



A patient about to look at their records

Welcome to this second report on progress in patients accessing their health records. Big changes are afoot.

The Record Access Collaborative (RAC) is a group of people and organisations all of whom feel that enabling patients to have access to their full electronic GP record is of importance –

- improving patients' health,
- improving relationships between clinicians and patients
- improving safety and the recording of care

THE AIM OF THE COLLABORATIVE

- to raise awareness of record access (RA) nationally and internationally
- to make RA as useful to patients and health care professionals as possible by linking data to facilitate understanding and empower patients to share decisions if they want to.
- to increase the take-up of RA by patients and practices, with possible extension to other healthcare organizations such as outpatient departments and pharmacies
- to support the development of national standards for RA.

REPORT ON MEETINGS

NHS Connecting for Health arranged two meetings, one with **suppliers** involved in record access and one for **interested organisations and individuals**. These were important as a first step in coordinating ideas and care and Marlene Winfield is to be congratulated on bring us together.

Outcomes included:

- an agreement to jointly investigate authentication issues
- an agreement to develop standards for good practice in record access to aid new clinicians involved in the field and to maintain and improve care. There remains debate on whether these will be standards or guidelines
- continued contact between the Connected Patient and others on the ground who are developing record access.

Kathie Applebee from NHS Connecting for Health visited Wells Park surgery in SE London to see how the PAERS/EMIS system was operating. There was discussion about whether the PAERS/EMIS system could be harnessed to enable patients to define any exclusions from their record before it was uploaded. This could be done in a semi-automated way, potentially saving a lot of time.

EMIS National User Group Conference: Record Access was discussed and a number of suggestions from practices will be incorporated into the EMIS PAERS system.

A delegate at the conference described a patient of his who had gone to the USA, got ill and used the EMIS /PAERS system to show the medics her records. All were suitably impressed and it improved her care substantially.

Royal Society of Medicine Conference: record access was discussed. Clinicians and managers' interests and fears were debated.

Professor Dennis Protti who holds the position of chair of health informatics at City University this Autumn came to learn about NHS IT and about record access. He will be visiting surgeries who offer record access in the UK. His paper in Informatics in Primary Care on Primary Care computing in England and Scotland: a comparison with Denmark offers useful insights into how a nation develops comprehensive IT in the health sector. http://www.radcliffe-oxford.com/journals/J12_Informatics_in_Primary_Care/issues/

INVOLVING PRACTICES

It is clear that practices are concerned about patients seeing their records. They are worried about:

- patients seeing upsetting information
- patients seeing mistakes
- patients seeing information that they should not see, such as third party information
- a general feeling that this is going too far.....

It will be important to enable practices to feel comfortable about record access while enabling patients to see complete medical records.

One approach may be to enable practices to switch on access from a certain date. This will enable them to ensure that simple systems are in place to prevent patients seeing data that would breach others' confidentiality.

EMIS/PAERS will be looking for more practices to expand the record access pilot.

THIRD PARTY INFORMATION

We have investigated the legal position here. If it is necessary for third party information to be put into a patient's record, it is acceptable for the data to be entered, but the identity of the information-giver must be kept out of the record. This has implications for how practices enter data whether they allow record access or not.

The RAC has written simple guidance on this – please see the Appendix to this paper. Your comments would be welcome.

PATIENTS' VIEWS

These continue to be canvassed. In general, experiences remain very positive, with patients keen to see the pilots extended. A number are keen to champion the concept of record access. The improved safety and empowerment are obvious.

The Record Access Collaborative now has a group of patients who are keen to see progress in the field and who are willing to commit time to it. In Hyde, they are recruiting more patients to register and a number are willing to cooperate on articles and interviews.

See Yvonne's Bennett's contribution at

<http://www.connectingforhealth.nhs.uk/casestudies/patientpublic/sharedhealthcarerecords>

And Fred Webber's http://www.connectingforhealth.nhs.uk/casestudies/patientpublic/fred_webber

DEVELOPING ONLINE ACCESS

EMIS/PAERS are continuing to receive feedback on the online access system. Revisions are being made as a result.

A wider pilot is expected to begin in early November. This will involve at least 1000 patients. The lessons from that will enable the system to go live, hopefully in early 07

We now have a GP group who are in touch with each other to share advice and ideas on record access. All those involved have direct experience of access either through the EMIS/PAERS kiosks, or as part of online access pilots.

The collaborative is contacting patient groups across the UK in order to begin discussions about record access and the possible impact it may have on their members.

In addition, we are now in touch with the Expert Patient Programme. <http://www.expertpatients.nhs.uk/> It seems logical that patients involved with the EPP are most likely to benefit from RA.

LINKS OUTSIDE ENGLAND

The Collaborative is now in touch with Scottish colleagues and will hopefully develop concrete plans for cooperation soon.

The Collaborative is in touch with the European Forum for Primary Care. <http://www.euprimarycare.org/> We are contributing to a paper on self-care and also hoping to present at a conference in 2007.

The website and blog is growing on www.icmcc.org This is still the best place to get summarized information and papers on RA.

Here are a few examples of developments and established record access programmes:

<http://www.ihealthbeat.org/track/url.cfm?u=43158&rurl=www%2Eihealthbeat%2Eorg%2Findex%2Ecfm%3FAction%3DdspItem%26itemID%3D125562>

<http://www.bizjournals.com/southflorida/stories/2006/09/25/story7.html?b=1159156800^1348870>

The Czech Republic is well advanced in Record Access

<http://www.izip.cz/index.php?p=14>

HARNESSING THE TECHNOLOGY FOR PRACTICES

Using the medical viewer technology means that GPs can have access to their patients' records on the move. This will make visits safer and more convenient. EMIS/PAERS has linked with Pearl Medical to enable this on Blackberries and a number of practices are signing up for this facility already..

AUTHENTICATION

This is the process ensuring patients that they are identified by the system so that only the correct person will be allowed to look at the records. There are significant complexities about this and EMIS/PAERS will be working with NHS Connecting for Health to ensure there is a simple approach for all patients in the NHS.

MEETING GOALS

We are well on the way to meeting the goals we set ourselves 2 months ago. The early goals are summarized below

Goals of Records Access version 1.0

	Patients	Clinicians	Systems	System suppliers
Short Term (0-3 months) Until Jan 07	<ol style="list-style-type: none"> 1. Ensure patients are able to voice benefits as well as risks in whatever way they wish 2. Recruit 1000 patients and 8 practices 3. Try to identify "champions" amongst the public who can articulate issues 4. Continue to gather feedback from patients about the system 5. Identify groups of patients with particular 	<ol style="list-style-type: none"> 1. Support the first clinicians who decide to support RA in their own practice 2. Encourage the first clinicians to join the collaborative and further define benefits 3. Try to identify key clinician champions who can articulate issues 4. Inform the wider clinical community by using all methods of communicating including key web-sites, journals, 	<ol style="list-style-type: none"> 1. Try to understand what framework needs to exist to enable RA to flourish within a health community 2. Be clear what future we are trying to create 3. Clearly identify stakeholders and their different needs 4. Explain why such a framework needs 	<ol style="list-style-type: none"> 1. Ensure the system is robust and able to show all aspects of the medical record that it is supposed to show at the patient facing end 2. Try to understand terminology that differentiates normal from abnormal results and how this should be presented to

	<p>RA needs – homeless, patients experiencing domestic violence, children</p> <ol style="list-style-type: none"> 6. Identify a solution that allows health personnel to see medical records in an emergency if they are suddenly unable to give consent 7. Continue contacts with patient groups and extend to Expert Patient Programme 	<p>magazine, radio and television articles. Purpose is to inform a healthy discussion and not to “score points”</p> <ol style="list-style-type: none"> 5. Share this with other clinicians around the world 6. Share what we have done locally with other countries in the world including America and a 3rd world country too 7. Define a research goal that can benefit patients eg extension of Joy Project or negating the “Shipman Effect” and try to gain funding for it 	<p>to happen at a local level</p> <ol style="list-style-type: none"> 5. Ensure there is a link between the local CRDB and the national CRDB 6. Help inform a paper to put forwards to ICMCC for further consideration from the collaborative 7. Begin discussion on 3rd Party data and mental health issues 8. Be clear about what the assumed benefits and risks are and ensure systems are in place to capture / detect this within the medium term and long term time-scales 9. Build a relationship between the NPfIT and RA to ensure they go in tandem and support each other 	<p>patients.</p> <ol style="list-style-type: none"> 3. Begin developing the system to promote patient self-management 4. Continue developing SecureID – 2 factor authentication 5. Ensure the system is resilient and fit for the purpose of Records Access
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APPENDIX 1

SUGGESTED GUIDELINES FOR RESPONDING TO THIRD PARTY INFORMATION AND RECORD ACCESS

Definition

3rd party information in this context means: "information about the index patient given to the clinician by a non-clinician".

Legal background

The clinician has a duty to keep confidential the identity of the person providing the 3rd party information.

The clinician has a duty to put the data provided by the 3rd party in the index patient's record, ensuring that the identity of the giver of that information is kept out of the record.

Current practice in handling incoming letters

Practices will continue to file 3rd party information arriving in letter form and it is important that they do so, as they may contain important data relevant to the patient's health.

Some practices file letters before having been read by the clinician, some file them after.

If letters are filed before being seen by the clinician, it is difficult to eliminate data that would identify the providers of any third party information.

A clinician seeing the letters first enables safeguards to be put in place, as well as being able to anticipate issues for the patient such as a change in medication.

Record Access creates a new situation

If patients and practices without patient record access follow the current access law, there is time for the practice to examine the records for 3rd party information. Instant access means that admin systems need to ensure that what a patient sees is within the current legal framework.

Managing a 3rd party encounter face to face or on the phone

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.

Managing 3rd party information in an incoming letter

If the practice reads letters before scanning them, 3rd 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.

IT solutions

1. A cut-off date. Patients can see their summary record going back, but can only see detailed data after a certain date that can be set individually by each practice. This enables practices to reconfigure their administrative processes to ensure safety.
2. A physician-defined sealed envelope in which problem data is placed.
3. Scanning letters into an inbox, this is then viewed and filed (like lab links). i.e. not seen by patient until filed.