



THE RECORD ACCESS COLLABORATIVE: THE FINAL PROGRESS REPORT FOR 2007

Welcome to the Record Access Collaborative Progress Report which covers the last 3 months or so. As always activity and developments in the field have been steady.

In the UK, Wales is developing full records access to practices. **HealthSpace** has begun its pilots, accompanied as always by controversy. **EMIS/PAERS** has gone national, switching on all EMIS practices for record access if they want to take it up.

In Europe, we feature France and Germany as they begin trials of record access. **In the US**, Microsoft and Google are entering the field, stimulating a lot of controversy, reflected here.

Patient experiences are featured again and remain very positive.

As an introduction, however, we feature 2 important contributions. The first is a letter from the GMC endorsing record access in principle – we see this as reassuring to clinicians. Also, a link to an interesting and balanced overview of record access from the BMJ.

Currently, the best website to understand the varied aspects of record access is:
<http://recordaccess.icmcc.org/>

Letter on Record Access by Sir Graeme Catto (GMC-UK)

Sir Graeme Catto, President General Medical Council, UK



Records Access

The GMC's statement of the values of the profession *Duties of a Doctor* and our core guidance [Good Medical Practice](#) emphasise the importance of doctors working in partnership with patients. To achieve this, doctors and patients need to communicate effectively with one another, and doctors must provide patients' with information that they want or need to know in order to make decisions about their care. For example in *Duties of a Doctor* we say that doctors must:

Work in partnership with patients

- Listen to patients and respond to their concerns and preferences
- Give patients the information they want or need in a way they can understand
- Respect patients' right to reach decisions with you about their treatment and care
- Support patients' in caring for themselves to improve and maintain their health.

We welcome and support the use of new technology, including records access systems, which can make a significant contribution to the provision of information patients need in order to make decisions about their care. Of course, patient access to records, on request, has been a requirement under the [Data Protection Acts](#) since 1991. The current Act provides safeguards for patients themselves, and for the privacy of third parties. Clearly these legal obligations must be met, whatever means is used to give patients access to records.

Providing access to records outside the context of the Act does introduce some new questions, including the need to record information in a way patients can understand, how bad news, for example from test results, is communicated to patients, and how patients' privacy can be maintained.

These are not new issues of principle, but practical matters that need to be addressed sensitively. They do not undermine the principles of openness and honesty with patients, or of the benefits of partnerships with patients, which records access systems will foster, and that the GMC supports.

Letter to Dr. Brian Fisher, 31 October 2007, publication authorised by Sir Graeme Catto.

<http://www.patientra.co.uk/?p=771>

Potential of electronic personal health records

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Novel methods for helping patients to access and manage their personal electronic health data are emerging in the UK and internationally. **Claudia Pagliari**, **Don Detmer**, and **Peter Singleton** examine their potential benefits and challenges

Public demand for flexible access to health information and services is growing, encouraged by internet trends and policies promoting patient rights and empowerment.¹ In parallel, unprecedented global investment in healthcare information and communication technologies has been dominated by efforts to implement electronic health records, which promise improved quality and efficiency through better maintenance and availability of patient data.² There is considerable international interest in the potential of electronic personal health records to bridge these agendas, and NHS HealthSpace is set to become the world's first fully national system, although its capabilities are still limited in comparison with some European and US examples. We consider the potential of electronic personal health records and factors that are likely to influence their adoption in the UK, drawing on a new report from the Nuffield Trust.³

BMJ 2007;335:330-333 (18 August), doi:10.1136/bmj.39279.482963.AD

WALES POWERS ON

Welsh want to contact GPs online. They are also looking at their records online.

Almost four out of five internet users would like to be able to contact their GP practice online, according to a survey conducted in Wales. Informing Healthcare, the Welsh NHS IT programme, questioned 313 internet. A total of 78% said that they would order repeat prescriptions, book an appointment with their GP or update their details online if these services were available.

This month five practices, based in Anglesey, Bridgend, Cardiff, Llandysul and Swansea, have begun to test different aspects of Informing Healthcare's secure patient website My Health Online. In all five practices patients will be able to use My Health Online to book appointments and request repeat prescriptions and at three of the surgeries patients will also be able to look at their health records online.

http://www.ehiprimarycare.com/news/3169/welsh_want_to_contact_gps_online

EMIS supplies white label software for pilot

My Health Online - the new health website for Wales - is using software designed by Emis to facilitate the trial of new patient services such as GP appointment booking and repeat prescription ordering over the internet.

The pilot is being enabled by the Emis Access service - but as part of the 'white label' deal, the software has been provided to Informing Healthcare as a de-branded service rather than as an Emis product.

My Health Online is part of Informing Healthcare's plan to give each patient in Wales an electronic individual health record. In future, the project aims to offer everyone in Wales the opportunity to view their health record online.

.....Informing Healthcare started trials of My Health Online at five GP surgeries across Wales in October 2007. At three of the surgeries - in Anglesey, Bridgend and Llandysul - chosen groups of patients have the opportunity to access their own health records online, for a limited period, as well as trialling appointment-booking and repeat prescription services.

http://www.ehiprimarycare.com/news/3241/emis_supplies_white_label_software_for_pilot

ENGLAND AND CfH

Summary Care Record launched in Bolton

The first 48,500 summaries of patient records have been uploaded to the NHS Spine and out-of-hours staff in the Bolton pilot area will start using them over the next few weeks, Connecting for Health announced today.

Bolton in North-west England was the first primary care trust to take part in the NHS Care Records Service Early Adopter Programme. Final staff training is underway at the town's out-of-hours service which deals with, on average, over 5,500 calls per month from patients who require access to a GP outside of their own surgery's opening hours.

Connecting for Health (CfH) estimates that - with the current upload figure - around 900 calls per month could be from patients with NHS Summary Care Records (SCR).

http://www.e-health-insider.com/news/3145/summary_care_record_launched_in_bolton



Wait for early SCR results before rollout, says BMA

The BMA has told the Department of Health that it wants to see no further rollout of the Summary Care Record beyond the early adopter sites until the independent evaluation has been completed and ways forward agreed. It says it will advise doctors outside the early adopter primary care trusts (PCTs) against uploading information onto the SCR until the review has been published.

In a [letter to Ben Bradshaw](#), the health minister in charge of the National Programme for IT (NPfIT), Dr Hamish Meldrum, chairman of the BMA Council, sets out a series of recommendations from the BMA on the National Programme for IT (NPfIT).

The [recommendations](#) include a demand that the DH seeks a definitive legal opinion on the issues raised during the Health Select Committee hearings concerning the legality of the SCR and the Data Protection Act, that it works with the BMA to produce a code of practice for uploading information to the SCR and that it develops joint working with the BMA on a final public information campaign on the SCR.

http://www.ehiprimarycare.com/news/2997/wait_for_early_scr_results_before_rollout_says_bma

One quarter of patients favour records opt-out

Two-thirds of patients believe the government's consent plans for the Summary Care Record (SCR) are acceptable but one in four would opt out, according to a survey of more than 2600 patients. The survey found that 66% felt it was an acceptable plan for the government to write to every person in England about its plans for electronic records and assume those who do not object are happy for their records to be uploaded. However the survey also found that 25% would not wish their records to be uploaded and a further 18% did not know whether they would agree to their summary record being uploaded to the spine. The percentage of patients predicting they would opt out is much higher than the number, **less than half a percent**, who have actually opted out so far in Bolton, the first early adopter area.

http://www.ehiprimarycare.com/news/3016/one_quarter_of_patients_favour_records_opt-out

HealthSpace opening up to 'advanced' users

Registration has started for 'advanced accounts' offering patients the opportunity to view their Summary Care Records on HealthSpace, the NHS online personal health register.

The service has opened up in tandem with the [launch of the first Summary Care Records \(SCRs\)](#). Nearly 50,000 of the summaries drawn from GP records in participating practices in Bolton have been uploaded on the NHS Spine for use by out-of-hours staff. More practices in Bury, Dorset and South Birmingham are also preparing to be early adopter sites for the SCR. Patients in Bury are the first to be offered their own route into their personal SCR.

.....Patients wishing to view their SCR will face stricter security checks than those using HealthSpace simply to keep personal record of their healthcare and wellbeing.

http://www.e-health-insider.com/news/3156/healthspace_opening_up_to_'advanced'_users

Uncertainty over legality of NHS Care Records Service

Health minister Ben Bradshaw has refused to release information on the legality of the NHS Care Records Service (NCRS) and played down suggestions the NHS database will breach European law.

Bradshaw was responding to Jeremy Wright MP who had contacted the health minister on behalf of one of his constituents Dr Paul Thornton, a GP in Warwickshire who is campaigning against the consent model for the NCRS.

Bradshaw told Wright that the legal advice "was not available in a format that was suitable for publication" and, in any case, was subject to legal privilege.

http://www.ehiprimarycare.com/news/3056/uncertainty_over_legality_of_ncrs

Celebrity's details illicitly viewed by NHS staff

Reports that the records of a celebrity were illicitly viewed by over 50 members of staff at an NHS hospital look set to further fan fears about the confidentiality of patient records in the NHS Care Records Service now under development.

Ironically, the incident was cited in board papers for North Tees Primary Care Trust only as an illustration of why it was necessary to tighten procedures for staff to access sensitive personal medical records.

http://www.ehiprimarycare.com/news/3045/celebrity's_details_illicitly_viewed_by_nhs_staff

OTHER APPROACHES TO RECORD ACCESS IN THE UK

EMIS to roll out patient access to records

EMIS is set to roll out patient access to records across all of its practices.

The primary care IT supplier, which provides GP systems to nearly 60% of the UK market, has been testing patient record access for more than a year in a handful of practices.

In May the company announced it was looking for an additional 100 practices interested in enabling patients to view their records online. Dr David Stables, co-founder and clinical director of EMIS, said 120 practices had signed up but only about 30 practices had gone on to provide access to patients and there were currently about 20 to 30 record views each day.

.....Dr Stables said experience with other EMIS innovations, such as online appointment booking and repeat prescription requesting, showed take up was slow initially although 25% of EMIS practices now use online appointment booking and a higher percentage use repeat prescription requesting.

http://www.ehiprimarycare.com/news/3121/emis_to_roll_out_patient_access_to_records

Increasing e-access for patients

Secure internet access to the EHR is being piloted by the Record Access Collaborative (RAC). More than 180 patients at a handful of EMIS surgeries can now access their full medical record, including test results, consultation and medication notes, via any internet-enabled PC with a web browser. Currently, 30 practices have configured the software to activate the service.

.....**Other innovative projects** are being run by Marple Cottage surgery, Stockport, and The Red House Surgery, Hertfordshire, enabling patients to effectively add to their electronic healthcare record.

At Marple Cottage, an online system is currently being trialled with asthma patients, who can complete regular reviews of their condition from home. Patients check their condition against a protocol online and, if necessary, complete and securely return a template assessment form using the EMIS Access system to the practice. This is reviewed by the asthma lead, who files it in the patient's record and creates a personalised self-management plan.

<http://www.ehiprimarycare.com/Features/EMIS%202/>

PATIENT EXPERIENCES

“What benefits have patients experienced by accessing their electronic health records?”

GA

I am in the process of returning from an EU country back to the UK. I have been having treatment for cancer, and it has been invaluable to refer to my electronic NHS record to remind me of treatment I have had in the UK. I am now collating all my medical records here for my imminent return (x-ray, etc) in order to keep my records updated for future reference. There is no National Record of Health in this country. All records are to be kept by the individual. There is still a lot to be said in favour of The National Health system, despite the adverse reports it sometimes gets.

IB

I have a longstanding medical condition and find it fantastic that I can visit France & a doctor there can access my records (with my permission) and know exactly what has gone before. In my experience the medical profession does not always accept the information a patient can provide!

http://www.patientra.co.uk/?page_id=137

Michaela

Having got internet access to my records I can honestly say its fantastic! I have been able to check my records to ensure they are correct, and it has given me control over my own life and health. I can see so many benefits for this to go worldwide. It is reassuring to know what Doctors are writing in their files about you, and you can share this information if you have to see Doctors in Hospitals etc.

Using the internet access records has meant both myself and my Husband are in control of our health, my husband is diabetic and he has given me access to read his records, I understand what he needs to do to ensure a healthier longer life because of this and we are both working together to ensure this!

We support this very much and believe it can make a huge difference to people, GP's and the nations health.

<http://www.patientra.co.uk/wpc/?p=13#comment-3364>

MM

I am a lifelong sufferer from Bipolar Disorder. I have had Records Access for several months and it has changed completely my relationship with the NHS.

After my regular consultations I am able to review my on-record notes at ease. With the best will in the world it is very difficult to absorb all that is said in what is sometimes a lengthy consultation. If I think that the records do not accurately reflect the consultation I can contact my GP to ensure the records are changed.

The results of any tests I may have – in my case 3-monthly blood tests – are available to me in detail as soon as they are received at the surgery, to be acted upon where necessary.

The ability to order prescriptions and make appointments cannot be underestimated in a world which is hectic for the patient, the clinician and the administrative staff at the surgery.

However, for someone with my condition, I consider the most important benefit of Records Access is the ability I have to allow a clinician, away from my GP practice, to access my medical history. In my worst periods of crisis I am exhausted, frantic and rarely in a fit state to relate my history to someone. Additionally, a sufferer from Bipolar Disorder frequently does not want to 'relive the past' as this only adds to their trials. With my full consent, and only with my consent, will a clinician be able to obtain a full medical history without me going through the ordeal of recounting my medical history and, importantly, be able to start to treat me rapidly.

I can understand that some patients are worried that their private records will be available to those they would prefer not to have them but I do not consider that even a remote possibility. I would additionally like it to be possible for me to nominate someone to give permission in my stead by allowing them to have the access codes. I would not, however, be willing for my records to be accessible throughout the NHS. A nationwide system on that scale would only be a recipe for disaster.

I might add that I spend part of each year in France where I am reassured that my local 'medicin general' could have access to my UK records if necessary.

<http://www.patientra.co.uk/?p=507#comment-13394>

Major trial of PHRs starts in Germany

Germany's largest health insurance fund, Barmer, is working on a three year research study looking at the benefits and acceptance of personal health records. Barmer will use ICW's web-based LifeSensor technology to offer a personal health record to its seven million members at a cost of 23.80 Euros per individual per year, provided they have a PC with an internet connection.

http://www.ehealthurope.net/news/3238/major_trial_of_phrs_starts_in_germany

Sesam Vitale - 2 smartcard

The Sesam Vitale-2 will contain a photograph of the user, vital medical details, and a secure patient identifier. Critically, the Vitale-2 will allow patient control over clinical access to patient records, as it will be required to unlock access to the central EHR system, the DMP.

Roll-out of the Sesam Vitale-2 began April 2007 in the Ile-et-Vilaine, in the Bretagne region. In summer 2007, the system is intended to be rolled out in the Pays-de-la-Loire, and from autumn 2007 throughout the rest of France.

Links on French DMP and ehealth programme

http://www.sante.gouv.fr/assurance_maladie/actu/dmp.htm

<http://www.ehealthurope.net:80/Features/item.cfm?docId=195>

Microsoft launches HealthVault

Microsoft has launched a major personal health record initiative based on a secure website that allows users to store and share their health records using a free online service. The HealthVault portal allows users to store and share their medical histories, immunisation details, and data from monitoring devices such as glucose and cholesterol levels. A dedicated health search engine will enable easy navigation and organisation of users' health data.



Users will be able to download medical information, such as laboratory results or x-rays, from the web sites of their healthcare provider. They will also be able to directly download data from HealthVault-compatible digital health monitors and devices, and store the data on their PHR. Individual users will then be able to elect to provide access to parts of their PHRs to their doctor, family member or carer through a secure email invitation. Microsoft stresses that all data stored in HealthVault will be secure and pledges it will not mine or sell data.

http://www.e-health-insider.com/news/3105/microsoft_launches_healthvault

HealthVault Stirs Debate over PHR's Privacy and Proper Role

October 23, 2007 | While [HealthVault](#) is more connectivity platform than product — contrary to popular belief, it's not a personal health record (PHR) by itself — people already are taking sides on its approach, just weeks after the official launch. (See "[Microsoft Debuts HealthVault](#).") Even though HealthVault is not a PHR on its own, many of the more than 200 other companies that have agreed to use the Microsoft platform are integrating HealthVault technology into their own PHRs.

Last week, the bipartisan Coalition for Patient Privacy, headed by Deborah Peel and her Austin, Texas-based [Patient Privacy Rights Foundation](#), sent a [letter](#) to members of Congress urging passage of national privacy legislation to supersede HIPAA. Peel has emerged as a staunch supporter of HealthVault....

.... "Current laws do not adequately protect electronic health records, leaving the marketplace for 'personal health records' and other products the 'gold rush' of Health IT," the letter reads. ..., "When patients do not trust doctors or the health care system to protect their privacy, they withhold information, they delay or avoid care, and they become sicker."

http://www.digitalhcp.com/newsletters/index_10232007.htm

Microsoft's New Online Tools Face Obstacles, Competition

Large health insurers have offered Web-based PHRs for a couple of years and believe they have an advantage over outside vendors, such as Microsoft, because they can preload each enrollee's PHR with claims information (Girion, *Los Angeles Times*, 10/5).

Microsoft hopes that individuals will grant physicians, clinics and hospitals the right to transmit prescriptions, test results and other medical information directly to their HealthVault account (*iHealthBeat*, 10/4). However, providers have little incentive to share the data or resources to populate an electronic record, the *Wall Street Journal* reports. "Consumers are just not that excited about these" PHR services, Elizabeth Boehm, an analyst at Forrester Research, said. 6% of consumers are using a Web-based program or personal computer software to track their health information, while 94% use paper records (Guth, *Wall Street Journal*, 10/5).

<http://www.ihealthbeat.org/articles/2007/10/5/Microsofts-New-Online-Tools-Face-Obstacles-Competition.aspx?topicID=52>

The Veteran Association's long experience with record access is described here

The VA has been experimenting with different approaches to record access over the years. There is a new pilot which has begun offering full access. It seems to have been very successful so far. The second half of this presentation explains the pilot and its outcomes. Here are 2 screen shots. MHV means "Medical Record Viewing" ROI means "Return on Investment"

Fears, Facts, and Urban Legends

- MHV Pilot did not
 - Increase patient advocate complaints over content of the medical record
 - Result in even one congressional complaint
 - Result in even one report of a patient misinterpreting or overreacting to medical data
 - Increase requests for chart amendment
 - Support the argument that mental health patient access to medical records should be restricted
-

Fears, Facts, and Urban Legends (cont'd.)

- MHV Pilot did
 - Improve veteran satisfaction as measured by anecdote and a research project
 - Reduce the volume of ROI requests
 - Reduce the volume of paper printed in response to ROI requests
 - Result in 1 chart amendment request
 - Convert the medical staff into MHV supporters