

# GUIDELINES FOR ELECTRONIC RECORD SHARING WITH PATIENTS



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## 1. INTRODUCTION

This document distils experience in patient record access (RA) of over 35 years in UK general practice and in the USA.. It supports the process of patient record access which evidence and experience shows benefits both patients and clinicians <sup>1</sup>. Organisations such as Kaiser Permanente in the US, having offered record access for some years, have concluded that patients find it useful and relevant while clinicians find that it enhances care <sup>2</sup>.

We start from the premise that people should be able to see all of their health data. However there are some limited situations in which it is legally not possible in the UK.

Most of the following discussion is based on access to the primary care record. However, there are excellent examples of access to hospital records in specific specialities <sup>3</sup> and conclusions can largely be extrapolated from them also.

### **The aims of this document are:**

- to enable clinicians to use and implement RA safely and with confidence.
- describe what a record is and how it fits into health and disease management
- to support a “partnership of trust” between the patient and the clinician / organisation
- offer a set of good practice guidelines
- make clear what the limitations on access are, through examples called use cases and demonstrate how to deal with these limitations
- offer relevant advice about the design of systems that offer RA
- to describe how to proactively write a record and make attachments to it so that it can be legally and safely accessed by the patient
- to begin to ensure that patients experience a consistent service, if not an identical one

### **Who this document is for**

The document is primarily for clinicians. We know that many clinicians are concerned about Records Access (RA) in general and about a number of specific, legitimate and important issues, such as third party information. This document is to help them have more confidence in the process and to reduce their need to invent ways of managing these perceived risks.

It is also for the public in general and those who are patients at any time. We hope that it will be useful and informative for them – and also help them feel more confident about this new process.

It is also, for designers of systems that enable RA, whether the systems are electronic or otherwise, for record system commissioners, system providers and data processors.

It is also for any others interested in using and developing RA

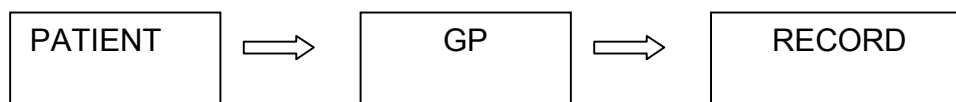
### **The global potential for RA**

Evidence is accumulating that RA has significant benefits for both patients and clinicians<sup>4</sup>. There is a moral case for RA, and this is expressed variably across the world. Even if RA is not formally recognised, we think that its benefits are important enough for the WHO to be working to spread it across the world. Indeed, coordinating this kind of approach globally has potential for savings of time and resources. RA does not have to be electronic – paper access and even spoken presentation of the record contents is also helpful.<sup>5</sup>

**Record access creates a new environment.** Patient record access, in the UK, does not create new legal challenges<sup>6</sup>. RA has to fit in to the existing legal framework. It does not alter it. In the past, however, issues of access meant that patients would have to ask for access on every specific occasion. This meant that:

- the practice had time to consider the request. It could be a leisurely broker between the patient and their information
- the patient usually had a specific reason for access
- access tended to be linked to complaints
- access was a reactive process following past events
- It did not have many connotations of benefit for practice or patient
- It slowed down processes of care and communication

In the traditional arrangement, the patient could only access the record through the GP.



The new situation can be described like this: both patient and clinician have equal access to the record



Access to the electronic record by the patient at any time they choose puts pressure on practices to be more honest and to have accurate and legally consistent recording. As a result, experience so far suggests a better outcome for patients and practices.

Electronic health records and access to them are most likely to be useful to patients and carers, secondary users and health care administrators when they are used within an efficient and transparent framework of information governance.

#### **Settings for record access**

There are many settings in which, and many professionals with whom, a patient may view or share their record:

- GPs
- Hospitals
- Community clinics
- Opticians
- Pharmacies
- Wherever clinicians work and reside
- Any clinician

There are many media through which patients may choose to view their records:

- Online
- On kiosk
- CDs, memory sticks
- Mobile phones, i-pods, PDAs
- Paper records
- e-cards

## 2. WHAT DO WE MEAN BY A RECORD?

Most work on RA has been in primary care because the record in the UK tends to be the most complete. The core of the GP record usually consists of:

- Consultations including medications prescribed
- Results
- Letters
- Other health info such as allergies, vaccinations.
- Administrative entries

The record often also includes future goals, prognoses, targets, progress markers and outcomes as well as current progress, data and past history.

The record is written primarily for the clinician and for communication between clinicians. It is important that RA does not reduce the effectiveness of these traditional functions. There is increasing evidence that the record becomes, in addition, useful to patients and carers, secondary users and health care administrators when it is used within an efficient and transparent framework of information governance.<sup>7</sup>

The form of the record will vary depending on who has produced it, for what reason, in what part of a health care system and in which country. Nonetheless, there are some important and relevant characteristics that affect the way people see and respond to seeing their record and writing it.

Perhaps the most important issue is that substantial parts of a health record and its meaning are subjective. It is partly an accurate impersonal representation of an event and it is also a subjective and partial view, generally by a clinician and coloured by their medical gaze and their personal ideas and prejudices. Even test results are interpretable and their meaning varies, even within one system of coding.

In addition, there are many systems of coding medical terms and there are inconsistencies in agreeing meaning between systems of codes. Hopefully, this will be less of a problem with universal coding.

This mixture of objectivity and subjectivity can make understanding the record difficult for patients. It also means that different interpretations of the record are rational and inevitable. Clinicians write a partial truth.

We refer to methods of reducing the difficulties that patients may experience when trying to understand their records later in this paper.

### **3. WHAT DO WE MEAN BY RECORD ACCESS?**

Effective and useful record access has been described by Kaiser Institute for Health Policy<sup>8</sup>. Patients should be able to see:

- The whole accurate, contemporaneous record, available anywhere
- The record should enable patients to understand what they read and help them make use of that information
- Tailored and targeted health information and decision-support
- Should offer reminders for appointments and gaps in care
- A facility to allow them to enter data of their own
- A portal to a range of facilities
  - Advice on improving health and managing disease
  - Interactive links to others
  - Be capable of implementing behavioural changes to improve the outcomes sought by their care

If different systems are developed for record access in the UK, It will be important that access and authentication is not only of the highest standard, but should be similar, or preferably the same process in all systems to avoid confusion.

## 4. LEGAL BACKGROUND

The GMC<sup>9</sup> makes it clear that, in the UK, RA is seen as an accepted approach to ensuring a transparent and honest relationship between clinicians and their patients. In principle, in the UK, patients have the right to access all health information held about them, with 2 exceptions

**The Data Protection Act 1998**<sup>10</sup> and **Access to Medical Reports Act 1988**<sup>11</sup> state that a patient (including “Fraser competent” children) or anyone authorized by the patient are entitled to access their records including reports supplied by a medical practitioner for employment purposes or insurance purposes. Parents of children who are deemed not “Fraser competent” are entitled to access their children’s medical records. Access can only be denied where the information:

- may 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 had not consented to the disclosure.

### **What is the definition of serious harm?**

There is no formal definition, it appears, of serious harm. The GMC has tried to offer clarity in the context of withholding information when seeking consent to treatment. In guidance on consent the GMC says:

‘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 are poor at deciding whether information is likely to harm a patient. The clinician is more likely to consider data to be damaging to a patient than the patient is their self.<sup>12</sup>

Clinicians experienced in record access suggest that there are very few items that will need removing.

**The Freedom of Information Act 2000**<sup>13</sup> gives people a general right of access to information held by or on behalf of public authorities unless that information would, or would be likely to, endanger the physical or mental health of any individual, (including the applicant, the supplier of the information or anyone else).. However, medical records are exempt from the requirements of the Act, because they include personal information provided in confidence, and/or in any case where disclosure is prohibited under the Data Protection Act (see s40, s41 and s44) [http://www.opsi.gov.uk/acts/acts2000/ukpga\\_20000036\\_en\\_4](http://www.opsi.gov.uk/acts/acts2000/ukpga_20000036_en_4)

The Copying Letters to Patients initiative <sup>14</sup> enabling patients to see all letters written about them, is advisory only. However, this initiative is being adopted across the NHS, with general acceptance by patients and clinicians

Data Governance. Every clinician needs to be aware of the guidance on data governance which is most conveniently available at <http://www.dh.gov.uk/en/Policyandguidance/Informationpolicy/index.htm> and [www.informationcommissioner.gov.uk](http://www.informationcommissioner.gov.uk).

**General advice is summarised by the Information Standards Board** <sup>15</sup>:  
You must maintain the confidentiality of all patients/clients and, working in partnership with patients/clients, understand and uphold the principles of informed consent and disclosure of confidential information in accordance with all relevant law and guidance produced by the professional regulatory bodies and others.

Patients/clients have a right to know when information is recorded about them and their care, how the information will be recorded and how their information may be used in the future.

Patients/clients have a right to access their own records. You must respect their decisions to limit or extend your or another healthcare professional's access to their information, however, exceptions may apply where, in your professional judgement, to restrict or withhold information would cause serious harm to the patient or others.

When you are responsible for personal information of patients, you should - taking reasonable measures - assure yourself that the system provided by your organisation to record patient/ client information is effectively protected against loss, damage and security, ensuring that you use the system appropriately.

You should keep up to date, and adhere to, law relating to information and record keeping, eg. Access to Health Records (1990), Access to Medical Reports Act (1998), Data Protection Act (1998) and the Freedom of Information Act (2000).

## 5. SECURITY, REGISTRATION, AUTHENTICATION

### **Registering the patient for RA at the practice.**

It is essential that the correct patient is given the correct record. Photo-ID is a pre-requisite at registration, or sight of appropriate household bills for identification.

### **Authentication**

Again, we would recommend that a patient can only be authenticated for RA with photo-ID: driving licence, passport or picture freedom pass.

### **Level of security**

The ideal security is provided by 2-factor authentication: something you know (pin/password) and something you hold (card or token that generates random numbers).

**Informed consent for RA.** Patients must be given information about benefits and risks. This should be as evidence-based as possible. Some of the contentious issues outlined in this paper should be explained simply but fully to them.

An example of information for patients can be found at Appendix 1.

### Implications for suppliers.

It is likely that some patients will want 2-factor authentication and some will not. It may be best if systems can manage both approaches.

## 6. GUIDELINES FOR WRITING RECORDS THAT CAN BE SHARED

### **Language and interpretation**

The record should be written as a summary of the encounter for medico-legal purposes and also so that the viewer (patient or clinician) understands what is happening to the patient and what should happen next. Coding needs to be accurate and consistent.

The record needs to be written as accurately as possible. There are competing claims. On the one hand, as the record is primarily for clinician communication, it needs to be clinically accurate and this may involve highly technical information which must not be made less informative for the patient's sake. On the other hand, if the record is to become useful for patients the clearer and simpler the writing the better.

In many situations, there is no conflict. Clearer writing is helpful to both clinicians and patients. "Heart attack" may be as clear as "MI". In some situations, information will have to remain technical and relatively impenetrable and the patient will need to rely on information attached to the record for explanation.

### Implications for clinicians

Write as 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 RA or not. This is good legal practice in any case.

Avoid local abbreviations if possible.

If the record has to be technical, so be it.

### Implications for system suppliers

Automatic added information linked to key aspects of the record is essential. The links need to make it as easy as possible for patients to understand medical jargon.

### **Writing the record with speculation**

Clinicians are concerned when patients see their thoughts and speculations about future possibilities. Is it appropriate to tell a patient with a few months of tingling in their arm that MS is a possibility? Is it appropriate to share with a patient that colon cancer is a differential diagnosis when a patient presents with diarrhoea? It may be important that the clinician record speculation to remind them to take these into account in future for the patient's better care.

RA does encourage honesty. This can lead to occasional uncomfortable conversations with patients. However, evidence and experience confirm that patients welcome and demand openness and that clinicians are best advised to share these options and decisions with patients <sup>16</sup>. Again, this data is currently available to patients under current legislation in any case. Electronic RA merely speeds up the process.

#### Implications for clinicians

It is acceptable to write speculation in the record. It is best to share differential diagnoses with patients.

## **7. RECORD ACCESS, SELF-MANAGEMENT AND SHARED DECISION-MAKING**

Access to medical records may be most effective when accompanied by information to improve patients' understanding and use of the data contained within the record. Increasingly electronic forms of record access are accompanied by interactive sources of information or communication,

There is some limited evidence that record access improves compliance<sup>17</sup> and supports positive health behaviour such as smoking cessation<sup>18</sup>. In general, self-care and shared decision-making have been shown to improve outcomes and to reduce the use of health services<sup>19</sup>. For patients to maximise their involvement in their own health care, they need to understand their current care and management. Record access is a pre-requisite for this.

Patient involvement will be enhanced if record access links the data in the record to information about the patient's health conditions. Information sources need to offer accredited and regularly updated information. They may include:

- decision aids
- leaflets
- videos
- links to local support groups, clubs and places of interest
- links to NICE
- links to Map of Medicine
- links to NHS Choices
- links to voluntary agencies
- links to interactive sites and blogs

### Implications for clinicians:

Harnessing record access for shared decision-making offers significant potential benefits to patients and practices. Highlighting to patients the benefits to them of using their records responsibly is very important. Emphasise that the practice and PCT will be happy to explain/enhance information that the patient gleans from their record.

Being enthusiastic and positive about shared decision-making is likely to be influential in encouraging patients to become involved.

### Implications for system suppliers

Patient data must be linked to information and advice that will enable patients to understand it better. In addition, the data should be linked to sites or information that helps patients take more control over their own health and helps them manage their clinicians better.

In particular, it would be helpful if reminders for key health interventions could be integrated into the record. For instance, reminders that BP needs to be taken, or that diabetic control could be improved.

Patient involvement would probably be enhanced if these reminders were to be combined with the facility for the patient to access relevant guidelines that explained in lay language good practice in that condition. For example, if a diabetic was reminded that their BP needed to be reviewed while, at the same time, they were directed to the NICE lay guideline for BP control in diabetes.

#### Implications for patients

Patients will find access to their records more fulfilling if they choose to learn more about their condition or tests by looking at sites that have links to their medical record. This will give them a broader understanding and the opportunity to compare the care they actually receive with what they should receive

## 8. TEST RESULTS

Patients have the right to see their investigation results. They also have the right to have them explained and this can be complex. Not only may the meaning and significance be difficult for professionals to decide at times, the seeming simplicity of “normal” and “abnormal” often does not apply unless the context is known. In addition, a normal result may imply that action needs to be taken (dysuria with a normal MSU), while an abnormal test may be of no significance (minor deviation from the normal range in a Full Blood Picture)

So, patients may need a fair amount of explanation to make use of test results. Enabling access to results with explanation may safely reduce demand on practice time.

It is important that patients do not see frightening results without ready access to a clinician for explanation. Ideally results with serious implications should be communicated by the clinician before the patient can see the result through record access.

### Implications for system design:

1. Test results should not be viewable by patients until seen by a clinician.
2. A test result should be accompanied by general explanation about the test.
3. A test result should also be accompanied by a comment by a patient’s clinician about the meaning of this particular test for this particular patient. For instance – “repeat test in 1 month” “results improving” “slightly abnormal but of no significance”

### Implications for clinicians

If your system enables the clinician to put comments on test results, it would be useful to make these comments as comprehensible to the patient if possible. For instance: “kidney function is stable, please repeat in 3 months” “Test is abnormal, but you are on the correct treatment”

Inform those patients who use an appropriate system that they will be able to see test results. Explain that this will save both them and the practice time in most cases. Explain that in some systems they will be able to see information about the tests written by you that will help them understand the result. Explain that the practice will be happy to explain test results if there is any confusion.

### Implications for patients

Patients can be assured that the clinician has seen the results of any tests they view and is happy for them to view them.

Test results that patients cannot see may not be viewable because there is a delay in the arrival of the test or because the clinician has chosen not to share the result without being present with the patient.

## **9. USE CASE: THE PATIENT SHARING THEIR RECORD WITH SOMEONE ELSE**

Patients should feel free to share their information with whomever they choose. Experience suggests that patients commonly share with their family and NHS staff. For instance:

- older people pass their security details to younger members of the family to enable them to monitor the older person's progress and care
- patients show key aspects of their record to relevant clinicians such as consultants, OOH clinicians, emergency doctors in crisis situations.
- Sharing with carers, friends or spouses who can act as advocates on the patient's behalf. This is more common when patients are disabled or mentally ill.

Overall, experience with sharing is positive. It enables family members to support people more effectively with virtually no risk.

### **Risks that patients need to be aware of if they share records with others:**

- someone will see something the patient doesn't want them to see such as sexual, social, mental, drug and alcohol abuse, genetic health data
- someone who sees the data may be able to infer something about the patient which the patient did not want them to know eg:
  - they are on contraception
  - they were in London when they said they were in Manchester
- someone could steal their identity
- someone could steal some aspects of data that are valuable.

The current feeling is that patients should be able to exclude from view specific parts of their record if they choose. It would need to be made clear to them that excluding information from clinicians could lead to harm because the clinician might not have all the information they might need to make safe decisions.

### **Sealed envelopes**

NHS CfH is hoping to introduce "sealing" as a way of enabling information to be stored but preventing its being shared unless certain preconditions are met. The current proposals are for 'sealed' and 'sealed and locked' records and 'clinician sealed records'.

<http://www.connectingforhealth.nhs.uk/systemsandservices/nhscrs/publications/staff/glossary.pdf>.

The rules around this are still being developed but it is hoped they will be able to give further confidence to patients and clinicians that their data is safe and secure and can only be accessed by those with legitimate relationships. Improper

sharing could lead to serious reprimand as it potentially undermines the trust in the system.

Implications for system designers:

Patients should be able to exclude specific parts of their record from view. These are called “sealed envelopes”.

**Sharing under coercion**

This could happen if the patient is a **child** (see below) or if the patient is in an **abusive relationship**. If the practice discovers this, it may be possible, in some systems, to stop access for that patient so that the abuser or coercer does not use the data to the patient’s detriment.

People have speculated that patients might be offered financial inducements by insurance companies to release the record directly to the company without going through the practice. Legislation may be required to clarify this situation. In general, medical input can modulate and clarify otherwise stark information in the record, generally to the patient’s benefit.

Implications for system designers

It should be possible to switch off access for specific people.

Perhaps also create a view for patients to use under coercion that only they know about (rather like a home alarm that they type in if a burglar asks them to switch the alarm off. It switches the alarm off BUT also informs the police!)

Implications for clinicians

Most sharing of access leads to substantial benefits to the patient and causes no problems. Coercion, if discovered, should be stopped.

Record access may prompt some patients to share their data from one service provider with other professionals or carers who may, in turn, identify problems with its completeness or question the appropriateness of care. Denigrating colleagues to patients should be avoided since this can undermine the doctor-patient relationship. The GMC's guidance for good practice contains recommendations that are applicable in this context :-

- Work with colleagues in the ways that best serve patients' interests
- Never discriminate unfairly against patients or colleagues

- Never abuse your patients' trust in you or the public's trust in the profession." [Give reference]

## 10. USE CASE: THIRD PARTY INFORMATION

Record Access creates a new situation. If patients and practices without electronic patient record access follow the current access procedures, there is time for the practice to examine and process the records for the management of 3<sup>rd</sup> party information. Instant access by the patient to the electronic record will require that administration systems are in place to ensure that what a patient sees is within the current legal framework.

### **A third party who gives information does not want their name to be disclosed**

A patient's wife has told you that her husband drinks heavily and that she wishes you to act on the information, but does not wish to talk to her husband directly about it and does not wish you to reveal her identity to her husband.

The clinician is allowed to withhold notification and information if disclosing the records means giving information about a third party, unless the third party consents or it is reasonable to disclose without his or her consent. When deciding whether disclosure is reasonable without the consent of a third party, you should take into account:

- The duty of confidentiality owed to the third party
- The steps taken to obtain their consent
- Whether the third party is capable of giving consent
- Any express refusal of consent by the third party

### Recommended action:

You need to record the information so that you can address the patient's medical needs when he next attends the surgery.

You should note that although you are not obliged to tell the patient that sensitive and confidential material has been withheld, it is normally good practice to do so.

You should also consider that there is a possibility that information given by a third party. – for example the patient's wife in your scenario- may not necessarily be factual or accurate or may even, in some circumstances, be malicious. You should be aware that a patient is entitled to challenge the validity of computerised and manual data and to have errors corrected.

### Implication for system design:

A clinician sealed envelope may be needed here. That is, the facility to hide information from the patient that is legitimately in the record.

### **Managing a 3<sup>rd</sup> party encounter face to face or on the phone**

This section explains a recommended approach for talking to the wife who has told the clinician about her husband and his drinking. She wishes to remain anonymous but would like you to take action.

#### Recommended action

For the majority of instances, it is sufficient to explain to the person giving you the information that the person to whom this information refers will be able to see it but the identity of the provider will be protected. Usually the giver of information will be content.

If that is not the case, then it may be possible to encourage honest discussion between the provider of the information and the index patient.

If that is not possible, explaining that it is the clinician's duty to record the information and protect the identity of the provider of information is usually sufficient.

#### Implications for system design.

Clinician sealed envelopes, as above.

#### **Managing 3<sup>rd</sup> party information in an incoming letter**

In this situation, we are concerned that letters coming into a practice may contain information about the patient provided by a non-clinical person, such as the wife. Usually, it is not clear whether permission for disclosure has been given.

#### Recommended action:

If the practice reads letters before scanning them, 3<sup>rd</sup> party information can be handled by:

- Censoring the identity of the giver of information
- Keeping the letter out of the system, while ensuring that the clinician knows the letter exists, ensuring that the data is transmitted to the next practice when the patient moves.
- Writing to the giver of info perhaps to get permission for sharing.

It remains a risk to the practice if the practice scans letters without reading them first so that patients would be able to read letters before the clinician could make them safe.

#### Recommendation for system design

Developing a "holding area" in the system for letters to be held after they have been read but before they have been filed.

#### **Case Conference minutes.**

Case conferences are 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 record of the discussion commonly includes information from a wide variety of people, both professional and lay.

Should the family see the record?

Also, should the child see the record when they are older, when they may not have been informed about the meeting or the process of child protection to which they were involved?

Recommended action:

In the UK, members of the family and carers receive minutes of the meeting, so those can be filed in their records.

However, it may be best if a cover note (usually the 1<sup>st</sup> page of the document) be placed in the child's record. This will inform the child, if they were to look at their records years in the future, that the meeting took place, but will not include the detailed information and identities of informants contained within.

Implication for system design:

Clinician sealed envelopes as above.

## **11. USE CASE: PSYCHIATRIC AND 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>20</sup>.

Practices are worried about allowing patients with Serious Mental Illness access, fearing litigation and distress. Nonetheless, patients with SMI have as much right to see their record anyone else. Discriminating against patients with mental health problems is likely to make mental health stigma worse. In such cases practices should approach the mental health services that the patient is accessing to make a joint decision about whether to enable RA for the patient with serious mental illness.

### **Third party information on psychiatric letters**

This should be handled as any other third party information. See above.

### **Non-psychiatrists' data**

This includes counsellors' and psychotherapists' data. Many keep records separate to the regular shared record. This is because it is felt that the clinician's thoughts and speculations form a large part of this kind of record. It also contains a record of the patient's fantasies and dreams which it is felt would be open to misinterpretation by others.

However, the patient is entitled to see these counsellors' and psychotherapists' records subject to the legal constraints that are described above.

Ideally it should be made clear whether comments are speculation or theorising or diagnostic labels.

### **Are there other situations when doctors should keep information away from patients?**

Clinicians are often keen to ensure that speculative diagnoses or thoughts are kept away from patients on the grounds that it may be frightening. The legal position does not support this position, unless the clinician can show that it would cause the patient or someone else serious harm.

In some situations, it may be most helpful to control the timing of delivering information.

The answer, in essence, is therefore – No

## 12. USE CASE: CHILDREN

In general, parents have an automatic right to access their children's records until the children are "Fraser competent"<sup>21</sup> From that point/stage, parental access is only acceptable with the child's permission. There is no specific age for competence and the reality is that access has to be negotiated with particular children in relation to particular issues. The position is different in Scotland - as s66 of the Act deals with the age and competence of children to exercise powers under the Act [http://www.opsi.gov.uk/acts/acts1998/ukpga\\_19980029\\_en\\_7#pt6-pb7-l1g66](http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_7#pt6-pb7-l1g66)

The law is complicated on the question of parental responsibility - which is what gives a right of access to a child's records. The key issue has been marriage (not co-habitation) until relatively recently, so unmarried fathers of children have no right to access their child's record, if the child was born before 2002 (Northern Ireland), 2003 (England and Wales) and 2006 (Scotland). There is more detail in the GMC booklet 0-18 Years - guidance for all doctors. [http://www.gmc-uk.org/guidance/ethical\\_guidance/children\\_guidance/appendix\\_2.asp](http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance/appendix_2.asp).

Of course, it is arguable that records may be disclosed to others with an on-going relationship with the child, but it might be safer for clinicians to check with a person with parental responsibility before doing so.

It is important to note that there is a difference between giving a child access to his/her records, and allowing the child the right to control others' access. Competence to exercise these rights might be reached at different ages.

Access to look at old immunisation details to fill in a form may be acceptable, while access to medication details such as contraception may not.

There needs to be the opportunity for parents to remain involved with record access if it is in the child's best interest, although this should be with the explicit agreement of the child if they are past a certain age and competence.

### **Parents cohabiting have access to their children's records up to the age of 10y**

See notes above – there are variations in different parts of the UK and depending on the age of the child.

Both parents are legal guardians and this should not usually cause difficulties. They are likely to find access helpful in keeping track of routine issues such as allergies and immunisations and details of the children's health problems.

### **Cohabiting parents with a child with Fraser competence.**

At this point, which cannot be described as a certain age because children mature at different rates, it will become necessary for parents to no longer have access to their child's records without the child's permission. This permission, in

most cases, will be readily given. However, if there are private issues ranging from child protection to acne treatment, the child has a right keep them to him or herself.

Implications for system design:

One approach might be to automatically stop access for the parents/carers when the child reaches 10y of age. This would be to stimulate discussion within the family about whether parental access should continue. The age is a compromise: it is unlikely that many children would be deemed Fraser competent at that age.

Advice to clinicians:

Options include:

1. Do not allow access for any children below a certain age, say 16y
2. If the record access system has an automatic disconnect when the child is 10y old, the practice could distribute the following kind of leaflet if and when the family approach the practice for access:

“Dear parent/carer,

Record access is useful and you will want to continue it.

However, as a child grows up, he/she can increasingly take responsibility for themselves. The record access system has automatically cut off parental access at 10 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. They hold the pins and passwords
2. Parents, carers and the child all have access to the child’s record. 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 truly,

..... “

**Parents/carers who are not living together with a child with Fraser competence.**

The parents/carers have the same rights as if they were cohabiting.

**Parents/carers who are in dispute over key issues involving a child’s health.**

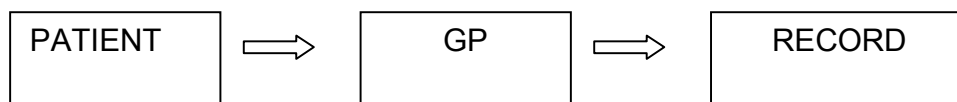
Both parents/carers have equal rights to the child’s records, subject to Fraser competence. In this situation, however, there are risks that the child may be coerced by one or both parent/carers in one direction or another.

Again, electronic record access can make decisions more immediate and it also means that negotiations around access are more likely to be held within the family rather than be brokered by a professional. The new set of relationships may look more like this:



Both groups having independent access to the record

Compared with the traditional situation:



The family only has access to the record through the professional.

**The practice knows that the child is being coerced.**

Record access may need to be halted for the whole family. This would need to be a decision for the practice with advice from their defence organisation and/or the GMC.

Implications for system design.

The system needs to be able to switched off by a practice for specific individuals.

### 13. USE CASE: RESPONDING TO ISSUES OF ACCURACY AND INTERPRETATION IDENTIFIED BY THE PATIENT

There is good evidence that health records are inaccurate both with regard to demographics and health information.<sup>22</sup> Record access enables clinicians to improve the quality of the record, for which they have a legal responsibility. Patients can raise different kinds of queries about accuracy and interpretation.

The following advice is in accordance with the British Medical Association (BMA) and Primary Care Information Service (PRIMIS)<sup>23</sup> and aims to preserve the reason and context of the original entry but remove the implication of an inaccurate or incorrect code. Furthermore, it aligns with the Data Protection Act 1998<sup>24</sup> and the Good Practice Guidelines for general practice electronic patient records<sup>25</sup>, which state that: **“Personal data shall be accurate and, where necessary, kept up-to-date”** and that **“it is important that records do not contain information which may mislead another health professional using them”**<sup>26</sup>

It is worth reminding clinicians that an audit trail exists for all entries in an electronic record: it is not possible to totally remove any data. It may not be visible, but it does remain in the system and can be extracted if needed.

#### **Queries about interpretation**

The commonest query is that what is written either in a letter or in the GP record does not agree with the patient’s recollection. “This not what was said to me.” “I did not express myself in that way”. “This was not made clear” “He spent very little time with me, I can’t see how he could have come to those conclusions”

This is important information for the clinician and can be used to explain and clarify a process. Often, explaining the clinical thinking behind a decision or a conversation helps understanding and improves satisfaction.

#### Advice for clinicians

A note explaining the patient’s views can be 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.

#### Advice for system designers

It would be helpful if patients’ additions could be highlighted.

#### **Queries about clinical facts**

This is less common. “I was never proven to have a heart attack even though the record says I did” “It was my right leg, not the left”

In this situation, the clinician needs to establish what is known of the facts. Was the diagnosis of MI actually disproved? Which leg was it?

#### Advice to clinicians

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

**If an entry is no longer accurate because the original diagnostic condition is now 'resolved'**, it should remain on the system because it remains an important aspect of the patient's medical record but SHOULD have an additional code added to highlight the current situation. For example, rather than removing or editing an original diagnosis for a patient diagnosed as suffering from Asthma as a child but now as an adult no longer having any symptoms, an additional code should be recorded that states that the Asthma is resolved (21262). Note: Read codes for Hypertension resolved (21261) Epilepsy resolved (21260) Diabetes resolved (21263) and Psychosis, Schizophrenia + Bipolar affective disorder resolved (212T).

**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 Read code and a comment conveying the meaning of the original entry should be added in free text after the Read code. For example, where 'Myocardial Infarction' has been entered and subsequently (following investigation) the problem was found to be 'Chest Pain', (Read code 182..) – 'originally recorded as Myocardial Infarction and on investigation ruled out'

**If an entry is incorrect and should not have been entered in that particular patient's electronic record**, an administrative code should be used to explain why the code is being deleted from the incorrect patient's record. The practice should refer to its clinical system guidelines on deleting codes. One example is "9R9.." = error entry deleted. E.g. diabetes mellitus code C10.. has been added to the wrong patient's record. Add code 9R9.. and free text a comment like: "*diabetes mellitus (C10..) deleted as wrong patient-instructed by xx*". Then delete C10.. code from the incorrect patient's record. Alternatively, because the original entry will still be present on the clinical system audit trail (and can not be amended by system users) but may not be visible in screen another option is: Before deleting the code entered against the wrong patient, add free text comment such as "*added in error against wrong patient's notes instructed by xx*" and then delete the code. This way the audit trail will show the code that has been deleted and the reason why it was deleted. This process will also be helpful if the member of staff who removed the entry subsequently no longer works at the practice

**Diagnostic Improvement** – In this case a patient presents on several occasions and the diagnosis is refined over time. For example, on the first occasion a

patient may present with a dry cough, subsequently with a chest infection and, following a chest X-ray, a malignant neoplasm might be identified. 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. The decision on whether to record a symptom or diagnosis code depends on the clinical judgment of the practitioner. However, it is important to strike the right balance between describing morbidity in diagnostic terms and entering the main symptom. Where the clinical management of the patient is closely aligned to a likely diagnosis, the opinion of the clinician/GP diagnosis should be entered. For example, ergotamine preparations are prescribed for a patient whom the GP considers to have migraine, but not simply for a headache. Where a likely diagnosis cannot be made without further investigation, the main symptom should be entered.

If there is a dispute about 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 patient's 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

#### **CfH/NHS process for ensuring accuracy**

Copying Letters already allows access without data checking

PRIMIS have developed a tool called Chart which allows practices to see the quality of the data in their clinical systems and the opportunity to see how it compares with other practices around the country, This has primarily been developed to help practices to prepare their records in anticipation for the upload of summary care records data to the Spine.

Another potential key test is for the patient to view their own data and confirm or refute its accuracy based on their own understanding.

## **14. SUMMARY AND CONCLUSION**

Health records can be safely shared with the blessing of patients. This can help patients to gain a better understanding of their health and give clinicians an opportunity for their records to be checked and so reduce the risk of any errors. A change of culture, such as patients accessing their own medical records, can create fear, distrust and unhappiness. We hope that we have reduced some of the fears, distrust and worries that we have heard expressed about record access. We also hope that we have brought to your attention some of the opportunities of enabling patient access to records as well as some of the risks of sharing.

We hope that record access becomes the norm for clinicians and patients. We hope that a new level of mutual trust between patients and clinicians will develop based on a healthy understanding of each other's perspective. This will help us to deliver a truly world class service as more and more patients and clinicians choose to share health records.

# **Patient Information Leaflet and Consent Form**

## **Online Health Record Viewing System (EHR)**

**Our surgery** is piloting a system that allows you to view your medical record using a personal computer (PC) and the internet. Before you can begin using the Online Electronic Health Record (EHR) viewing system we require you to register and consent to use the system.

### **What is the Online EHR Viewing System?**

The system is a website that allows you to view your medical record over the internet from a PC. It allows you to easily and quickly view the electronic medical information held about you by the surgery.

The information is presented to you in a format that is easy to navigate and offers you links to resources such as patient information leaflets about diseases, tests, investigations, support groups and medications etc. There are also links to websites such as NHS Direct Online and Patinet.co.uk where you can find additional information to help you understand and educate yourself about what you read in your health record.

### **Registering and consenting to use the EHR viewing system**

To be able to use the system you must have a PC with a web browser such Internet Explorer (version 6 or later) and have a connection to the internet.

You must also register with the practice and sign a consent form before you start using the system. Before you sign the consent form you should be happy that you understand what the system does, what your responsibilities are and how your data is stored. When you have had enough time to understand this you should consent by signature and hand the consent form to your GP receptionist.

Once you have consented you will be issued with a series of numbers that you must remember to allow you to access the system from any PC.

Any data held by the practice concerning you is subject to the regulations laid down in the Data Protection Act (1998). The consent is between you and your surgery.

### **How do I use the Online EHR Viewing System?**

Using your PC web browser enter the web address [yoursurgerywebaddress](#) and click the link “How To Register” for full illustrated instructions to setting up EMISaccess on your HOME PC.

Once you have signed into EMISaccess you must select the ‘View Medical Record’ section which will further prompt you to enter the password specifically assigned to allow you to view your online EHR.

When you have been correctly identified the system will allow you to view the parts of your medical record as described below. Use the menu and links to view each area of your medical record. There is an online help section to help you use the system.

### **What can I see on the Online EHR viewing system?**

The system allows you to view the following areas of your medical record:

- A summary that gives you the most important and recent entries in your health record.
- Consultations including: date, practitioner seen, reason for visit, history, examination, outcome, investigations, etc. Your practice may allow all patients access to this information only after a certain date. This is because they want to ensure that you cannot have access to information that you do not have a legal right to see. This is third party information – information given by someone else about you. It is very unlikely that the practice holds such information about you, but they may not want to take the risk and so will ensure procedures are in place to safeguard both you and third parties.
- Medical Record showing diagnoses, investigations, and procedures
- Allergies.
- Patient Information Leaflets linked from the diagnoses in the medical record section.
- Results showing all investigations such as blood results, liver tests, blood pressure etc.
- Vaccinations.
- Medications.
- Letters to and from the GP.

The system also allows you to send messages to your practice using a system in EMISaccess (if your practice has enabled this).

### **Why have an Online EHR viewing system?**

There are many reasons to provide you with access to your medical information. A few of them are listed below:

‘We want to develop a culture of openness, honesty and trust; to ensure that patients have the information they need to make informed choices; and to enable patients to become equal partners with health care professionals in making decisions about treatment and care.’ This is the response to the Department of Health from the enquiry into the Bristol Royal Infirmary Enquiry.

‘Patients have the right to see their medical records, though in practice much communication between professionals is not available to the patient concerned. Patients often do not know why they are being referred, or what is being said about them’ The NHS Plan. This practice believes that it is important for improved patient care and education that you are involved in your healthcare as much as possible

**Advantages to you, the patient:**

- No queuing to get results
- You can check the accuracy of your medical record
- It empowers you to become more involved in your medical care

**Where is my confidential medical information held whilst I am viewing my online EHR and who has access to it?**

The information you view on the online system comes from the clinical system at your surgery. Portions of this information are encrypted (this means it is very difficult for someone else to intercept and read the information) and securely sent from the GP practice system to your PC web browser.

None of the medical information that is shown on the online system is held permanently on any computer except the computer which holds the original data in your surgery.

When you log off from the online system or if a problem occurs with your computer, for instance a power failure, all your confidential medical information is cleared from the system.

Using the online system does not allow any extra people to view your medical information other than the people who would normally have access to it in the GP practice.

**How will other people be prohibited from seeing my record?**

To view your online EHR you have to identify yourself with passwords and PINs that only you know. Unless you reveal this information to someone else you will be the only person able to access your medical record via the online system

**What if I find an error in my medical record or if I see someone else's medical information?**

If you find any errors or missing information in your medical record you must inform the practice immediately or discuss it with your GP. If you see someone else's medical information you should immediately exit from the system and inform the practice.

**Are there any risks for me?**

There may be something in your history you don't want any family members to see. It might be information you had put to the back of your mind and are now confronted with.

The record is designed to be used by doctors for doctors. There will be abbreviations and technical terms. However, most patients understand most of what they read and the information linked with problem titles offer detailed explanations. Please ask if you do not understand

Results can be difficult to understand. Results may be abnormal and cause you to worry. The system includes information about tests to help you.

You might want to tell the doctor something about your spouse/partner/child etc in confidence.

1. If the doctor records the information and the patient then sees this it could cause problems.
2. If the doctor doesn't vital information may get lost or forgotten
3. The information may be malicious and again cause problems

**What if I don't want to register to use the PAERS System?**

If you do not want to register to use the PAERS System you can still use all the practices' services exactly as before. Your decision not to register will not affect your treatment or your relationship with your GP practice in any way.

**REMEMBER TO LOGOUT FROM THE SYSTEM WHEN YOU ARE FINISHED.**

## APPENDIX 2: ADVICE FOR SYSTEM SUPPLIERS

### **Authentication**

It is likely that some patients will want 2-factor authentication and some will not. It may be best if systems can manage both approaches.

### **Linking information with data**

Automatic added information linked to key aspects of the record is essential. The links need to make it as easy as possible for patients to understand medical jargon.

Patient data must be linked to information and advice that will enable patients to understand it better. In addition, the data should be linked to sites or information that helps patients take more control over their own health and helps them manage their clinicians better.

In particular, it would be helpful if reminders for key health interventions could be integrated into the record. For instance, reminders that BP needs to be taken, or that diabetic control could be improved.

Patient involvement would probably be enhanced if these reminders were to be combined with the facility for the patient to access relevant guidelines that explained in lay language good practice in that condition. For example, if a diabetic was reminded that their BP needed to be reviewed while, at the same time, they were directed to the NICE lay guideline for BP control in diabetes.

### **Test results**

4. Test results should not be viewable by patients until seen by a clinician.
5. A test result should be accompanied by general explanation about the test.
6. A test result should also be accompanied by a comment by a patient's clinician about the meaning of this particular test for this particular patient. For instance – “repeat test in 1 month” “results improving” “slightly abnormal but of no significance”

### **Sealed envelopes:**

Patients should be able to exclude specific parts of their record from view. These are called “sealed envelopes”.

### **Switching off access**

It should be possible to switch off access for specific people.

Perhaps also create a view for patients to use under coercion that only they know about (rather like a home alarm that they type in if a burglar asks them to switch the alarm off. It switches the alarm off BUT also informs the police!)

**Managing incoming letters**

Developing a “holding area” in the system for letters to be held after they have been read but before they have been filed.

**Young people**

One approach might be to automatically stop access for the parents/carers when the child reaches 10y of age. This would be to stimulate discussion within the family about whether parental access should continue. The age is a compromise: it is unlikely that many children would be deemed Fraser competent at that age.

**Patients writing in the record**

It would be helpful if patients' additions could be highlighted.

## APPENDIX 3: ADVICE FOR CLINICIANS

### **Writing records**

Write as 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 RA or not. This is good legal practice in any case.

Avoid local abbreviations if possible.

If the record has to be technical, so be it.

It is acceptable to write speculation in the record. It is best to share differential diagnoses with patients.

### **Shared decision-making**

Harnessing record access for shared decision-making offers significant potential benefits to patients and practices. Highlighting to patients the benefits to them of using their records responsibly is very important. Emphasise that the practice and PCT will be happy to explain/enhance information that the patient gleans from their record.

Being enthusiastic and positive about shared decision-making is likely to be influential in encouraging patients to become involved.

### **Test results**

If your system enables the clinician to put comments on test results, it would be useful to make these comments as comprehensible to the patient if possible. For instance: “kidney function is stable, please repeat in 3 months” “Test is abnormal, but you are on the correct treatment”

Inform those patients who use an appropriate system that they will be able to see test results. Explain that this will save both them and the practice time in most cases. Explain that in some systems they will be able to see information about the tests written by you that will help them understand the result. Explain that the practice will be happy to explain test results if there is any confusion.

### **Record access and coercion**

Most sharing of access leads to substantial benefits to the patient and causes no problems. Coercion, if discovered, should be stopped.

### **Third party information**

You need to record the information so that you can address the patient’s medical needs when he next attends the surgery.

You should note that although you are not obliged to tell the patient that sensitive and confidential material has been withheld, it is normally good practice to do so.

You should also consider that there is a possibility that information given by a third party. – for example the patient's wife in your scenario- may not necessarily be factual or accurate or may even, in some circumstances, be malicious. You should be aware that a patient is entitled to challenge the validity of computerised and manual data and to have errors corrected.

For the majority of instances, it is sufficient to explain to the person giving you the information that the person to whom this information refers will be able to see it but the identity of the provider will be protected. Usually the giver of information will be content.

If that is not the case, then it may be possible to encourage honest discussion between the provider of the information and the index patient.

If that is not possible, explaining that it is the clinician's duty to record the information and protect the identity of the provider of information is usually sufficient.

If the practice reads letters before scanning them, 3<sup>rd</sup> party information can be handled by:

- Censoring the identity of the giver of information
- Keeping the letter out of the system, while ensuring that the clinician knows the letter exists, ensuring that the data is transmitted to the next practice when the patient moves.
- Writing to the giver of info perhaps to get permission for sharing.

It remains a risk to the practice if the practice scans letters without reading them first so that patients would be able to read letters before the clinician could make them safe.

### **Young people**

Options include:

- Do not allow automatic electronic access for any children below a certain age, say 16y
- If the record access system has an automatic disconnect when the child is 10y old, the practice could distribute the following kind of leaflet if and when the family approach the practice for access:

“Dear parent/carer,

Record access is useful and you will want to continue it.

However, as a child grows up, he/she can increasingly take responsibility for themselves. The record access system has automatically cut off parental access at 10 years old. This is designed to encourage your child and the family to consider how to proceed in the future. Your options include:

- Only the child has access. They hold the pins and passwords
- Parents, carers and the child all have access to the child's record. The pins and passwords are shared.
- 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 truly,

..... “

**Discussions about accuracy**

A note explaining the patient's views can be 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.

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

## **APPENDIX 5: IMPLICATIONS FOR PATIENTS**

Patients will find access to their records more fulfilling if they choose to learn more about their condition or tests by looking at sites that have links to their medical record. This will give them a broader understanding and the opportunity to compare the care they actually receive with what they should receive

Patients can be assured that the clinician has seen the results of any tests they view and is happy for them to view them.

Test results that patients cannot see may not be viewable because there is a delay in the arrival of the test or because the clinician has chosen not to share the result without being present with the patient.

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