

| |
|---|
| <p>THE RECORD ACCESS COLLABORATIVE: ACCESS TO YOUR HEALTH RECORDS – MAKING IT WORK FOR PATIENTS</p> |
|---|

DRAFT**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 restrictions¹. There is good evidence of substantial benefits for patients².

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.

DEVELOPING AND SUPPORTING THE ACCESS COLLABORATIVE

The collaborative is intended to be a network of organisations and individuals who are interested and supportive of RA. This will include NHS Connecting for Health (NHS CFH) in England, private companies, common interest companies, groups such as the NHS Alliance and Patient Information Forum, and individuals. It will also include patients and patients' groups.

This will entail:

- identifying interested parties
- developing their strengths
- developing mutual communication and support
- developing opportunities for all
- encouraging learning
- avoiding conflicts of interest or, if unavoidable, finding ways of minimising them.

¹ DoH 2004. 'Better information, better choices, better health: Putting information at the centre. www.dh.gov.uk/publicationsandstatistics/publications

² <http://recordaccess.icmcc.org/>

Field Code Changed

BENEFITS OF RECORD ACCESS TO PATIENTS AND CLINICIANS

Most patients want to see their health records. People say that they understand about 60% of what they see without any change of clinician writing style. Although a minority, mainly those with psychiatric difficulties, are upset about what they see, they still feel accessing their record was the right thing to do. RA appears safe, even for patients with serious illnesses such as cancer.

Evidence of benefits includes:

- Increased trust in/ with their clinicians
- An improved relationship with their practice
- Improved compliance in medicine-taking
- Some evidence that preventative health behaviour is encouraged
- Obtaining their own health information without needing to contact the practice (allergies, immunisations)
- Empowering patients to care for themselves more effectively
- Using consultations with their clinicians more effectively
- Saving time for themselves and the practice
- Correcting errors in the record.

These are significant benefits and are summarised on the ICMCC website <http://recordaccess.icmcc.org/> . By designing appropriate and additional functionality, benefits can be enhanced further.

RAISING AWARENESS OF RA

RA is no longer a new concept. The challenge remains to bring the ideas and the reality to a wide audience and, in the process, both identify the obvious benefits but also examine any real difficulties that arise.

The aim of this aspect of the collaborative would be to:

- marshal the evidence for safety and evidence-based benefits
- advise on or carry out research on RA
- examine and address practitioners' fears and concerns, including:
 - o fears that RA will lengthen consultations
 - o concerns that RA will expose clinicians' data quality and encourage litigation
 - o concerns over security and confidentiality
 - o concerns over third party information
 - o fears of losing control over aspects of the clinical encounter and management of the patient.
- examine and address patients' fears and concerns
- ensure that ideas and achievements are disseminated and heard
- link RA with other key processes such as training, Patient and Public Involvement (PPI), performance management
- link with specific interest groups such as patients with long-term conditions.

There are a number of organisations who are likely to be very important in the field of RA. These include:

- British Medical Association
- The Royal Colleges
- The Healthcare Commission
- NHS Connecting for Health, including their Patient Portal and Connected Patient workstreams, and the Care Record Development Board (CRDB)
- The NHS Standards Board

The sorts of **activities** that are likely to be helpful include:

- Organising workshops and conferences
- Publishing articles in the academic and medical press
- Attracting national press interest
- Obtaining case studies of benefit
- Bringing patients and clinicians together for mutual learning
- Producing research data
- Attending GP user groups of the different software houses
- Developing an international website
- Producing a fortnightly report that keeps members up to date with progress in the field.

Many of these are already in hand.

TO MAKE ACCESS AS USEFUL AS POSSIBLE FOR PATIENTS

By linking data with health information, we can harness access for health improvement. For instance:

- linking diagnostic codes with patient information leaflets
- linking drug names with information leaflets
- linking diagnostic codes with health advice
- linking data with advice on good practice, such as National Service Framework (NSF) or patient-facing NICE guidance
- identifying gaps that can support patients in self-care: reminding diabetics of they are overdue for BP checks, for instance.

A VARIETY OF SYSTEMS

Within the UK there are a number of organisations and individuals working towards record access in different ways, at different speeds and to different degrees. A number of different systems are available, doing different aspects of the task.

HealthSpace (www.healthspace.nhs.uk)

The current plan is that people will be able, starting from 2008, to begin to see a summary version of their health records, on a home computer using a protected web service called HealthSpace. At first, they will be able to access medications and allergies, and later other summary information about care and treatment...

Field Code Changed

They will also be able to add information such as access needs, treatment preferences, and eventually self-monitoring information. People must choose to access their records using HealthSpace, and register. The registration process is currently being devised.

GraphNet (www.graphnethealth.com)

This company allows integration and collation of confidential clinical data between different IT health systems. It also offers the potential for sharing between health and other systems, such as Social; Care and Health and Education. It has enabled Hants and Isle of Wight share records for 1.5 million patients between GP practices and hospitals.

GPmail (www.gepmail.co.uk)

Dr Paul Cundy, a GP who is also a member of the BMA GP IT committee has developed a process which enables patients to enter into their own GP electronic health record specific data such as blood pressure and peak flow. This is available to a number of practices, with many thousands of entries having been made.

Foldercare (www.foldercare.co.uk)

Designed by GP Dr Richard Fitton and his patients, the system organises medical data concepts in ways that make it easy for lay people to understand medical terms and ideas. Foldercare also develops new ideas and thinking in the field.

Renalpatientview (www.renalpatientview.org)

Young people with renal problems in Wales and Edinburgh are allowed to see their renal records. A lot of data centres on the investigation results and what they mean. This has been enthusiastically taken up by the patients and their families and appears to have reduced demands on the hospital team.

PAERS/EMIS/InPractice Systems (www.paers.net)

This system is designed by doctors in collaboration with EMIS, and now includes InPractice systems. The system enables patients to see their full electronic GP records, on a kiosk in the waiting room, via a touch screen, patients being authenticated with their fingerprint. The screen contains the same data as held by the GP but reformatted so that it is easier to read and navigate around. The data is linked to health information for the patient. The Health Information Portal (HIP) is available to practices now.

In addition, net-based access is currently being piloted. It may be possible to enable 60% of practices across the country to offer net-based access by the end of 2006.

Internationally

In the US in particular, there are a number of systems that enable record access. A number are referenced on the ICMCC website. Some of these systems link

access with targeted health information. US doctors have also linked RA with email consultations. The driver for RA in the US is that it is part of a package that keeps patients well, reduces demands for healthcare and is an efficient use of technology.

In summary, there are a number of different systems both within and between countries. There are lessons to be learnt from each other and options for coordinating development.

TO SUPPORT THE DEVELOPMENT OF NATIONAL STANDARDS FOR RA

There is a need for clarity in the use of RA. There are risks that, as RA becomes more available and more routine, that it will be applied in ways that may be counterproductive to good care and improving relationships. In addition, standards will make it more likely that RA will be taken up, as they will be seen as good practice to which clinicians will aspire.

The aim of this aspect of the collaborative would be to:

- work with individuals and organisations who are already interested in drawing up standards
- if asked, to cooperate in writing the standards

As at July 2006, discussions continue between the Royal College of General Practitioners (RCGP) and the NHS Standards Board about how these standards might be drawn up and under whose auspices.

CONCLUSION

We expect that the concept of record access will have increasing acceptance across the NHS and internationally. The collaborative should be able to support patients and clinicians in getting the most out of the technology and the relationships that flow from it.

We expect that, over the next few months, the collaborative will be bringing people, ideas and technologies together to enable patients to get the most benefit out of access.

Dr Brian Fisher
brian.fisher403@ntlworld.com
mob: 07949595349

Field Code Changed

**For the Record Access Collaborative
July 06**