



Welcome to the latest RAC Progress Report!

We aim to keep you up to date with international developments in patients accessing their own health records. We are keen to keep dialogue going across the world in this field – we all have a lot to learn from each other. You can find a lot of ideas and thinking on the website www.icmcc.org

As usual, there has been a lot going on, both in the UK and elsewhere.

In the UK, the highlights are perhaps:

- the Early Adopter sites for the Summary Care Record going live in 2 areas of the UK.
- The continuing enlargement of the 100 practice pilot enabling an increasing number of practices to enable full patient record access
- The pushing forward of the eHealthCard that is now being offered to practices in the UK
- The resignation of Richard Granger who runs the IT programme in the UK. This may offer a more open approach to IT development

In Europe, the recent ICMCC conference in Amsterdam highlighted record access and offered a number of concrete developments, in Estonia, the Czech Republic and in the Netherlands.

But first, developments outside Europe.

DEVELOPMENTS OUTSIDE EUROPE

New Record access services in Arizona

Cigna Medical Group, Cigna's physician network, in mid-2006 began offering online services at its 17 health care centers in Arizona. Patients can use the RelayHealth service to schedule or cancel appointments, refill prescriptions, request lab results or a referral, e-mail their physician and manage their personal health records online.

Senior plan members will be able to access the online health services at no cost, but other Cigna members will be charged a fee, the *Business Journal of Phoenix* reports.

http://www.bizjournals.com:80/phoenix/stories/2007/04/09/daily14.html?from_rss=1

Survey: E-health records don't have to jeopardize privacy

Sixty-three percent of respondents said that the transition to electronic health records could be made without compromising their privacy, compared with 25% who disagreed, according to a new Harris Interactive survey, [Computerworld](#) reports.

Seven out of 10 U.S. residents said they are satisfied with the way physicians and hospitals handle and protect their personal health data. However, 50% of respondents said they think patients do not have control of how their personal health information is used by organizations, such as insurers, employers and government health agencies.

Alan Westin, a professor of public law and government at Columbia University who helped design the survey, said the results found that a majority of the public is ready for EHRs, but "about one-quarter of the public remains skeptical and worried about such systemic computerization, and it will take highly robust and transparent new privacy and security programs to overcome these fears" (Havenstein, *Computerworld*, 3/26).

The survey also found that 17% of respondents have withheld data from their providers because of concerns that the information might be shared, [Health Data Management](#) reports. Twenty-one percent of respondents who describe their health to be fair or poor said they have withheld data. www.computerworld.com/action/article.do?command=viewArticleBasic&articleId=9014378

April 24, 2007 | WASHINGTON — Even in healthcare, the battle for the hearts and minds of fickle American consumers is shaping up to be an epic struggle of convenience vs. privacy — though the scales currently seem heavily weighted toward the latter.

At least that was the general consensus among three technology executives and a few hundred healthcare industry types during a panel discussion at the World Health Care Congress Tuesday morning.

In an impromptu survey of attendees, 52 percent would want any first responder to have access to their personal health records during a medical emergency, while another 22 percent would be comfortable if a good Samaritan on the scene could read their basic medical history. "Care covers privacy in a crunch," said the panel's moderator, Jim Guest, president and CEO of Consumers Union.

At other times, though, privacy is the clear winner, and not necessarily for the better, according to the participants, who included Peter Neupert, corporate vice president for health strategy at Microsoft, Google vice president Adam Bosworth, and Intel chairman Craig Barrett.



Why Policymakers Need to Know About PHRs

- Widespread adoption of electronic Personal Health Records (PHRs) is a key component of strategic plans for a national health information infrastructure, which experts consider essential to achieving significant improvements in health care quality and efficiency. PHRs are increasingly relevant to policymakers because:
- PHRs can serve as a tool to engage and empower consumers to play a larger and more active role in wellness, self-care, and disease management, with important dividends in quality improvement and cost containment.
- PHRs can collect and consolidate health information from both consumers and providers across the care continuum, including the home.
- Lessons learned from recent natural disasters highlight the importance of portable personal health information in response and recovery efforts.
- The full potential of PHRs and other consumer empowering tools cannot be realized without policy intervention.

High-tech system helps Kodiak clinic put medical records online

Kodiak Community Health Center in Alaska has adopted an electronic health record system that lets patients access their records anywhere at any time, the [Kodiak Daily Mirror](#) reports.

The clinic partnered with GCI ConnectMD on the pilot program, a move that kept costs low, according to Brenda Friend, executive director of Kodiak Community Health Center. The service is one of the state's first deployments of a Web-based EHR system. The system will work over the ConnectMD network, the largest medical network in the Pacific Northwest.

Patients can use the secure online system to find information about various health conditions, review their lab and test results, and refill prescriptions.

<http://www.kodiakdailymirror.com/?pid=19&id=4846>

Hospital network launches Web-based health records

Kettering Health Network in Ohio on Tuesday announced a new pilot project in which patients and their physicians will be able to access Web-based individual health records with information from various physicians, labs and hospitals, the [Dayton Business Journal](#) reports.

Kettering on June 1 rolled out the program, called DaytonHealthKonnnect, for the 6,800 network employees and their dependents who are insured by Anthem Blue Cross and Blue Shield. The program later will be expanded to all Kettering Health Network patients, regardless of their health plan, Frank Perez, Kettering Health Network CEO, said (Kershaw-Staley, *Dayton Business Journal*, 6/12).

The individual health records include information from Anthem's insurance-claim database and medical files from Kettering affiliates, the [Dayton Daily News](#) reports (Lamb, *Dayton Daily News*, 6/13).

The systems uses a red light to alert physicians and patients to health issues that require attention, a yellow light to indicate issues that need monitoring and a green light for issues in good standing (*Dayton Business Journal*, 6/12).

<http://dayton.bizjournals.com:80/dayton/stories/2007/06/11/daily7.html>

Area firm tests 'smart cards' on N.Y. patients

A hospital visit might soon be safer and speedier with a new patient "smart card" that aims to reduce health-care paperwork and protect against medical errors.

In coming months, patients at Mount Sinai Medical Center and nine other New York City metropolitan hospitals will get a wallet-size health card that can carry the equivalent of 30 pages of medical records, everything from blood type to echocardiograms.

The 64-kilobyte card was developed by Siemens Medical Solutions, based in Malvern and Erlanger, Germany. About 1,000 cards have been issued so far, and Siemens and Mount Sinai expect about 5,000 to 10,000 to be distributed by the end of the year to a regional network of hospitals and clinics that serve patients of diverse nationalities and many languages.

In all, 100,000 plastic cards will be doled out over the next 18 to 24 months to residents of New York and northern New Jersey as part of a pilot plan.

The hospital system is using the cards to reduce medical errors, make it easier for patients to communicate with their doctors, present records that are more complete, and minimize the number of insurance-claim denials.

"The smart card helps us identify exactly who we are talking to," said Jack Nelson, chief information officer at Mount Sinai, which serves New York's wealthy Upper East Side and less-wealthy Harlem.

http://www.philly.com:80/inquirer/business/20070618_Area_firm_tests_smart_cards_on_N_Y_patients.html

And, below, does this feel like a familiar theme?

National Medical Database Could Be Identity Theft Magnet

The federal government's efforts to create a nationwide health information network could exacerbate the increasing problem of medical identity theft, according to some privacy experts, the [Newark Star-Ledger](#) reports.

A report released last year by the World Privacy Forum said that medical identity theft is increasing and could affect millions of U.S. residents annually. The report noted that a database of patients' health records -- such as what has been proposed by the Bush administration -- could add to the problem. "The mantra is that digitization of patient records will improve health care, reduce fraud, reduce medical errors and save lives. But this does not account for the challenging reality of medical identity theft," it said.

Medical identity theft can be used for insurance fraud schemes, to obtain medical care in another person's name or to obtain prescription drugs illegally. The crime can result in the altering of patients' medical records, which could lead to misdiagnosis and harmful treatment, the *Star-Ledger* reports.

National Coordinator for Health IT Robert Kolodner said his office "is pursuing a deliberative, comprehensive and integrated approach to ensure the privacy and security of health information within a nationwide health IT infrastructure."

However, critics say the Bush administration has failed to emphasize privacy as a top priority. <http://www.nj.com:80/news/ledger/index.ssf?/base/news-11/118369737583930.xml&coll=1>

DEVELOPMENTS IN THE UK

BMA votes against a central Spine

Doctors have called for a public inquiry into NHS Connecting for Health (CfH) and have called on the BMA to advise doctors not to co-operate with the centralised storage of medical records.

The National Programme for IT was the subject of strong criticism at the association's annual representative meeting (ARM) this week where doctors claimed the NHS IT project was doomed to failure unless a grip was taken on the project and that patient information held on the NHS Care Records Service (NCRS) was not secure and confidential.

Doctors backed a motion, against the advice of Dr Richard Vautrey from the BMA's working party on NHS IT, which called on the association to advise doctors not to co-operate with the proposed centralised storage of all medical records which they claimed seriously endangered patient confidentiality.

<http://www.ehiprimarycare.com/news/item.cfm?ID=2827>

Record Access for diabetic patients

Diabetic patients in Carmarthenshire, Wales are piloting new electronic health records which will share all information about their care and check-ups by GPs and specialists.

Informing Healthcare, the Welsh Assembly Government programme for NHS IT, has created the shared electronic diabetes record to bring all the patient's information together so that the whole treatment history is in one single record.

<http://www.ehiprimarycare.com/news/item.cfm?ID=2702>

The Early Adopters

Dr Gillian Braunold explains how pragmatism and common sense are the touchstone of the summary care record early adopters, which are already shaping policy for future roll-out.

By Dr Gillian Braunold, National Clinical Lead for GPs, NHS Connecting for Health

http://www.ehiprimarycare.com/comment_and_analysis/index.cfm?ID=201

Scottish GPs insist on explicit consent on shared records

GP practices must remain the data controller for GP records even if databases are held within a hosted environment, Scottish GP representatives have agreed.

In a special debate on information sharing and confidentiality at the Scottish Local Medical Committees' (LMCs) conference last week GPs also insisted that Scotland's explicit consent model should remain for all information held by practices.

<http://www.ehiprimarycare.com/news/item.cfm?ID=2655>

Summary Care Record now caters for cautious patients

Members of the public who don't think they want their summary care record shared but would still like to keep their options open for the future are being offered a new Orange 'keep their options open' choice of a record that is recorded but only shared when they give their explicit consent.

This latest evolution of the consent model for Summary Care Records was unveiled at a Friday press demonstration of the SCR led by Connecting for Health's joint GP clinical lead, Dr Gillian Braunold.

She explained that the new option had been introduced following the commitment given last November by the then Health Minister Lord Warner when he said that people can choose not just to have their SCR record shared but to not have any SCR created and stored on the national database. Engineering this 'red light' option gave rise to the new orange option on the three traffic light consent states.

Any patients unsure about the SCR should go for Orange, says Dr Braunold. "Orange exists for patients who say I'm not sure about this, but if I'm sick I would like to be able to give my consent."

If they choose at a later date an orange patient can ask their consent flag to be changed to read 'expressed consent' for a particular instance of their record being shared, such as for use in unscheduled out of hours care.

An Aside: a poem about those bad days.....

Today I do not want to be a doctor by Glen Colquhoun

Today I do not want to be a doctor.
No-one is getting any better,
Those who were well are getting sick again
Those who were sick, sicker.
The dying think they will live,
The healthy think they are dying.
Someone has taken too many pills,
Someone has not taken enough.
A woman is losing her husband
A husband is losing his wife.
The lame want to walk,

The blind want to drive,
The deaf are making too much noise,
The depressed are not making enough.
The asthmatics are smoking
The alcoholics are drinking
The diabetics are eating chocolate.
The mad are beginning to make sense,
Everybody's cholesterol is high,
Disease will not listen to me, even when I
shake my fist.



When the insurance company turned loose
the bill collectors, one obstetrician settled
for the price of gratitude.

EMIS seeks 100 pilot practices for patient record access

100 EMIS practices are being recruited to pilot online access to records for patients. While those involved are adopting a softly softly approach to the extension of this service currently being piloted by a few, the implications are fascinating.

The project opens up GP-held records to patients, and from there enables patients to go on and share them with whoever they choose in a way Connecting for Health can only dream of as it continues to struggle with professional bodies, consent models, sealed envelopes and the like. Ironically of course it is also EMIS, the primary care company that has been most at odds with CfH, that is leading the way.

The initiative also focuses attention on an aspect of health care IT that many believe will be the driving force behind the way systems are developed in future with records held separately from the applications that created them and available to view anywhere in the world.

<http://www.ehiprimarycare.com/news/item.cfm?ID=2685>

By Laura Donnelly, Health Correspondent, Sunday Telegraph

03/06/2007

Thousands of patients will be able to read their GPs' notes online in a scheme pioneered by doctors who took over the surgery of serial killer Harold Shipman.

More than 700,000 patients will be offered an internet service that lets them see all their notes and scans, collect test results, and even provide crucial details of their own medical history to unfamiliar doctors treating them outside their normal surgery or while on holiday.

The scheme, which gives patients a password allowing them to see their full GP record from anywhere with internet access, is to be tried out by 100 practices. But it could be extended to every surgery and patient in the UK if it proves successful.

BMJ House of cards
Michael Cross
BMJ 2007;334:772-773
doi:10.1136/bmj.39171.643368.47

Michael Cross has written a sane and balanced view of patient record access in the UK.

<http://www.bmj.com/cgi/content/full/334/7597/772?hits=10&FIRSTINDEX=0&HITS=10&fulltext=house+of+cards&searchid=1&resourcetype=HWCIT>

Record Access – the time has come!

An article by your humble editor and others offering an overview of current approaches and a preview of what will be possible soon. We feel this is a useful summary of the current situation with a summary of the research.

<http://recordaccess.icmcc.org/files/RABJGP.pdf>

A PATIENT VIEW

Another patient view – how Record Access changes things for the better

Yes, it has helped already, I feel that a full stop has been put at the end of the sentence and tied my support network all up nicely. It is the ultimate privilege to be able to access notes.

Knowing that there will be a note on my records that I can access makes everything to do with my overall treatment easier and I don't worry about one agency not knowing what the others are doing or saying or arranging.

As all service users I know myself better than other people and now that I can access the regular blood test results I know what readings to look out for instead of being confused by the things that a receptionist may tell me over the phone (i.e. this level says high and the other level says low and then it says SEE YOUR DOCTOR! This has worried me in the past and I think there's something more wrong with me than there is.

Knowing that I have had access to all the notes and results will definitely help to keep the time I spend with the doctor at my regular check up appointment which is about every month or 6 weeks or so. This saves my time, the doctor's time and also the time of other patients and doctors as each consultation takes less time with explanations.

There have been times when I have been waiting to know what a particular hospital department or consultant has written to the GP about me, causing concern and tension, but now I can find out exactly what has been written about my care straightaway.

It is a lovely, positive way of being given a CHOICE over what I do see and what I chose not to see and for me, as a service user, to be involved at every stage of any part of my progress and treatment.

EUROPEAN DEVELOPMENTS

ICMCC Conference in Amsterdam May 07

One of the key themes was record access for patients. There was wide-ranging discussion about both the opportunities and the difficulties in dissemination and implementation.

The European initiatives and all the presentations can be clearly seen on www.icmcc.org

In the Amsterdam conference, a submission to the World Health Organisation on Records Access was further crystallised. The details are also on www.icmcc.org. The final recommendations, in summary, are these:

ACTIONS FOR THE WHO

- 1 The WHO should recognize the significance benefits accrued by full RA to the personal health record.
- 2 The WHO should promote RA as a key aspect of care.
- 3 The WHO should ensure that health services around the world enable patients to see their full personal health record if they want to. The administrative, cultural and technical infrastructure to support RA should be encouraged.
- 4 The WHO should support research into RA and how it can be best harnessed for patient care.

Holland is moving towards records access

The issue remains contentious for many family doctors in the Netherlands, but a small group of doctors, linked with the largest patient organisation, is slowly building bridges with ideas.
www.patientenepd.nl

As always, we welcome comments and reactions to these news items. Please send to brian.fisher403@ntlworld.com