



MARCH PROGRESS REPORT  
OF THE  
RECORD ACCESS COLLABORATIVE

**INTRODUCTION**

The record access collaborative is being developed as a service to the public, patients, the NHS and industry. The aim is to bring together those who have an interest in seeing record access more widely available and maximising benefits that flow from it.

The NHS has made a clear statement of principle that patients should be able to access their records, subject to legal safety restrictions<sup>1</sup>. There is good evidence of substantial benefits for patients<sup>2</sup>.

**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.

**IN THE LAST FEW WEEKS**

RA continues to expand. In the UK, one pilot of full record access has started and another, of restricted access, will be starting in May.

There is more publicity and awareness of the benefits and the risks. One approach has been by Dr Hannan in the UK who has placed his video lectures

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<sup>1</sup> DoH 2004. 'Better information, better choices, better health: Putting information at the centre. [www.dh.gov.uk/publicationsandstatistics/publications](http://www.dh.gov.uk/publicationsandstatistics/publications)

<sup>2</sup> <http://recordaccess.icmcc.org/>

and those of one of his patients on You Tube.  
[www.youtube.com/watch?v=LW4OcgVyB4w](http://www.youtube.com/watch?v=LW4OcgVyB4w)

In the US and Canada, there are a number of other developments in record access in different parts of the country. As we have seen before, there appears to be little coordination between groups.



“Somehow your medical records got faxed to a complete stranger. He has no idea what’s wrong with you either.”

## UK NEWS

**The EMIS/PAERS pilot**, in which 100 practices are being recruited to expand the provision of full record access online, is the first RA pilot to kick off.

Patients will be offered full access to their record. Practices concerned about past data that might be unsafe because, for instance, it contains third party information, will be able to start access from a certain date. This would apply to consultation data only – patients will be able to see past results, correspondence and problems.

The process is free to practices and patients. There will be guidance for practices on potentially difficult issues such as dealing with third party information.

<http://www.ehiprimarycare.com/news/item.cfm?ID=2488>

**The Guardian highlighted the work of Amir Hannan, GP in Glossop.**

The article highlighted the fact that, parallel to NHS Connecting for Health, developments are steaming ahead. Amir's practice is harnessing the same process that is going out to the 100 practice pilot.

<http://technology.guardian.co.uk/weekly/story/0,,2033496,00.html>

A Radio 4 interview on the same topic can be accessed here.

<http://www.bbc.co.uk/radio4/today/listenagain/>

<http://news.bbc.co.uk/1/hi/health/6323587.stm>

**NHS Connecting for Health are soon to start their HealthSpace Early Adopter sites.** At least 2 PCTs, and maybe more, will be examining the upload to the Spine of the first tranche of the Summary Care Record. <http://www.e-health-insider.com/news/item.cfm?ID=2543>

They will be using the experience to shape progress over the next year. One of the key early lessons will be to what extent the public will refuse their records to be uploaded onto the Spine. Early signs suggest that reaction is very muted – which is encouraging. More details can be found here:

[http://www.connectingforhealth.nhs.uk/delivery/programmes/healthspace/viewing\\_yoursummarycarerecord?searchterm=early+adopter](http://www.connectingforhealth.nhs.uk/delivery/programmes/healthspace/viewing_yoursummarycarerecord?searchterm=early+adopter)

**The BMA's views on uploading information** following the recent diplomatic settlement were given by James Johnson, BMA Chairman recently. In general, the BMA feels that a useful compromise has been reached.

In addition, the committee debating the way forward visited the US to look at access operating at industrial strength.

"A visit to see the IT system used by the Veterans Administration in the US was an indicator of the later advantages for the ministerial taskforce, Mr Johnson said.

The VA system is the 'largest enterprise-wide health information system' and includes a computerised patient record system for all VA centres.

"The VA was interesting for us in that, for such a large system, they did not experience any of the problems we have encountered here. They simply amalgamated databases together and created one large database of patient records.

"Patients and doctors cannot change data, but they can make amendment notes. Erasing a record is not possible, but a patient can ask to have their views added if they dispute any details in their records."

[http://www.e-health-insider.com/comment\\_and\\_analysis/index.cfm?ID=193](http://www.e-health-insider.com/comment_and_analysis/index.cfm?ID=193)

In our view, it shows yet again that, with simple safety procedures in place, RA can be offered safely and with great benefit to both patients and clinicians.

**Skepticism remains on the opt-out/opt-in agreement** and about patients being able to refuse to have their record on the Spine. Dr Paul Thornton has published a critique of the agreement.

<http://www.ardenhoe.demon.co.uk/privacy/decoy.pdf>

**The healthCard is now available.** This enables patients to carry, on a card with a USB attached, their full GP record extracted from the GP the last time they were there. <http://www.e-health-insider.com/news/item.cfm?ID=2470>

The advantages are that the patient carries the information with them and access to it is easy and straightforward. However, presumably, while the data is in the patient's pocket, data could be changing on the GP record, so the card data may well be out of date. Also, it may be that issues such as third party information will not have been screened for.

**Will daily NHS routines will be robust enough to safeguard confidentiality?**

Here is an article that suggests that daily NHS life may not be compatible with Spine-based routines. This may feed into the public's concerns about confidentiality.

<http://www.computerweekly.com/Articles/2007/01/30/221461/nhs-security-dilemma-as-smartcards-shared.htm#ContentContinues>

**Copying letters to patients.** In a welcome move, Patricia Hewitt reminded Trusts about their commitment to enabling patients to see correspondence about them. Of course, if full record access becomes a reality, patients will have easy access without Trusts or practices having to copy individual letters.

<http://www.ehiprimarycare.com/news/item.cfm?ID=2474>

**The Health Select Committee in the UK Parliament** is investigating the uses to which the Electronic Record is being put. The RAC, linked with the NHS Alliance, has made a submission to the committee.

[http://www.parliament.uk/parliamentary\\_committees/health\\_committee/hcpn070205.cfm](http://www.parliament.uk/parliamentary_committees/health_committee/hcpn070205.cfm)

**National patient voluntary groups are joining the Record Access**

**Collaborative.** They will find the information we provide useful and they will promote the benefits of RA to their members. In addition, the RAC will find their advice and input valuable in guiding progress.

**The Improvement Foundation has joined the Record Access Collaborative.**

The IF is a national primary care-based organisation that promotes good practice and redesign approaches across the country. We hope to run a number of events together.



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“Your medical records are safe with us.  
We take patient privacy very seriously.”

## PATIENTS' EXPERIENCES

**My illness, my record** is an article by Tessa Richards, assistant editor, BMJ. She looked at the benefits of full RA for patients in general and carers in particular. She stressed how access would have helped her look after her father better by countering the fragmented care he was receiving. BMJ 2007;334:510 (10 March), doi:10.1136/bmj.39146.615081.59

**Here is a recent patient experience of RA** reproduced in full. Our thanks both to the patient and to Dr Hannan for making this available

28 February 2007

### My 'Records Access' Experience

My 90 year-old Aunt recently died in the care home where she had been living for the past five years. I was her next of kin and held Power of Attorney for her, a responsibility complicated by the fact that my Aunt lived in England and I live in Australia.

Most of her affairs could be managed with the use of modern technology and annual visits to the UK. But it was between these visits that I felt frustrated when trying to gauge how my Aunt was actually feeling, whether she had any medical problems and how they were being handled. Speaking with her on the phone was sometimes difficult because she could not always hear me clearly and when she wasn't well she could be a bit confused.

When I spoke to staff members at the care home, they could mostly only give me a general picture of my Aunt's state of health. When I was particularly concerned I phoned my Aunt's surgery. This was helpful but I couldn't always contact a doctor who had seen my Aunt recently. It was during one such call when Dr. Hannan spoke to me about the 'records access'. My Aunt was enthusiastic for me to have the access and it was quickly set up.

What a boon this turned out to be. Now I could get complete and current medical information. I could see what problems or symptoms had prompted the doctor being called, what the results of the examination were and what had been prescribed or recommended.

The back history, referrals, results of hospital visits and tests was also valuable information and enabled me to ask more relevant questions, by phone or by email. I also believe that as a result of my overt interest in my Aunt's health, through 'records access,' my Aunt got more regular and thorough attention. The staff at the care home were also more forthcoming in accurately describing what was happening. All this information meant that as my Aunt was declining in her final weeks I was kept in the picture, almost day-by-day as the end approached.

It's unfortunate that we, my Aunt and I, only had the benefit of 'records access' for such a short time, but I am very grateful for having had the opportunity to participate in it.

## DEVELOPMENTS IN THE US

**Health Information and Management Systems Society conference highlighted Personal Health Records.** One subset of consumer health information, namely personal health records (PHRs), took a high profile at HIMSS. "We must empower consumers to manage and maintain their health," explained Dr Holly Miller, co-ordinator of clinical internet strategy for the Cleveland Clinic.

The problem, however, is that there is no uniform definition of a PHR. In fact, several constituencies are developing their own standards for various forms of PHR, with no guarantee the groups will reconcile the divergent approaches.

More details at <http://www.e-health-insider.com/news/item.cfm?ID=2520>

**Concerns about confidentiality in the US.** "We have concerns any time medical records are aggregated into electronic databases," said Allen Gilbert, executive director of the Vermont chapter of the [American Civil Liberties Union](http://www.american-civil-liberties.org/). "Most people feel medical records are some of the most private information that exists about them. Once it is put into an electronic format, you run into all the problems you have with any electronic record, which is hackers getting in even when you've done everything you can to make it as secure as you possibly can." <http://www.vermontguardian.com:80/local/032007/MedicalRecords.shtml>

**Here is a rather scary approach to RA.** Applied Digital Solutions might make an initial public offering for VeriChip, a division of the company that manufactures an implantable microchip that allows physicians and other health care providers to have access to patient identifications and medical records.

The chip, which contains a series of numbers that can link to patients' medical records, is smaller than a grain of rice and is inserted under the skin.

According to the *Times*, VeriChip has marketed the microchip as the "most secure and reliable way to link people with their medical records," but the device has "gained almost no traction in the marketplace," in part because of privacy concerns

**An approach to telemedicine.** Seeking efficiency, cost-effectiveness and improved communication with patients, physicians in a Michigan health system have been testing a Web portal for virtual office visits. Patients using eVisit's MyHealth portal can see lab results, order prescription renewals, and schedule live appointments.

<http://www.healthcareitnews.com:80/story.cms?id=6343>

**Patients at three hospitals and 100 outpatient clinics can use a website to pay medical bills, schedule physician appointments and eventually access their personal health records** The Healthview Portal Web site, which was developed by IBM and Duke University in 14 weeks, is intended to provide patients with more control over their health data by enabling them to access their information from any computer with an Internet connection.

Clinical data -- including prescriptions, lab and X-ray results, and immunization records -- will be available online in about two months. The system by the end of the summer will offer electronic prescriptions. Eventually patients could use the system to receive consultations with specialists or second opinions online.

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**Mar 07**  
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