they tended to focus on patients' views of the concept of electronic access and its potential impacts. In fact, a recent review found only a small number of studies that addressed patients' access to, and actual engagement with, electronic medical data.<sup>22</sup> The majority of these studies evaluate a variety of different electronic Record Access systems and describe patients who were able to view and comment on the systems, their records and impact. Patients in these studies were therefore provided with access to their records electronically during the research period.<sup>4,6,22-28</sup>

Electronic access, like paper-based access, has also been viewed positively in studies where patients were provided with electronic access.<sup>6,23,25,27,29</sup>

Similar to patients who had experience of accessing their paper-based records, patients who accessed their electronic records found electronic records useful, acceptable and easy to access.<sup>4</sup> The impact of electronic records has also been explored. A number of studies with patients who were provided with electronic access have also shown that patients believe that it improves their relationships with clinicians by breaking down barriers, providing them with reassurance, and improving confidence and trust in clinicians.<sup>4,25,27,29</sup> The SUSTAIN study of patients who had direct access to their records over the internet in Sweden found that access increased patients' confidence and trust in physicians.<sup>30</sup>

It is also already known from previous research on patients using PAERS that:

- patients feel more in control and more confident through having access to their medical record, being able to view letters written about them from GPs to hospitals, being able to collect results quickly, etc.
- patients find the system easy to use and feel that they can understand most, but certainly not all, that they read
- patients are concerned that the information be accurate and feel that they could correct inaccuracies
- patients are concerned about issues of security but this appears to be a minority issue
- a small proportion are upset by what they see, but the majority of that small group still feel that they would want to continue having access to their records.<sup>3</sup>

Electronic Record Access has also been perceived by patients as providing an improved opportunity for involvement. Patients welcome the opportunity to negotiate what is recorded in their medical records. This includes beliefs, values and wishes for care, as well as providing the opportunity to correct inaccuracies.<sup>4,26,31,32</sup> Patients view this as an opportunity to develop a medical record that reflects patients' perspectives, fostering an environment of open dialogue and partnership, and supporting continuity of care.<sup>31</sup>

Despite variations in the frequency of use, studies have also demonstrated that patients feel better informed about their health and health care, and that this promotes a sense of control, and a sense of illness ownership.<sup>4,29,33,34</sup>

Central to access issues is that of trust: 'Better communication bolsters trust', which Kirshner cites as 'perhaps the most significant and influential component of the patient–doctor relationship'.<sup>35</sup> Winkelman contends that trust motivates self-care and is pivotal in determining whether a patient merely 'looks at' or 'uses' his or her medical records (quoted in Protti and Eggert).<sup>36</sup>

### Issues of concern – confidentiality and security

Although Record Access is viewed positively, patients have concerns about the security and confidentiality of patient records in general. They feel that access provides the potential for unauthorised access to health information<sup>2</sup> and security issues were commonly raised in studies exploring electronic Record Access.<sup>3,4,20,37,38</sup> Suggestions for overcoming these concerns include improved security and patients having the right to give or withhold consent for professionals accessing their information.<sup>2,4,39</sup>

### Clinicians' views about patient access to records

Although patient enthusiasm is clear, clinician enthusiasm is far from universal. Clinicians are concerned that patients will be confused or misled by their records. They are concerned too that mistakes and confusion will be exposed, and that that this provides the opportunity for litigation.<sup>19,29</sup>

In fact, in the US, there is good evidence to suggest that where Record Access has been introduced there has not been an increase in litigation above the general background rate.<sup>12,40</sup> Moreover, some studies have demonstrated that, despite initial misgivings, clinicians later believed that Record Access improved communication with their patients, given time-limited consultations,<sup>29</sup> and empowered them.<sup>41</sup>

Despite theoretical misgivings about patients having access, UK consultants who reviewed the letters they had written about cancer patients were reassured by the experience.<sup>19</sup>

### Summary

Patients value access to both paper and electronic medical records. They report that access helps break down barriers between patients and doctors, thereby improving consultations and their relationships with health professionals. They also feel better informed and have a sense of control over their own health and health care, and believe that Record Access provides the opportunity to be more involved in the recording of information that promotes a sense of illness ownership. Patients express some concerns about confidentiality, particularly with regard to unauthorised access to health information. However, the advantages outweigh the disadvantages. Clinicians are also beginning to realise the value of improved communication with patients as a direct consequence of patient Record Access. As electronic patient records become more accessible, research is needed into how patients use the information they have accessed and the impact that Record Access has on health outcomes and relationships with clinicians.

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## Appendix III: electronic record systems outside the UK

Record Access is currently available in a variety of formats across the world and includes paper-based access, sophisticated electronic access systems and systems that enable patients to access their records via the internet.<sup>1-3</sup>

Many systems with similar applications to PAERS have been created, mainly in the US and Canada. These include: the web-based patient Clinical Information System (patCIS);<sup>2</sup> Winona Health Online, a web-based service that gives people access to health information, allowing them to create their own medical record and communicate with local healthcare providers;<sup>4</sup> CliniViewer, a tool that organizes and presents the clinical information in multiple records;<sup>5</sup> and PAMFOnline, an integrated Electronic Medical Record (EMR) system with eHealth application.<sup>6</sup>

Another example is iHealthRecord ([www.ihealthrecord.org/](http://www.ihealthrecord.org/)), by Medem Incorporated. Patients retain control and responsibility for their own iHealthRecord, which will eventually include interfaces to EMRs and health plans. It offers secure email consultation with physicians, automatic email medication recall warnings, automatic education programmes tailored to individuals, online reminders, and improved access to records.

### The Personal Internet worked Notary and Guardian (PING)

PING (<http://mit.dspace.org/bitstream/handle/1721.1/36383/6-805JSpring-2002/NR/rdonlyres/Electrical-Engineering-and-Computer-Science/6-805JEthics-and-Law-on-the-Electronic-FrontierSpring2002/49DBDE08-3EC9-491A-AC55-E35030BDBDFE/0/ping.pdf>) at Boston's Children's Hospital, US, is a web-based and patient-controlled personal medical records system. It integrates data from multiple care centres and networks, providing patients and families with a confidential and collaborative means of managing their clinical documentation. Its founders contend that the keys to a successful personal health record include patient control over permissions, safeguards to protect patients, and interoperability (data can be included from multiple sources) facilitated by data exchange using public/open standards.

Another example, My CARE Source – soon to be expanded to include patient access to online lab results and electronic health records – offers an enhanced 'portal' to personalised disease management support for cancer patients at Grand River Hospital in Kitchener, Ontario, Canada. Patients can monitor symptoms and/or side effects of treatment by accessing care plans. Validated health information and tracking tools promote informed choices and instil a sense of autonomy and control.

The Department of Orthopaedics and Sports Medicine, Seattle, US, has developed the Patient Health Information Management System (PHIMS). PHIMS permits patient consultations. Not only can patients manage their general information and record details of medical problems over time, but consulting physicians are also able to review information and clarify details with a patient prior to a scheduled appointment.

Additional examples can be seen at [www.informatics-review.com/records.html](http://www.informatics-review.com/records.html).

Record Access thus enables access to information to support self-care and shared decision-making. It also responds to patients' expressed need for more information. It can also be seen as a right to one's own health information, which, to some extent, is enshrined in law. It also offers the potential for truly shared care in which both patient and clinician create an agreed record.

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## Appendix V: the Steering Group and Project Group

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