

PATIENT RECORD ACCESS – THE TIME HAS COME

Dr Brian Fisher MBBCh MSc¹ (a), Dr Richard Fitton² (b), Charline Poirier, PhD³ (c),
Dr David Stables MBChB⁴ (d)
(a)GP, Wells Park Practice
(b) GP, Hadfield Medical Centre
(c) Ethnography/user research consultant
(d) Medical Director, Egton Medical Information Systems Ltd

ABSTRACT There are now a number of systems across the world that enables patients to view their electronic health records. These include kiosks that have fingerprint authentication and also net-based access. The paper outlines the approach taken by the UK NHS and explains the legal underpinning of access.

Starting from the premise that record access is here to stay, the paper outlines the research on benefits and risks of record access, concluding that, with simple precautions, record access is safe and affords many benefits to both patients and clinicians. It goes on to consider possible impacts of record access on the way records might be written as a co-produced document and emphasizes that national standards for record sharing need to be written.

Keywords: record access, patient empowerment, record sharing

Introduction

Current NHS plans that NHS Connecting for Health's Healthspace will, by 2008, support patient access to the Spine, through the National Care Record Service. This is expected to be a summary of the GP problem list probably excluding mental health, sexual health and some infections. These summaries will need to be discussed with individual patients, probably starting late 2006. Healthspace is designed to support patients in self-care. Patients will eventually be able to specify which parts of their record are to be placed in "sealed envelopes" with access restricted to specific NHS professionals (NHS Care Records in England Connecting for Health 2005)

¹ 1 Wells Park Rd, London SE26 6JQ, UK, Tel: 020 8291 6898 Fx:020 8699 2552, brian.fisher403@ntlworld.com

² 82 Brosscroft, Hadfield, Glossop, Derbyshire SK13 1DS, UK, Tel 01457 860860 Fax 01457 857735, Richard.fitton1@btopenworld.com

³ 59 Carlton Mansions, Randolph Avenue, London, W9 1NR, UK, Tel: 020 7328 1563, Charlinepoirier@gmail.com

⁴ Park House Mews, Off Broadway, 77 BackLane, Leeds LS18 4RF, UK, Tel 0113 2591122

This paper describes developments that will enable patients to have access both to their full and their summary medical records in the surgery and on the web. It outlines the current legal framework and explores how record access (RA) may impact on many aspects of care. It also briefly discusses the key role of design.

RA is currently available in a number of different forms across the world. In the UK, kiosks, designed outside the NHS Connecting for Health programme, offer access to the full GP electronic record with linked health-related information. Access is authenticated by fingerprint and PIN to protect access, and the touch screen and reformatted records make content and navigation easier to understand. (PAERS 2004). A web-based service is being designed with other functionality possibly including the ability to rectify errors.

A number of practices in the UK are using RA in the surgery. One surgery allows patients to take away their records on a USB memory stick or on a CD. Patients in some practices can insert health data such as BP and Peak Flow directly into their record. In the US a number of HMOs offer RA. (Eklund B, Joustra-Enquist I. (2004)). In all situations, security and legal protection are of the highest order.

So, RA is on the way. What do we know about it? What will it look like? What is its likely impact?

1. Legal underpinning

The legal underpinning to RA includes the Access to Medical Records Act, the Data Protection Act and the Freedom of Information Act.

Access to Medical Reports Act 1988 (Access to Medical Reports Act 1988) establishes a right of access by individuals to reports relating to themselves provided by medical practitioners for employment or insurance purposes (subject to exceptions, broadly similar to those for the Data Protection Act, described below).

Data Protection Act 1998 (Data Protection Act 1998) states that patients or anyone authorized by the patient, parents of children under 16 or a 'Gillick competent' child are entitled to access their medical records. Access can only be denied where the information:

- may cause serious harm to the physical or mental health, or condition of the patient or any other person
- may relate to or be provided by a third person who had not consented to the disclosure.

The Freedom of Information Act 2000 (Freedom of Information Act 2000) gives people a general right of access to information held by or on behalf of public authorities. The Act provides that information is exempt if, inter alia, its disclosure under the Act would, or would be likely to

- endanger the physical or mental health of any individual, (including the applicant, the supplier of the information or anyone else)
- endanger the safety of any individual.

The **Copying Letters to Patients** initiative (DOH (2003)). enabling patients to see all letters written about them does not have any legal underpinning but raises many of the

same issues as RA,. It is slowly being adopted across the NHS, with general acceptance by patients and clinicians.

2. What do we know about RA?

75% of patients who have been registered to use the electronic kiosk access system have looked at their notes - the same proportion as those who looked at their paper records which are being phased out in most general practices. Some patients access their records repeatedly; most only do so occasionally for specific purposes.

Clinicians are often initially sceptical and worried about the impact of RA. (Fisher B, Britten N. (1993)) They fear that mistakes and confusion will be exposed and that litigation may increase. There is no evidence, however, that this is likely to occur. (Baldry M., Cheal C., Fisher B., Gillett M., Huet V. (1986)). On the contrary, evidence is clear that RA improves relationships between clinicians and patients. Experience with RA tends to convince clinicians that its benefits outnumber its potential problems, and many have become quite enthusiastic (Protti D, Eggert C. (2005))

The benefits of RA appear to be substantial. Patients describe improved trust in their doctors, improved confidence in their clinicians, (Baldry M., Cheal C., Fisher B., Gillett M., Huet V. (1986)) and they feel more informed and in control of their condition and its management.(Pyper C, Amery J, Watson M, Crook C., (2004)) There is some evidence for improved health practices by patients – for example, improved compliance in heart failure. (Ross SE, Moore LA, Earnest MA, Wittevrongel L, Lin CT. (May 2004)) In general, patients are keen on RA in principle (National Programme for IT, (7 October 2003.)) and in practice. (Pyper C, Amery J, Watson M, Crook C.,(2004)). Additional advantages of RA include that it can be used to reduce recording errors and thus increase patient safety, (Fitton Richard, personal communication) and that patients looking up information in their records can save time for practices.

If integrated into daily practice, we expect that RA will not result in an increase in consultation time, although this has not yet been formally measured. On the contrary, we predict that RA will help patients focus their medical agenda and ultimately, RA will end up saving time and foster compliance.

There are risks, to be sure. 10% of patients were upset by what they read, although the vast majority of those were still pleased that they had seen the notes. Patients with cancer, in particular, were overwhelmingly pleased to have read their full GP records. Evidence suggests that patients with psychiatric problems can find seeing their notes distressing (Baldry M., Cheal C., Fisher B., Gillett M., Huet V. (1986)). However, the experience can be harnessed therapeutically. There are potential risks if the process is not handled carefully, if, for example, patients see frightening information before it has been discussed with them or if they are able to access third party information. Simple precautions in letter and result handling, however, can virtually eliminate these risks. Experience so far has been with enthusiastic committed practices, and it may be that such safety precautions may not be so strictly adhered to when the majority of practices will be able to offer access. This is

one of many reasons that a set of national standards of managing RA are essential and urgent.

Confidentiality is well-maintained in the waiting room kiosk-based approach: the system uses both fingerprint and pin identification and there are simple but effective ways of ensuring that it is only with the patient's permission that the record may be seen by anyone else. A web-based approach may be more prone to abuse: despite secure access, it is possible that members of the family, for instance, will be able to see records, perhaps by glancing over patients' shoulders or by coercing them. However, as with internet banking and other protected sites, once the record has been delivered, the patient becomes responsible for its security.

Overall, RA appears to be safe and practical when used with simple precautions and education. In order to guide beginners and to clarify procedures, there is a need for NHS and international standards and guidelines.

3. To what use do patients put RA?

Current research suggests that patients use RA to prepare for consultations and recap after them; for finding information that they would otherwise have to ask the practice for, such as immunization history; it helps understand the history of a particular condition; improves awareness of their condition; enables them to pass on information obtained when visiting hospitals or when taking sick elderly parent to A & E. In general, they say that they feel more of a partner in their health care. (unpublished data NHS Connecting for Health)

4. What impact could RA have on daily clinical life?

Consultations (when they work well) find agreement on a description of what is going on and develop and understanding of how to manage it. The shared record, if we get it right, offers a new dialogue in which clinician and patient learn from each other. Thus, the task is not only to foster ease of use for the clinician, it is also to make the record useful for the patient. The electronic record could change from a repository of recorded clinical information for clinicians to a tool of communication and health management used by patients and health professionals. This could affect the structure, processes and outcomes of records in a number of ways.

4.1. Reading the record.

GPs' notes are full of abbreviations, technical terms, and other impediments to lay understanding. Patients tell us that they understand on average 60% of the record as it is currently written. If patients start relying on the record to make sense of their health and to participate in their own care, recording will have to change to improve lay understanding. For instance, writing "Heart attack" for the patient's benefit rather than "MI".

This might mean that clinicians need to spend more time writing in the record. However, technology can help to write efficiently with predictive text, automatic correction and glossary or information boxes, reducing time and effort while maintaining reliability. Technology can also provide lay interpretation of medical terms. One system currently enables patients to see information about most of the Read codes by touching the screen to reveal a Patient Information Leaflet on the topic.

4.2. Making sense of data

Quantitative data, such as investigation results are another restricted area of clinical knowledge. This data currently makes immediate sense to clinicians but is not generally meaningful to patients. RA could make sense of data for patients. For example, blood pressure, blood glucose and lipids can be displayed as charts and diagrams with normal ranges and including clinicians' comments on their significance. Technology could develop clinicians' informal practice of illuminating descriptions with drawings.

4.3. Issues of equity and design

The design of RA will also need to ensure equality of care. Ethnographic studies suggest that patients have different native mental models or world views of health which structure their behaviours around health. (Poirier, C. (2000)) A patient's world view and particular health goals will affect their motivation to adopt and use their record. Design needs to be increasingly universal to ensure equity of access. It will need to relate medical information to the goals and needs of patients.

4.4. Correction of errors in the record

Experience has shown that RA can aid the correction of recording errors. These errors often involve patient identification. They also often pertain to aspects of a consultation, for example, to a description of conditions or symptoms described by the patient, or even outcomes.

In pilot studies, we have found that patients are able to point to inconsistencies in prescribing and test results. Studies are being conducted to quantify error reduction outcomes in records provided by RA.

4.5. Ensure continuity of care

The patient can also help in the sharing of information that the record contains with appropriate health professionals. There are a number of examples where carrying records on holiday has made medical intervention safer.

4.6. Patients entering their own data

A number of practices have experience of patients adding data directly to their record by email. Peak Flow and BP would be the obvious candidates here. Design would need to ensure that the data was viewed by the clinician before being entered into the notes so that any relevant clinical response could be made.

5. CONCLUSION

In summary, we see RA as significantly improving shared care and improving not only trust in clinicians, but trust by clinicians for their patients. It appears safe when used with simple precautions. It is likely to form the bedrock of future choice and shared decision-making.

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