



## **GROWING THE IDEA!**

### **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.

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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/>

It has certainly been a busy few weeks in the record access field! Most heat and little light by the Guardian campaign in the UK which, having printed misleading information, unfairly claims significant policy change. Actually, more a clarification of a previously rather vague situation with regard to refusing to have one's medical record placed on the Spine.

## DEVELOPMENTS IN THE RECORD ACCESS COLLABORATIVE ITSELF

### **Patient groups**

National UK patient groups are beginning to become involved in the Collaborative. We shall be meeting them over the next few weeks to define how best we can share information and advice.

### **WHO submission.**

The Collaborative is writing a submission to the WHO to ensure that record access is put on the agenda. When we have produced a reasonable draft, we shall ask your advice for final drafting.

### **The ICMCC site**

[www.icmcc.org](http://www.icmcc.org) has a substantial and growing section on record access. Much of the research is summarized there as is current events and plans. An active blog is linked to the site and you are welcome to both read and write on it.

### **The NHS Alliance conference**

The NHS Alliance is a grass-roots organisation that brings together all facets of primary care for mutual support and development of policy that has a significant influence on the Dept of Health.

Brian Fisher from the Collaborative presented there and generated interest in record access among practices. A number will be likely to join the EMIS /PAERS pilot in the New Year.

<http://www.nhsalliance.org/news.asp>

<http://www.nhsalliance2006.co.uk/presentations.htm> - click on Brian Fisher's presentation

### **Primary Health Care Specialist Group**

This influential primary care computing group hosted a discussion on record access recently with Dr Hannan and David Stables, members of the Collaborative. They made trenchant comments on the current developments and changes are being made as a result.

<http://www.phcsg.org.uk/index.php?p=conferences>

### **Bethesda conference**

Richard Fitton from the Collaborative worked hard at a conference in Bethesda recently. The group will be publishing soon a paper that summarises both the opportunities for record access and the hurdles that need to be overcome.

### **ICMCC conference**

There will be a conference run by the ICMCC in Spring in the Netherlands. There is a call for papers out now. Record Access is a strong theme. Members of the Collaborative are on the scientific committee for this conference.

<http://2007.icmcc.org/>

### **Baltimore conference**

Technology, Behavior and Urban Health

International Conference on Urban Health

October 31-November 2, 2007

Wyndham Baltimore Inner Harbor Hotel

*"Harnessing the power of Technology to Achieve Behavior Change and Improve Urban Health"*

More information is available now at the conference website

[www.icuh2007.com](http://www.icuh2007.com)

Members of the Collaborative are on the scientific committee for this conference.

### **Decision aids study**

A study on decision aids to be made available for patients on the record access kiosks has been completed recently. Funded by NHS Direct, the study examined whether the free DAs available on the Cochrane Database ([decisionaid.ohri.ca/index.html](http://decisionaid.ohri.ca/index.html)) would be directly useful to patients in SE London. A number were and will be placed on the PAERS/EMIS kiosks.

Meanwhile, DAs elsewhere continue to be widely used.

<http://www.chicagotribune.com/news/nationworld/chi-0612110202dec11,1,1598072.story?coll=chi-newsnationworld-hed&ctrack=1&cset=true>

UK NATIONAL DEVELOPMENTS
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### **Guardian newspaper campaign**

The paper ran a campaign pointing out the risks posed by the Spine. Some of these risks are real but the scale was exaggerated. The impression was gained of a highly dangerous and unstable system that would be unlikely to benefit patients.

[http://www.guardian.co.uk/uk\\_news/story/0,,1953041,00.html](http://www.guardian.co.uk/uk_news/story/0,,1953041,00.html)

After the NHS made it clear that patients would only be able to keep their records off the Spine if they could prove resulting substantial mental distress, a recent statement by Lord Warner appears to simply confirm the point. The paper, however, claims a victory.

<http://politics.guardian.co.uk/publicservices/story/0,,1975036,00.html>

The government does appear to be approaching a compromise with the profession and patients that may be useful and enable the system to move on.

[http://www.wired-gov.net/WGArticle.aspx?WCI=htmArticleView&WCU=ARTCL\\_PKEY%3D43179](http://www.wired-gov.net/WGArticle.aspx?WCI=htmArticleView&WCU=ARTCL_PKEY%3D43179)

<http://www.ehiprimarycare.com/news/item.cfm?ID=2361>

On the other hand, in a different context, here is an example of a large number of records being stolen – with no serious consequences, it seems.

<http://www.daytondailynews.com:80/n/content/oh/story/news/local/2006/12/13/ddn121306aetna.html?cxtype=rss&cxsvc=7&cxcat=16>

### **A distributed database.**

This may offer a more appropriate solution. The EMIS/PAERS approach does not require a Spine. The full GP record is called for by the patient and is under the control of that patient. This approach can offer most of the functionality of the Spine, but only through the consent of the patient. Meanwhile the data is far richer and potentially more useful.

We would be happy to host a discussion on this.

### **HealthSpace pilots**

These will be starting soon. Patients will be enabled to see their allergies and prescriptions and issues such as authentication will be explored. A very welcome move.

<http://publictechnology.net/modules.php?op=modload&name=News&file=article&sid=7182>

### **EMIS/PAERS pilot**

7 practices having piloted online access to the full GP record and lessons having been learnt – a wider pilot will begin in the New Year. There are a number of practices who are keen to try this approach to record access and 100 practices will be hopefully recruited over the next few months.

### **National standards for record access**

The Collaborative is keen that national (and international) standards be developed. A conversation with Cecilia Pyper resulted in a commitment by the Connected Patient Programme that discussions on this topic will begin in the New Year.

We look forward to this important process.

## PATIENT THINKING ON RECORD ACCESS

### ICMCC blog

There are many comments there for people to follow.

<http://blog.icmcc.org/?p=9>

### Foldercare.

This, patient-driven site is developing guidance on record access and other EHR-related topics.

<http://www.foldercare.co.uk/>

### A patient's guide to record access

Yvonne Bennett has written this guide. We reproduce here an edited version. If you want to read more, please let me know.

### Advantages ☺ (A patient's perspective)

#### **GP/Healthcare**

The patient has an active role in their own healthcare and develops a good relationship with their GP and Practice.

#### **Access abroad**

You may be in another country and taken ill. You may decide to allow the doctor access to your records (a personal decision). It might be that you forgot to order your repeat prescription and need it to be ready on your return. You can do this by using an internet café.

#### **Casualty or outpatients**

If you are going to see a healthcare professional in hospital you can allow them to see your records online if there is a computer in the room or print out the relevant information and take it with you. This can be very helpful to the consultant.

#### **Relatives having access**

***Only if you wish*** you could share all your records with relatives or just part by printing the part you wish to share.

#### **Saving Time**

Blood results, x-rays or letters can be checked. If they are normal it saves you time not having to travel to the surgery. It also leaves a free appointment allowing the doctor to see someone who is in need of an appointment.

#### **Information for Forms**

If you need to know when you had your immunisations or what allergies you have, you can look them up.

#### **Better understanding**

If you did not understand the conversation with the doctor or nurse, you can look at the record of that consultation. Patients have found that that makes the discussion easier to understand and remember.

You will also find that the information buttons explain technical terms for you. This can be extremely helpful.

### **Medication Information**

You can easily check information about any medication prescribed by clicking on the **blue** '?' button listed next to your medication in the list. This also includes information on how to take the medication You can check what results mean or check a condition and some help guidelines. There are links to support groups e.g. Diabetes UK.

### **Security**

It's as safe as internet banking ***IF*** you keep your passwords secure. You wouldn't leave your bankers card and pin numbers lying around (particularly at work) and then wonder how someone managed to withdraw money from your account. Don't leave your passwords where they can be found. This may also include at home if you don't want family members to view your records. Don't use obvious ones such as names, birthdays or anniversaries etc.

### **Disadvantages** ☹

#### **Forgotten History**

There may be something in your history you don't want any family members to see. It might be information you had put to the back of your mind and are now confronted with it!

#### **Complex information**

The record is designed to be used by doctors for doctors. There will be abbreviations and technical terms. However, most patients understand most of what they read and the information buttons linked with problem titles offer detailed explanations. Please ask if you do not understand

#### **Test Results**

Results can be difficult to understand. Results may be abnormal and cause you to worry

#### **3<sup>rd</sup> Party Info**

You might want to tell the doctor something about your spouse/partner/child etc in confidence.

1. If the doctor records the information and the patient then sees this it could cause problems.
2. If the doctor doesn't vital information may get lost or forgotten
3. The information may be malicious and again cause problems

## INTERNATIONAL DEVELOPMENTS

### **US employers enable record access for employees**

Large US employers are planning to enable their employees to have record access. Presumably on the basis that it will improve health and reduce care costs.

<http://www.chron.com/disp/story.mpl/business/4382914.html>

### **Germany opens the way to access**

Through a smart card.

<http://www.dw-world.de/dw/article/0,2144,2268824,00.html>

### **An increasing number of US residents have record access**

But the developments are rather chaotic and lack standardization.

<http://www.informationweek.com/news/showArticle.jhtml;jsessionid=P3SCMC0G0WFKUQSNDLPCKH0CJUNN2JVN?articleID=196603941>

### **Another approach using a smart card.**

<http://www.ehealthnews.eu/content/view/360/26/>

The disadvantage of using a smart card is that the data will soon be out of date.