



This document has been written by members of the Record Access Collaborative, a group of practices, professionals and patients who are interested in promoting patients having access to their full GP record. It is designed to give your practice enough information to enable you to decide whether to join the 100 practice pilot. There is further advice and documentation available to make setting up easy.

1.1 Online Electronic Health Record (EHR) Access system

Your practice has expressed an interest in becoming involved in a pilot project to allow patients to view their medical record via the internet. This document introduces some of the issues surrounding access to medical information and gives some advice on how to manage and administer this access. Further details and documentation are available on request and if you choose to proceed.

1.1.1 What is the Online EHR Access system?

The online EHR access system allows patients to view the contents of their full GP electronic medical record from any internet enabled PC using a web browser. Authenticated access to the record will be securely controlled using passwords and PINs issued to the patient specifically to allow them to view this information. During the course of this pilot, we shall be introducing an additional level of security called a 'one time use authentication token'. Once this becomes available, practices will be able to trial this as well, if they wish.

The patients will be able to view:

- A summary that gives them the most important and recent entries in their health record (e.g. allergies, current medications, active problems)
- Consultations including: date, practitioner seen, reason for visit, history, examination, outcome, investigations, etc. There is a facility to enable practices to start access to consultations from a date of their choosing.
- Medical Record showing diagnoses, investigations, and procedures.
- Patient Information Leaflets linked from the diagnoses in the consultation and medical record section.
- Results showing investigations such as blood results, liver tests, blood pressure, x-rays etc, with links to information leaflets .
- Vaccinations and medications.
- Letters to and from the GP.

The information is presented in a format that is easy to navigate and offers 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 Patient.co.uk where patients can find additional information to help them understand and educate themselves about what they read in their health record.

In this initial phase of the project patients will only be able to view their information - they will not be able to add or change what they see in any way via the online system.

The Online EHR Access System Patient Information Leaflet gives detailed information for the patient. The Patient Information Leaflet is a template and can be altered by the practice. The 'contract' is between the individual practice and the patient and therefore the practice has to be happy with the wording of the PIL and the consent form

1.1.2 Feedback from the Online EHR Access system

An important aspect of this project will be the feedback from the patients and staff at the various practices involved.

1.2 Managing patients' access to the Online EHR system.

1.2.1 EMIS Clinical System

Patient Record Access is available through the EMIS Access system – the practice must have this installed.

In the EMISaccess area of your EMIS clinical system you will be able to sign up patients for the Online EHR. This will issue the required PINs and passwords to allow access. All the details for how to do this will be available when you need them, or on request.

Using the documentation, patients can be offered a summary of the benefits and risks and sign up for access. This can be done without a doctor's intervention, over the reception counter.

1.2.2 Patient Requirements

To use EMISaccess and the Online EHR system, patients will require a PC with internet access and a suitable web browser (e.g. Internet Explorer version 6 or later). They will also have to have registered to use the system, consented and been given the required passwords and PINs.

1.3 Information and advice for clinicians, practitioners and practices using the Online EHR System

1.3.1 Background

The NHS Plan laid down the idea that patients should have access to their electronic health records. HealthSpace is the approach taken by Connecting for Health to record access. We are in close touch with HealthSpace.

In addition, if we want patients to exercise more choice over their dealings with the NHS, then they need information about what is happening to them. Record access is a pre-requisite to empowerment.

A related initiative by the government is called Copying Notes to Patients, a process which the whole NHS was meant to embrace by April 2004.

<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/CopyingLettersToPatients/fs/en>

This approach to access, in effect makes redundant the actual copying of letters.

There are now about 20 practices in the UK enabling their patients to see their full GP electronic record both online and through kiosks in the waiting room. We have drawn on their experience extensively. In addition, there are hundreds of thousands of patients in the US who have record access – clinicians involved in the US are very enthusiastic. We have drawn on their information and ideas.

1.3.2 Evidence of benefit

We have been showing patients their records on paper for many years, at Wells Park Practice. Our published experience, easiest to see at www.icmcc.org which includes investigating the reactions of patients with cancer to seeing their records, suggests the following conclusions, so long as simple safety procedures are carried out, as described later:

- It enhances communication between clinician and patient.
- It increases the onus on the clinician to tell the truth
- It increases patient satisfaction
- It enables patients to correct data errors, the commonest ones being demographic data, but the errors can also be about clinical process and outcomes.
- Patients feel better informed and almost always reassured, even when they read bad news.
- Patients feel they understand about 70% of what they read.
- It appears to improve compliance and support health education messages, such as smoking quit rates
- It is likely to improve self-care

1.3.3 Safety Issues and recommended actions

Whilst accepting the benefits of record access, practices also worry about the safety of full record access. The commonest concerns centre on third party information, litigation, seeing bad news and children. Our experience has been that the following simple precautions avoid much risk. It does mean that whoever reads the letters or results needs to see them from a lay point of view.

- **Third party information:** the identity of the provider of third party information must remain concealed from the patient. The data that a third party provides can be seen by the patient, (for instance, if a wife reports the drinking of the husband but does not want herself to be identified) but the identity of the giver of that information must be kept from the patient reading the record.

We recommend that records are checked for third party information before access is enabled. We have further documentation on this issue if you need. Practices will be able to allow record access to consultations after a date of their choosing. This will allow practices to ensure appropriate recording practices are in place.

- **Serious test results and potentially frightening letters** should probably be excluded until a face-to-face meeting. When reading letters or checking results, look for new frightening information that you feel patients should not be expected to see on their own without discussion and putting into context.

We recommend that the practice should ensure that clinicians read letters and results before they are included in the records. If this is not possible, the practice will be enabling patients to see information before it can be put into context by the practice.

- **Children.** There are no legal precedents that cover this area, except for the usual “Gillick competence” approach. It is essential that children’s records are only seen by the parents/carers with the child’s permission. Different surgeries have developed different policies. The simplest is that record access is only allowed for children over a certain age, say 10 years old.

We recommend that access should be disabled when a child reaches 10. We shall be consulting on the best approach to this issue over the next few months.

- **Carers.** Patients are often keen for their family to have access to their records. Sometimes younger members can use the computer more easily, sometimes access to the data could make care a great deal safer. In our view, so long as people are not being coerced, it is up to the patient.

1.3.4 Changes in style and culture that may be needed.

- It would be helpful to write notes in as clear a style as possible. However, patients reading even handwritten records say that they understand 60% of what they read.
- Derogatory comments are always unacceptable.
- All clinicians should be writing anyway as if patients can see whatever they write. Current legislation enables patients to obtain access to records on request, though GPs are allowed to charge for this access. Doctors can only censure access if:
 - It may cause serious harm to the physical or mental health, or condition of the patient or any other person
 - It may relate to or be provided by a third person who had not consented to the disclosure.
- Third party information given to clinicians needs to be handled carefully, for instance when a mother tells you about her son's behaviour and asks you to intervene without revealing your source.
- Recording speculative differential diagnoses is only a problem if they have not been discussed with the patient.
- Do not write anything you don't want the patient to see. This open style does put a premium on honesty. It is best to explain that a colonoscopy is looking for cancer rather than write notes to yourself that a patient may see in the future.
- It is worth every member of the practice obtaining a reasonable understanding of the PAERS system in order to answer patient queries.

1.3.5 Ways by which the system can save time

- Patients can look at their results on computer (if you get your results by electronic links) without contacting reception.
- Patients can look at their immunisations on computer without contacting reception.
- Patients can read their letters without contacting a clinician.
- Patients can share information with family, carers and other healthcare professionals, reducing the requests for clinical information from the practice.
- We shall, in the future, be enabling the system to remind patients about key appointments, such as BP and medication reviews

Will there be an increase in consultation time?

There may be concerns that patients will want more explanation and ask more questions. Our experience is that access appears to be time-neutral. Some patients do take longer, but research also shows that:

- access is used by patients to keep consultations short. They do this by looking at the data beforehand and only asking about things they need to ask
- one paper showed that there was no increase in time taken.
- The practice will save time when people can look up their information without consulting anyone at the practice: allergies, immunisations – for forms etc

1.3.6 Will there be an increase in complaints?

There is no evidence for an increase in litigation as a result of access. On the contrary, the evidence is good that relationships are improved

1.3.7 Are patients made anxious?

A small minority are, most are reassured. The group of patients who have the most difficulties are patients with psychiatric problems. Research suggests that this group is still pleased to have seen the information even if it upset them. Upset can be therapeutic.

1.3.8 What if patients see errors in the records?

Research suggests that, at the moment, if patients see errors, they tell no-one. We see access as improving record-keeping. Patients should be encouraged to report errors. The commonest are simple demographic errors (evidence suggests that most practices have 10% demographic errors). If patients can tell us about them, accurate mobile numbers for instance, that can help practices significantly.

Patients do misunderstand entries sometimes. The vast majority are easily dealt with by simple explanation.

1.3.9 Is the record secure?

The main risk to security in the current system is that an attacker might guess or steal a patient's account log-in information and use it to log-in themselves. This risk is higher if patients use weak passwords, fail to keep their passwords secret, use public computers or do not keep their home systems patched up to date and protected from viral and trojan software. Token based two factor authentication will mitigate much of this risk.

A simple study conducted in two surgeries suggests that about 3/4 of patients are content with a pin and password, while a quarter would prefer 2 factor authentication.

It is possible that members of the family, for instance, will be able to see records, perhaps by glancing over patients' shoulders or by coercing them. As with internet banking and other protected sites, once the record has been delivered, we can assume that the patient becomes fully responsible for its security.

Conclusion:

You need to remember that this is a pilot – although we have drawn on 100s of patient years of experience, there may be unexpected events that you will need to deal with. There is an extensive network of clinician support to help.

We hope that this has given you enough information to decide to participate in the pilot. You can see an example of the record as seen by a patient at http://www.paers.net/ehr/test_login.asp If you would like to proceed, then please either contact:

- Dr Brian Fisher at brian.fisher403@ntlworld.com
or
- Rob Murgatroyd at EMIS Rob.Murgatroyd@e-mis.com

We can help answer questions or arrange to finalise the process.

**Record Access Collaborative
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