WHO Recommendation on Record Access (Draft)

1. AIM:

To ensure that patient record access (RA) is incorporated in WHO development plans.

2. WHAT

RA is the process whereby a user of a health service has the power to access their personal health record (PHR). The PHR means any health record holding information pertaining exclusively to that person. The PHR can be held centrally, when all health records, including community, GP and hospital, are held in a central store; or they can be distributed, stored in different places. RA thus means that a person can see all or part of the health information held about them.

Full RA means that citizens and their selected family, friends and carers can see and use all information, for instance, their full primary care record. A full primary care record would typically include a summary of their main health problems, letters to and from their clinical team, medication details, allergies, immunizations, investigation results.

Citizens should have active access to add personal information, like use of over the counter drugs or results from home monitoring devices.

3. WHY SHOULD CITIZENS HAVE ACCESS TO THEIR RECORDS?

3.1. Ethical reasons:

3.1.1 People increasingly have a right to see information held about them that is not damaging to national security. In some countries, access to health information is constrained by concerns for damage to the person and exposure of third parties. [1]

3.1.2 RA puts more emphasis on citizens and clinicians to use all of the rich material within the record. This use of the truth and its consequences leads to a more proactive and purposeful partnership of health creation and care.

Although it is extremely rare for clinicians to lie, it is not uncommon to be less than clear about the logic and the reasons for a particular course of action. For instance, if patients can read that an investigation has been carried out in order to exclude cancer, then it also becomes important that the clinician explains this at the outset when ordering the test.

3.2. Direct benefit to health

3.2.1 RA supports patients in being more informed about their health, disease and care pathways. We know that informed patients have both better outcomes and use health services less

3.2.2 RA can enhance this process by linking health information and advice to the record. For instance, problem titles can be automatically linked to information about that problem. There can be links also to national self-help groups, national guidelines for good practice and decision aids.[2]

Record access improves communication between national programmes, local care providers and patients and citizens. It allows the automatic updating and sharing of health and disease management plans between citizens', patients and carers. Care pathways, health behaviour and health plans that took twenty or thirty years or centuries to change could now change with record access in weeks or months.

3.2.3 RA seems to enhance compliance in patients with heart failure.

3.2.4 RA improves health promotion behaviour. There is some evidence that smoking quit rates are higher in patients who have RA.

3.2.5 RA helps patients keep track of fragmented care[3]. This can be a serious problem in many health services. Many patients, especially the elderly, are treated for multiple problems by various carers and institutions. Results may get lost, coordination can be poor. If a patient has access to their information, particularly by having access to their primary care record where most of this information is stored in summary form, they can take charge of failed linkages, if they so wish.

Record access may therefore also stimulate improvements in care across interfaces.

Record access allows patients to use valuable information about themselves to their own advantage. Expensive tests and results can be re-used and shared as and where the patient wishes to share them.

3.2.6 RA will establish portability of the PHR, also across national boundaries.

3.2.7 Poor health and behavior causes illness and illness causes disease. RA can stimulate behavioural changes in citizens. [4]

3.2.8 RA educates patients and their selected families and friends. Adults and children with health and disease learning needs need to take on new roles as participants in health creation and disease management. Knowledge and understanding are delivered to citizens and patients through the PHR. Care, monitoring of health and disease and implementation of procedures can be shared or delegated to citizens and patients using the shared record.

3.3. RA empowers patients

3.3.1 Patients with RA feel more in control.[5]

3.3.2 RA helps patients can find information out for themselves. For instance, through test results, care pathways or letters about them. Support information must be linked to these items, to enhance patients' understanding, involvement and commitment.

3.3.3 With RA, patients can have access to information about good medical practice, tailored to their personal health needs. For instance, by linking their health problems as viewed in their record electronically to information such as national good practice guidelines, diabetic patients can see if their blood sugar and blood pressure fall within good practice boundaries.

3.3.4. RA supports shared decision-making. The record can support this in many ways. Just having access to what your clinicians are saying about you, access to investigation results with interpretation, access to letters enables patients to take greater part in their care and health creation. In addition, if there are links to specific decision aids, patients are more likely to take decisions that change their management. [6]

3.3.5 RA helps patients understand their consultation better. Research suggests that patients who leave a consultation with a clinician unclear about what has been said can understand it more clearly by reading afterwards what the clinician has written.

3.3.6 RA helps carers and advocates support patients better. So long as permission has been freely given, carers can understand the patient's condition better and be up to date with their management. In this way, patients with dementia or mental health problems, for instance, can participate more in their care. [7]

3.3.7 RA will encourage citizens to add personal issues to the EPR, such as their use of over the counter drugs.

3.3.8 RA will promote the use of monitoring devices, as the results will be part of the EPR.

3.4. Improved record keeping

3.4.1 RA enables patients to correct their records. The commonest errors in UK records are demographic. RA allows patients to point out or indicate errors in their records and enables them to request for correction.[8]

3.5. Benefits to the health service

3.5.1 Patient with RA may need fewer appointments. Research suggests that, if patients have seen the information in their records that they need, they do not make unnecessary appointments.[9]

3.5.2 Patients with RA may take less time in consultations. Research suggests that patients only raise those issues that they have not been able to resolve by looking at their records. Of course, explanations of data that remain unclear may also result in longer consultations. Overall, evidence suggests that RA is time-neutral. [10]

4. COMPLEX ISSUES

These can be addressed by appropriate administrative and technical approaches
4.1. Access to their records by children and their parents
4.2. Third party information
4.3. Language
4.4. Patients with psychiatric problems
4.5. Litigation
4.6. Security and authentication
4.7. Insurance companies and solicitors trawling through records for business.

5. ACTIONS FOR THE WHO

5.1 The WHO should recognize the significance benefits accrued by full RA to the personal health record.

5.2 The WHO should promote RA as a key aspect of care.

5.3 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.

5.4 The WHO should support research into RA and how it can be best harnessed for patient care.

Signatories

Dr Brian Fisher MBBCh MSc, GP
Wells Park Practice
1 Wells Park Rd
UK-London SE26 6JQ
brian.fisher403@ntlworld.com

Dr Richard Fitton, GP
Hadfield Medical Centre
82 Brosscroft, Hadfield, Glossop
UK-Derbyshire SK13 1DS
Richard.fitton1@btopenworld.com

Drs Lodewijk Bos
President ICMCC
Stationsstraat 38
NL-3511 EG Utrecht
lobos@icmcc.org

REFERENCES

[1] Access to Medical Reports Act 1988 www.opsi.gov.uk/acts/acts1988/Ukpga_19880028_en_1.htm

[2] www.paers.net

[3] Richards T BMJ 2007;334:510 (10 March), doi:10.1136/bmj.39146.615081.59

[4] Ross SE, Moore LA, Earnest MA, Wittevrongel L, Lin CT. (May 2004) Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. J Med Internet Res. 20;6(2):e14.

[5] Winkelman WJ, Leonard KJ, Rossos PG.. 'Patient-perceived usefulness of on-line electronic medical records: Employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness'. J Am Med Inform Assoc. 2005 Jan 31

[6] www.icmcc.org

[7] Richards T BMJ 2007;334:510 (10 March), doi:10.1136/bmj.39146.615081.59

[8] Powell J, Fitton R, Fitton C. (2006) Sharing electronic health records: the patient view. Informatics in Primary Care 14:55-7

[9] NHS Connecting for Health unpublished data

[10] Op cit