

Potential of electronic personal health records

Novel methods for helping patients to access and manage their personal electronic health data are emerging in the UK and internationally. **Claudia Pagliari, Don Detmer, and Peter Singleton** examine their potential benefits and challenges

Public demand for flexible access to health information and services is growing, encouraged by internet trends and policies promoting patient rights and empowerment.¹ In parallel, unprecedented global investment in healthcare information and communication technologies has been dominated by efforts to implement electronic health records, which promise improved quality and efficiency through better maintenance and availability of patient data.² There is considerable international interest in the potential of electronic personal health records to bridge these agendas, and NHS HealthSpace is set to become the world's first fully national system, although its capabilities are still limited in comparison with some European and US examples. We consider the potential of electronic personal health records and factors that are likely to influence their adoption in the UK, drawing on a new report from the Nuffield Trust.³

What are electronic personal health records?

Although no universally agreed definition of an electronic personal health record exists,⁴ it has been described as “an electronic application through which individuals can access, manage and share their health information... in a private, secure and confidential environment.”⁵ Models vary in the extent to which the content of the record and rights of access are controlled by the patient or the healthcare provider, the range of tools that accompany it, and their interactivity. Simpler models include patient generated health and lifestyle records that are stored and managed using personal computer or web applications, and passive access to provider held records through waiting room kiosks, the internet, or digital copy (such as on a CD or smart card).

However, personal health record systems are becoming increasingly complex (box 1). Some are integrated with providers' information systems to combine personal record keeping, access to current electronic health records, and a range of information and communications functions. For example, patients of the US managed care organisation Kaiser Permanente have access to HealthConnectOnline, which offers records of allergies, immunisations, future appointments, diagnoses, instructions from past visits, and laboratory results as well as allowing patients to book appointments, reorder prescriptions, and communicate with healthcare professionals by email (figure).

Claudia Pagliari senior lecturer in primary care, Division of Community Health Sciences (GP Section), University of Edinburgh, Edinburgh EH8 9DX

Don Detmer professor of medical education, Public Health Sciences, University of Virginia, PO Box 800717, Charlottesville, VA 22908, USA

Peter Singleton principal research fellow, Centre for Health Informatics and Multiprofessional Education, University College London, London N19 5LW

Correspondence to: C Pagliari claudia.pagliari@ed.ac.uk

Accepted: 28 May 2007

Box 1 | Potential functions of electronic personal health records

- Access to provider's electronic clinical record (summary or detailed)—eg history, drugs, test results
- Personal health organiser or diary—eg clinics, doctors, tests, dates, non-prescribed treatments, scanned documents
- Self management support—eg care plans, graphing of symptoms, passive biofeedback, tailored instructive or motivational feedback, decision aids, or reminders
- Secure patient-provider communication for booking appointments, reordering prescriptions, or seeking advice (eg patient-doctor email)
- Links to static or interactive information about illness, treatments, or self care
- Links to sources of support—eg patient organisations or virtual peer networks
- Capture of symptom or health behaviour data—by self report or objective monitoring through electronic devices (fixed or portable)

Complex online personal records are also being used in Europe. The LifeSensor product (www.us.lifesensor.com/lsn/content/e4529/index_usa.html), which is available in Germany, Switzerland, Austria, and Bulgaria, allows patients to store and manage information about their current health status, medical history, results, images, and documents and also to authorise access for selected healthcare team members or caregivers to view, add, or update



Example of portal for electronic personal health records from the US

Box 2 | Current UK experience with electronic personal health records**Primary care**

Online access to the full electronic primary care record is being piloted in practices associated with a major system supplier.⁷ Patients of some eligible practices also have access to online appointment booking, prescription reordering, and secure email. (www.emis-online.com/products/access/)

Waiting room kiosks providing secure access to records and related patient information have been introduced in several general practices and are now available commercially (www.emis-online.com/products/health-information-portal/)

Some practices have offered patients copies of their electronic record on CD or USB memory stick for several years⁸

Smart cards are currently being marketed, on to which patients can upload their general practice record, for a fee, and view it using personal computing software (www.healthcard.co.uk)

Access to record via mobile phone and BlackBerry smart phone is also being piloted⁹ (www.ehiprimarycare.com/news/item.cfm?ID=2148)

Secondary care

Patient portals offering access to more specialised records, some with a range of additional features, exist or are being developed in several areas, including:

- Nephrology (www.renalpatientview.org)
- Paediatric intensive care (www.babylink.info/Edinburgh/BabyLink/Intro_page.aspx)
- Diabetes (www.dmag.org.uk/bird/aboutthisproject.asp)
- Maternity care (www.nhshealthquality.org/nhsqis/229.html)

Patient-provider email and remote submission of symptoms to electronic health records are also being tested in both sectors

information, although the system is not directly linked to provider records. In the future, the European Union electronic health insurance card may enable patients to access their online personal health record.⁶

HealthSpace (www.healthspace.nhs.uk/) is a secure online personal health organiser available to all patients in England. The system was initially launched in 2003 to store health notes generated by patients. However, its functions have since increased to include selection and booking of hospital appointments; storage and charting of health indicators such as blood pressure, peak flow, or weight; a calendar with the option to generate email reminders; a database of NHS contacts; and links to online health information. By the end of next year patients will be able to access their NHS Summary Care Record—a snapshot of the general practice record documenting allergies, adverse reactions, and drug treatment. Although HealthSpace will not provide access to detailed care records, clinicians can add data to the summary record with the patient's agreement. Other features under consideration include allowing patients to enter their needs or preferences, such as for wheelchair access or translators; greater use of text and email alerting; and enhanced tools for patients with chronic disease. The link with NHS Direct Online (www.nhsdirect.nhs.uk) also offers possibilities for integrating electronic consulting and education in the future. Although HealthSpace promises a national solution to electronic personal health records, it will be some time before its full potential is realised.

Compatible developments are taking place independently in several UK clinical settings. These have mainly focused on providing passive access to records, although systems with additional functionality

and interactivity are beginning to emerge. While most have been driven by pioneering clinical enthusiasts, commercial providers are beginning to enter this market, offering opportunities to scale up these developments for wider delivery (box 2).

What are the possible benefits and for whom?

Electronic personal health records have the potential to empower patients through greater access to personal data, health information, and communications tools, which may aid self care, shared decision making, and clinical outcomes. They may increase patient safety through exposing diagnostic or drug errors, recording non-prescribed medicines or treatments, or increasing the accessibility of test results or drug alerts. They may also reduce geographical barriers to patient care and act as a point of record integration, particularly in fragmented health systems, thus improving continuity of care and efficiency.^{10 11}

Although the number and quality of studies remains limited, existing research suggests improvements in communication and trust between patients and professionals, confidence in self care, compliance in chronic disease, and accuracy of records.¹²⁻¹⁴ Patients particularly value online reordering of prescriptions, laboratory results, disease management plans, trend charts, drug lists, and secure messaging.⁵

Surveys indicate that most patients would like to be able to access their health records.^{5 15 16} However, the most frequent users of electronic personal health records, and those for whom the greatest benefits can be expected, are likely to be patients with long term conditions, who have the most need to track their illness and treatments, and patients experiencing episodic periods of care or treatment that generate new needs for information or communication (such as in vitro fertilisation).^{5 17} The emergence of mobile and wireless applications that allow remote submission of data to a shared record offer new possibilities for patient monitoring and real time decision support. Additionally, electronic records may help to promote partnership between carers and health professionals through sharing information, or allow relatives to monitor the care and progress of elderly parents or children in hospital from a distance.

Factors influencing UK adoption and effectiveness**Privacy and security**

Anxieties around security and confidentiality have been expressed in most studies of patient attitudes to personal electronic records, particularly in regard to mental and sexual health data. This does not seem to have been a barrier where access to general practice records has been tried in the UK^{8 12 14}; however, some patients may wish to keep sensitive information off the central NHS record (called the spine).¹⁸ Although encryption technologies can help to prevent unauthorised access, the risk of privacy invasions may be greatest at the family level, whether the intent is supportive or malign (for example, in spousal abuse), which is difficult to control for.¹⁹ Growing experience

of online services in other sectors and traditionally high levels of trust in healthcare professionals are likely to help ease concerns about confidentiality.

Digital divide

Electronic personal health records have the potential to contribute to health inequalities through uneven internet access, although rising ownership of mobile phones and digital TV may help to ameliorate this if developers include these alternative media. Attention also needs to be paid to usability and training in order to overcome access disparities resulting from poor technical skills—for example, among elderly people. If these problems are effectively addressed, such records may reduce healthcare exclusion through flexible access to information and services.²⁰

Choice of model

Although patients may welcome passive access to records, the greatest benefits are likely to come from multifunctional, interactive systems that are integrated with providers' record systems and can support education, self care, and communication with the health service.⁵ However, this increased utility may decrease security, and patients will have to decide whether this risk is acceptable for them.³ It also creates an imperative for standards to ensure transparency of contributorship and access. Growing availability and use of digital health monitoring devices may create new sources of data that can be included in the record, although this information is unlikely to be beneficial unless clinicians are available to interpret and respond to it.¹³

In view of individuals' differing requirements from an electronic personal health record and the associated security issues, HealthSpace's cautious approach to access and interactivity is appropriate. Systems offering more comprehensive patient records or interactive support tools are likely to be pursued as optional supplements to HealthSpace, ideally integrating with local general practice or disease specific records systems. It is unclear whether wholly patient managed records will be adopted because the NHS is in a unique position to create joined-up health records for all citizens, reducing the advantages of patient managed systems seen in more disaggregated healthcare systems such as in the US.

The business case for personal electronic records in the UK has not been well established, and it remains to be seen which optional services patients and local care providers will be prepared to pay for. However, evidence that the UK is faring worse than comparable Western countries in meeting patients' wishes for easy access to their records suggests an unmet demand.¹⁶

Technical considerations

Incompatibility between different systems and databases remains a barrier to integrated records, although this will diminish with the adoption of consistent technology and data standards. Further work is required to ensure effective management of interactivity between patient and provider records

SUMMARY POINTS

Online versions of personal health records that allow patients to manage their health data are emerging in the US and Europe

Implementation of NHS HealthSpace is increasing awareness and provision in the UK

Electronic personal health records may improve the quality, safety, and efficiency of care

Key challenges include balancing security against utility and integrating diverse data sources and systems

and the balance between live and historical data. Methods of effectively managing interfaces between independent systems and HealthSpace will also need to be established.

People and organisational factors

To realise their potential, electronic personal health records must be integrated within care processes. This will require efforts to develop policies, conventions, and incentives for using such records as well as changes in attitudes and expectations regarding appropriate modes of transaction and the rebalancing of information and status differentials in the doctor-patient relationship.

Although no adverse effects have yet been reported in UK pilots, some patients may be distressed by what they read in their electronic health record.²¹ Healthcare professionals will need to be sensitive in their use of clinical terms and delay entering threatening diagnoses or test results until after speaking to the patient. Public education on the value of internet hygiene and password secrecy will also encourage more secure and appropriate use of online records.

Professionals and patients should be involved in the design, development, implementation, and evaluation to generate a sense of ownership and ensure that systems meet users' needs and are easy to operate. More immediately, measures to increase awareness of the potential value of personal health records to patients and the NHS are needed if these systems are to be adopted in the UK.

Future priorities

Current views on the value and risks of electronic records are highly polarised in the UK.^{22 23} Studies comparing responses to alternative models of personal health records in diverse consumer groups may help to shed light on acceptable boundaries and trade-offs and hence suggest ways of tailoring such systems to patients' needs. Ethnographic studies of usage by patients with different clinical and access needs would also be of value. Evidence of the impact of electronic personal health records on clinical, safety, economic, and psychosocial outcomes is urgently required. Although research conducted in other countries is useful, implementation of technology is highly context dependent and research within the UK is essential to inform strategic decision making. As the first fully nationalised electronic personal health records system, the implementation of NHS HealthSpace offers unique opportunities to inform the evidence base on this topic.

Contributors and sources: CP chairs the Edinburgh and Lothian eHealth Research Network. DD is president and chief executive officer of the American Medical Informatics Association. PS is a senior associate of the Judge Business School, University of Cambridge, and director of Cambridge Health Informatics Limited. All are actively involved in health informatics research, with longstanding interests in electronic personal health records. CP drafted the article, with input from DD and PS. All cowrote the Nuffield Trust report on which this article draws, which was based on a workshop organised by CP and facilitated by DD with PS as rapporteur. CP is guarantor.

Funding: The Nuffield Trust.

Competing interests: None declared.

Provenance and peer review: Not commissioned, externally peer reviewed.

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Medical education research remains the poor relation

Research into medical education is stagnating and urgently needs the resources to become more rigorous and relevant say **Mathew Todres**, **Anne Stephenson**, and **Roger Jones**

The requirement that clinical practice should be based on the best available evidence has been paralleled by calls for medical education to become more evidence based.¹⁻³ This has resulted, among other initiatives, in the establishment of the Best Evidence for Medical Education (BEME) Collaboration⁴ and the Campbell Collaboration, an off-shoot of the Cochrane Collaboration. The BEME initiative includes dissemination of best evidence to support medical education and the encouragement of a culture capable of nurturing more rigorous and better funded research.

Evidence from the United States suggests such nurturing is much needed. In 2004, Carline analysed reports of medical education research in two major North American journals (*Academic Medicine* and *Teaching and Learning in Medicine*) and found that only a minority of studies were supported by external research grants.³ She was critical about the quality, rigour, and generalisability of most of these studies. Her concerns were echoed last year by Chen and

Mathew Todres, research associate, Anne Stephenson, director of community education
Roger Jones, Wolfson professor of general practice

Department of General Practice and Primary Care, King's College London School of Medicine, London SE11 6SP

Correspondence to: R Jones
roger.jones@kcl.ac.uk

Accepted: 4 June 2007

colleagues,⁵ who advocated moving the focus of medical education research from learners to patient oriented clinical outcomes, thus increasing the relevance and its likely attractiveness to funders. A review of 290 medical education studies published during 2002 and 2003 found that only one quarter had received external funding; the median amount of

Table 1 | Details of medical education research published in three journals during 2004-5

	No (%) of studies (n=387)
Study design	
Observational, cross sectional	267 (69)
Longitudinal cohort	31 (8)
Before and after studies	31 (8)
Other	58 (15)
Focus of research	
Undergraduate medical curriculum	240 (62)
Continuing medical education	85 (22)
Postgraduate medical training	43 (11)
Other	19 (5)