

Conference report

Personal electronic health records: from biomedical research to people's health

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ABSTRACT

Access to web technologies and the increased bandwidth and capacity of these systems has facilitated the development of personal electronic health records (PEHRs).

This conference reports the key messages from the Friends of the National Library of Medicine (FNLM) meeting on PEHRs 'From Biomedical Research to People's Health' in May 2009.

The conference provided a comprehensive overview of issues and best practice for PEHR.

The key messages of the conference were:

- PEHR have the potential to ensure equity, continuity and healthcare quality
- electronic records may allow individuals to contribute to disease surveillance, public health and research in ways that were not previously possible

- we need to prepare carefully for a 'brave new world' in which a small number of commercial organisations may become trusted custodians of the planet's medical information
- ethical dilemmas are already emerging from the use of PEHRs – largely stemming from our experiences within the UK.

This report links the findings of this conference with key UK and European innovations. Informaticians, in conjunction with clinicians and solution providers, should both prepare for the realities of PEHR and more formally articulate their potential benefits and risks.

Keywords: electronic health record, ethics, personal health record

Background

The personal electronic health record (PEHR) remains undefined

The meeting was sponsored by the FNLM whose active patronage is 'Dedicated to increasing public visibility for, appreciation of, and engagement with NLM'.

Over 400 attendees, from policy makers to service providers and end users, came to hear and challenge various instantiations^a of PEHRs. Added breadth to the meeting theme came from confusion as to just what the term PEHR actually meant (see section 1). Some took it that the personal health record, electronic health record (EHR) or PEHR was any record about an individual, and some that it was any record of

clinical activity accessible to or held by the subject himself or herself, and to which he or she might (or might not) be able to add personal annotations. The variety of terms prompted Shortliffe to say that a PEHR was like a unicorn – everyone felt they knew what one looked like but no one had ever seen one!

1 PEHRs have the potential to ensure equity, continuity and healthcare quality

Themes emerged about what a PEHR is and is not; how it cannot be expected to save money, but that it can be part of a process of ensuring equity, continuity and healthcare quality.

^a *Informatics in Primary Care* defines 'Instantiations' as representing an abstract concept (in this case PEHR) by a tangible or functional example (e.g. Google Health) or at the very least a pilot application. Ed.

The PEHR will not save money but may be an instrument to promote equity

Lindberg observed that '[US] funding from government agencies [is] fragile' in these challenging times even though the American Recovery and Reinvestment Act¹ (ARRA) identifies \$19 billion for health informatics, specifically \$17.2 billion to provide 'meaningful use' of EHRs for all by 2014 with investment of \$2 billion in developing national standards for interoperability. He counselled against premature claims of savings from electronic records. Lindberg, one of the task force members advising the President, said that the first phase of the actions arising from the presidential announcements would be to identify millions receiving little current health care, and would not 'put granny back in the workforce and get her paying taxes' but would put more focus on working families.

This view is probably realistic. Expecting rapid returns on investment from electronic patient record systems is probably illusory. For example, in the USA computerised physician order entry systems (electronic prescribing systems) may take ten years to achieve a return on the initial investment made.²

The PEHR may improve equity of health care and make teams more efficient

Cutler (Harvard) suggested that the EHR could make a potential contribution to economic recovery through achieving the goal of universal health coverage, facilitated by improved efficiency of care, the introduction of more preventative strategies and acting on lessons learnt as to what works and what does not. He suggested over \$2 trillion could feasibly be saved over the next two years by acting on better information on what health activity is being carried out, and incentivising health teams and individuals appropriately for (better) productivity. He recognised that performance-dependent compensation for healthcare deliverers must make allowances for 'hard cases' and innovative practices through special risk adjustments. Similar debates on equity and consistency of compensation were being addressed in the UK.³⁻⁵

Telemedicine and telehealth

Sanders (Global Telemedicine Group) made an enthusiastic presentation of a vision for telemedicine and telehealth. This provided interesting indications of how the concept has moved on since the relevant

Cochrane Review.⁶ He also made a number of statements that could have been debated for many hours! These included an assertion that a nurse practitioner with telemedicine can be as good as an on-site certified physician, and a challenge to encourage/expect/require patients to be their own primary care providers. He finished his talk by suggesting that we cared more about (tuning the performance) of our car than doing the same for our own bodies, but observed that health technologies were poised to address this.

2 Electronic records may allow individuals to contribute to disease surveillance, public health and research in ways that were not previously possible

People volunteering their PEHR for research

Electronic health records are a \$2.5 trillion market (Hripcsak, Columbia University) and 50 billion 'facts' go into clinical 'notes' per annum. Patients could voluntarily put themselves (and their personal records) forward a priori to be considered for cohort research studies, he suggested, and he endorsed the need for President Obama's major spend on data exchange/terminology/interoperability standards.

ProRec UK has been established⁷ to contribute to facilitating interoperability and pan-European record sharing. There are 15 not for profit national ProRec centres, which collectively make up the EuroRec project (European Records Institute – www.eurrec.org). The institute was established on the premise that there was suboptimal use of electronic records across Europe.

A speaker from the University of Pittsburgh Medical Centre made a strong plea for new informatics to be introduced only after more planning and preparation than had previously been undertaken. He suggested that 'strategic insertion', where all parties worked together to develop, install and implement the application system, was likely to be considerably more productive than 'intrusion', where a more generic solution is imposed on an organisation which is expected to change to fit the way of working prescribed by the solution. It looks likely that the more positive concepts he described will be employed in the partnership between Pittsburgh, Newcastle-upon-Tyne NHS Trust and Cerner.⁸

PEHR for epidemiology, public health and surveillance and continuity of care – but limited by trust

Asking why the global risk profile of pandemics and bioterrorism, plus swine flu incidence, could not be coordinated worldwide from emergency room electronic records, Caplan (Centre for Bioethics, University of Pennsylvania) suggested that 'recreational genomics' (paid for and initiated by patients themselves) to indicate underlying clinical markers could perhaps be a 'step too far' in patient participation. Emergence of PEHRs 'demonstrated a lack of trust in organizational systems in health'. He did acknowledge that the quality, continuity and safety of care were improved by the availability of EHRs, alleging that US privacy (Health Insurance Portability and Accountability Act) regulations only served to confound the 'flower guy' trying to make hospital deliveries rather than to secure the individual's record! Considering what the UK calls 'secondary uses' of data⁹ for research purposes, Caplan additionally questioned who would be the trusted holders of such data and how they would be accredited (qualified) to control such data. Tangentially, he wondered whether consideration of health data from Atsugewi native American Indians for genetic factors underlying diabetes might defame their cultural origins in 'the Spirits' when the research suggested genetic factors originating in China. His novel suggestion to avoid complex consent issues when using records for secondary purposes was to propose the 'gifting of data to science'. Whilst the principle of 'data gifting' is clear, it will need to be thoroughly investigated by the Information Commissioner and other interested parties to ensure sensitive management if it is to be viable in the UK. The UK ethical perspective¹⁰ has resonance with this principle.

New types of health data might be collected

Brennan (University of Wisconsin) reported active use of PEHRs to support the understanding of health patterns. The reported usage also included data on 'every day experiences' and observations on daily living to produce a richer clinical encounter record. UK work demonstrates how patients can become involved in this process.^{11–14} She also recognised that it was important to 'engineer' PEHR processes to reflect what information people needed to use and to facilitate what they specifically wanted to share. She speculated that the next generation of PEHRs would interface closely with the working of clinics, an area where current UK developments could help to inform global development. The practical work in Wisconsin will be useful input to the overall determination of what is, in practice,

core to a PEHR. Similar activities are ongoing in the UK¹⁴ which complement those described by Brennan.

3 Preparing for a new world in which a small number of commercial organisations may be custodians of the planet's medical records

Multinational PEHR systems

Grave concern in my mind was raised by two commercial presentations from Microsoft Health (Mault) and Google, Research and Special Initiatives (Spector). Balancing corporate statements with genuine health domain sensitivity became challenging at times for the two speakers! Worrying concerns as to the model being established in the USA arose. The open nature of access to amendment functions and the apparent lack of any audit trails cast significant doubt over the quality of the record contents using either of the commercial platforms described. Given all the preparatory UK work and commentary on patient safety and robust electronic record requirements there will need to be considerable investigation, refinement of the solution and operational testing before either of these solutions is acceptable to the articulate UK end user.¹⁴

The Microsoft HealthVault record is controlled by the patient, who also decides what goes into it and who can (selectively) see and use the information on a case-by-case basis. I wonder how integrity and completeness is achieved in this record?

The Google speaker focused on the 'aggregative value' of their model, endorsing a development path that 'launched early and iterated often'. Whilst this may be a satisfactory paradigm for open source information technology developments, suggesting change 'on the bounce' for an operational decision support system for health is very worrying. The Google Health policy guidance for third-party applications suppliers states: 'Allow users to permanently delete and purge the data derived from their Google Health profiles; backup copies may exist for a short time'.¹⁵

The logic for such draconian editing was suggested to be: 'If a factoid is buried in chaff, can a clinician be sued for missing it?'

I wonder whether, if a fact is deleted that materially jeopardises the treatment decisions made, a clinician could counter-sue the record subject for compromising their professionalism? For a patient to be able to present, as fact, a selectively edited history of their clinical condition(s) would, I would have thought, 'drive a bus' through any resulting litigation attempts, and

runs totally counter to the principle in the UK of allowing no deletions but only attributed annotations to health records. As yet, the integrity, completeness and consistency of records when used as decision support for care delivery appears to be unsustainable under either of the solutions described. Details of both development plans are described explicitly in the slide sets of each speaker (Mault and Spector) on the FNLM website.

4 There are already ethical dilemmas from the use of PEHRs – largely drawn from experiences within the UK

Personal electronic health records: legal, ethical and semantic issues

Various speakers looked at the challenges presented by EHRs, many of which are being evaluated/addressed in the UK (e.g. Brennan¹⁹), and some of the following observations are well known to those active in the UK. Our data sharing concerns are expressed in the USA as questions regarding ‘data fusion’ – such as the recording of ‘drug X prescribed, drug Y dispensed and patient takes it but does not adhere to the formal regime specified’. Do UK systems (and strategic plans for patient-accessible records) cover such instances satisfactorily? Publications from the UK²⁰ explain other similar challenges.

Data quality and fitness for purpose

Data quality issues were frequently raised throughout the sessions, including:

- a one-eyed person being classified as ‘PERRLA’ (pupils equal, round, reactive to light and accommodation)
- questioning the value and veracity of later information in 17-screen/page records
- introduction of derived inferences providing a risk to data quality.

Complementary UK work continues¹⁷ and Downing reported the Oregon Study¹⁸ in which 2000 over 18 year olds polled for the US Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System indicated that over 99% agree that family history provides a valuable context to their own health and that a familial collective history, as an analysis tool, could identify inherited risk factors in real-world settings.

Does access to information reduce healthcare consumption?

Silvestre (Kaiser Permanente) claimed that benefits from their system deployment are in the order of 59% fewer phone calls, 30% fewer doctor’s visits and one million accesses to the Kaiser Permanente health encyclopaedia in three months. It will be interesting to compare this level of activity for three million active members with the rate of accesses to NHS Choices (NHS Direct and the Map of Medicine).

Sharing your PEHR in a theatre of war

The US Department of Defence (DoD) perspective on PEHR (Campbell) considered the contribution of an operational PEHR across multiple facilities and clinics, utilising store and forward facilities to get patient information back to land-based facilities from theatres of war. He acknowledged that there are still gaps in the provision of input to the primary care providers’ holistic record. Their MiCare project allows the military (and some dependents) to utilise either Microsoft or Google accounts for their PEHR. This gives the subject the capability to share their data with whomsoever they choose (see concerns above), through access to their longitudinal record, interaction with their healthcare team and participation in wellness and prevention initiatives in addition to self-care.

Summary

PEHR and equity in health care

The final session highlighted grand challenges for the future. Notably Shortliffe quoted President Obama as saying: ‘every 30 seconds a US citizen goes bust because of [burdensome] healthcare costs [payable by themselves]’.

He suggested that fixing the health system would not happen simply by installing EHRs, a point emphasised by Lindberg: ‘rebuild the healthcare system before you automate it’.

Lindberg observed that most of the day’s useful content (and its users!) were ‘born digital’, and their expectations of PEHRs present challenges in themselves to the existing solutions in operation. The prime user of electronic health systems should be redefined as the citizen/patient, who has access to systems which are directory-like rather than information silos – linking patient details to useful computer-based knowledge (e.g. Medline Plus files for professionals and a lay audience). Records would, he felt, also contain expressions

of patient treatment wishes (organ donations, preferences for resuscitation and end-of-life management) and accommodation of culture-based interventions (such as native or alternative therapies).

We have a lot to learn in the UK, with mixed experience from our steps in this direction. The pioneering work of Dr Amir Hannan, providing patients online access to their records, has been well received,²² while attempts to provide patients with their own web space have been less positively welcomed.²³

Setting examples of operational PEHR activity of the UK,²² its challenges and next steps²³ against commercial perspectives from US niche suppliers raised interesting questions of comparability, potential synergy and good opportunities for further dialogue and collaboration.

Conclusion

What better conclusion than to quote Lindberg: 'The overall aim [of the PEHR] is to "Get you better, keep you well, avoid you getting sick".'

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CONFLICTS OF INTEREST

None.

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