

DIGITAL TECHNOLOGY Opportunities and barriers for usage of personal health records in hospital – report from a workshop of the Health Informatics Unit at the Royal College of Physicians

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ABSTRACT

Personal health records (PHRs) are thought to offer benefits and are promoted by health policy makers and some healthcare systems. Evidence for usage by patients in hospital is limited.

This article reports a one-day workshop hosted by the Royal College of Physicians that considered the evidence of the value to patients and others, the challenges to adoption and use of PHRs and sought to identify the practical and research questions that need to be answered.

The purpose of this article is to provide readers with an overview of the issues and possible future for hospital application of PHRs in the UK's NHS, especially for supporting self-care, family carers and advancing person-centred care. It aims to share the experience and ideas of those taking part in the workshop and reference resources that we have found useful while highlighting areas for future research.

KEYWORDS: Personal health record, hospital, person-centred care

Introduction

Patient health records (PHRs) are 'a digital tool that helps people to maintain their health and manage their care. It may do this by enabling them to capture their own health and care data, to communicate with health and care services, and/or to have access to their care record'.¹ PHRs can be part of an integrated health care systems (such as Kaiser Permanente),² be linked to single systems (in primary care, outpatient care or single disease

management) or be a stand-alone depository of information of the patient.

In Europe, Estonia³ has probably the highest uptake of PHRs with 95% of all health information digitised and patients able to log into their own record. Sweden⁴ is using regional patient portals and registries of patients with chronic health conditions; since 2017 all patients have access to a patient portal.⁵ In the US, Kaiser^{2,6} has also made a patient portal available to all of its patients. Germany has seen attempts by insurance companies to introduce patient portals. France has an agreed standard for patient access but uptake has been low.⁷

It is NHS policy to make available 'personalised healthcare' by 2020. In 2014, the UK coalition government published *Personalised health and care 2020*⁸ with the 'ambition ... for a health and care system that enables people to make healthier choices, to be more resilient, to deal more effectively with illness and disability when it arises, and to have happier, longer lives in old age'. The document makes proposals for better access to digital information for health care professionals, service transparency, innovation and industry growth, and to help patients to 'enable me to make the right health and care choices'. In the same year the *Five year forward view*⁹ was published and gave a framework for action to use digital technology to 'shift power to patients and citizens, strengthen communities, improve health and wellbeing and, as a by-product, help moderate rising demands on the NHS'.

Previous research by the Royal College of Physicians (RCP) on PHRs created a 'landscape review' and a report about user insights;^{1,10} dissemination of PHRs was almost exclusively in primary care and outpatient care.

Development of PHRs for patients admitted to hospitals in the UK has been limited.

PatientView¹¹ is a system for renal patients to manage and monitor their condition through access to laboratory tests, clinic letters and list of medications, diagnosis and other treatments. Patients can set up alerts, monitor symptoms, download their records, share their information with others and are given limited access to their hospital electronic health record (her).

A personal child health record (eRedbook)¹² is under development which could give primary and secondary care teams the ability to access and provide information on a child's health,

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growth and development. This record will be accessible by the child's parent or guardian for children under a certain age.

Work is under way to develop an electronic smart prototype of current paper records: the 'All Wales pregnancy health record' in Powys (personal communication, Marie Lewis) is intended to serve as a PHR for women in community and hospital.

Clinical results of usage are often not reported widely but some implementation and benefits have been described in areas of primary care, in the care of patients with inflammatory bowel disease^{13–15} and for patients with prostate cancer.¹⁶

There is currently little published evidence on use or impact of PHRs by hospital patients or staff, before, during or after a hospital encounter.¹⁷

The aim of the paper is to explore opportunities and barriers for usage of PHRs in hospital by summarising inputs and discussions from a workshop of the Health Informatics Unit at the RCP.

Methods

A workshop on PHR usage in hospital was hosted at the RCP on the 06 November 2017. Participants included patient representatives, health informatics specialists, health service researchers and practicing physicians.

After keynotes from the authors, participants mapped patient's care through the hospital and examined use-cases around typical patient journeys in four groups with each group having input from a patient representative, a person with a clinical background, a health informatics specialist and a health service researcher.

Results

Potential benefits of PHRs along the patient journey in and out of hospital might include better information, efficiency, health literacy and activation of patients. This could free up time for clinicians to focus on complex issues that require detailed discussions with patients and their families.

Process mapping

The usage of PHRs can usefully be conceptualised in relation to planned and unplanned admissions over the three phases of pre-, during and post-admission.

Elective/planned admissions

Pre-admission, a significant proportion of hospital activity consists of planned procedures. Using a PHR, patients could access information and write notes that can contribute to a safe performance of the procedure. Ideally, some help or support can be given to enable patients to become familiar with the system so that they do not later need to learn it during or post-admission. During admission, a patient could use checklists (based on procedure standards and guidelines) and add comments on performance and aftercare which could provide alerts to staff about possible complications and also provide a record for any retrospective assessments. Post-admission aftercare could equally be documented in the PHR and shared with care teams in the community or the patients' home.

Unplanned/emergency admissions

Prior to admission for unplanned emergency admissions to hospital, patients using PHRs could enter information that could

speed up the admission process and provide patients views of what is important to them. Given that an increasing number of patients suffer with chronic health care conditions, up-to-date information about these conditions could be held in PHRs. Ten to fifteen percent of admissions to UK hospital departments are readmissions, in these patients' PHRs, information from the time after a previous discharge might inform care at the time of readmission and enable patients and their clinicians to learn about the prevention of future admissions. During emergency admissions, PHRs could help to reconcile medication schedules, give information about newly diagnosed conditions and contain schedules for investigations or appointments with clinical teams. PHRs could facilitate monitoring or pain and other patient-centred outcome measures. This could be shared with clinical teams to inform responsive care. In time, automated systems could identify discrepancies between patient-recorded information and EHR data such as medications or allergies. After an emergency admission, PHRs could facilitate transfers of care back to community teams.

Review of use-case scenarios

Participants discussed five use-cases of hypothetical patients admitted to hospital. One patient was admitted for elective prostate surgery, one had a semi-elective admission for a renal transplant, and three patients had emergency admissions for chest pain, diabetic ketoacidosis and pneumonia with delirium. It was assumed that an ideal PHR/electronic patient record (EPR) should be usable in a meaningful way by 80% or more patients of a given patient group.

Participants charted how a PHR/EPR could support a patient to a) become more informed about their health condition (including their safety) and receive care in a way they would like to, b) enable them to do more to care for themselves, and c) make a comment useful to care providers (eg incorrect information, most troubling symptoms).

Participants considered the likelihood of these patients being able to interact with the PHR, factors which might hinder patient access to their PHR and impact of access on conversations between this patient and clinicians.

Key points from the discussions were about the need to use PHRs as an extension of human abilities and not a replacement. The establishment of relationships between clinicians and patients requires trust and this is often helped by personal conversations with the advantage of body language and eye contact.

One of the themes of the discussion was the interaction with frail, elderly and possibly demented patients. The group felt that many might not be able to actively use a PHR. On the other hand, a PHR with a 'share' function that would allow patients to delegate some or all information to friends or family might be really useful for these patients. The function could allow insight into progress of the patient in hospital as well as reminders for follow-up clinics, allergies and medication lists.

A key concern of patients is to predict when they can go home and whether they will cope after an acute illness. The participants discussed whether a PHR could support patient-centred care by asking 'What would help to get you home?' and prompt sharing of concerns by patients early on in the course of their admission.

In order to make PHR attractive for patients, clinicians and providers will need to add functionality that is 'game changing'.

Game changing functionalities might include the ability for patients to assist with data entry, lead on discharge process or 'dial-up' follow-up appointments.

Discussion

The workshop isolated key areas of debate for implementation of PHRs in hospitals.

How much data is too much?

The amount of data that patients might want to access might be different from the amount that they are able to use in a meaningful way for their own healthcare. PHRs will face the challenge to find the balance between 'too much' and 'too little' data, which calls for co-design of the system with patients and then sensitivity to patients' particular needs at the time.

Equitable access and the 'digital divide'

As PHRs spread, challenges will arise around those who are less able or less willing to use these systems and who might become marginalised in the process. Some patients might have significantly more opportunities to participate in their own healthcare and this could drive commissioning and funding decisions with more resources allocated to areas with high engagement and visibility of need or less resources allocated as patients become more self-sufficient. Digital inclusion officers have been used to facilitate access¹⁸ in some industries.

Challenges are comparable with the changes in the banking sector where fewer branches are now available to offer face-to-face service. This has posed particular difficulties for some elderly patients with limited IT and eHealth literacy. At the same time, these challenges have led to better design and more usable formats of online banking as well as spread of usage from 'digital natives' to the broader population.

Integration of PHR to EPR

Hospitals throughout the UK are currently installing EPRs from a range of providers and with variable range of functionalities. Integration of NHS IT systems has previously been attempted but abandoned after an estimated bill of £10 billion.¹⁹ Integration between multiple providers or PHRs and EPRs might therefore be challenging. Many EPR providers have also been reluctant to allow other programs to write into the EPR or access data from it for other applications. For easy access or presentation of key items in EPR, standard definitions for data fields are needed and providers need to cooperate to allow devices to talk to each other. Otherwise, duplication will lead to errors and inefficiencies.

Safety

There are widespread concerns about data and system safety of information technology in healthcare, with patients worried about confidentiality¹⁰ and health care professionals worried about correctness of data.²⁰ In order to allow patients secure access to their data, a process of identity verification is needed to register and log in. This requires a reliable verification procedure by healthcare staff and will affect ease of access for patients and the cost of implementation to hospitals.

Cost

The price of implementation of PHRs in hospital will depend on the price of purchasing, implementing and maintaining the PHR as well as costs associated with training of staff and patients and any potential costs/savings arising from implementation. While a PHR might be a competitive advantage to attract customers to health service providers in the US this is less likely to be relevant to the UK market (Table 1).

It is possible that the control of the records by patients leads to a more focused pathway with earlier diagnosis, earlier treatment and earlier discharge. Equally, better information for patients and

Table 1. Key projected benefits and costs of personal health records for use in hospital

	Benefits	Costs (time or money)
<i>Patients</i>	Engaging with care	Hardware costs
	Ability to raise questions more directly	Time of training
	Information on what patients want to know about their health	Investment into interoperability
	Empowering to ask questions	Privacy, security
	Understanding more	Utility of data collected
	Drug reconciliation	Anxiety about extra information, borderline abnormal tests
	Prediction of future events	
<i>Clinicians</i>	Comprehensive overview of patients' journey	Time to write things down in an understandable way
	Up-to-date allergies and medication lists	Time to explain to patients additional questions
	Catching errors early	Potential for losing efficiencies
	Prediction of future events	
	Not needing to repeat message to relatives	
<i>Others</i>	Potential for gaining efficiencies	
	Community services, physiotherapists, pharmacy, seamless information transfer	Inequalities: not every patient can use/needs/understands PHR Upfront investment into infrastructure

health care professionals may lead to more diagnostic procedures, treatments and cost which may or may not be appropriate. While there is some evidence about the impact of PHRs on patient activation in the community, there is no data to inform this debate for patients admitted to hospital.

Conditions for spread

Participants of the workshop felt that conditions for spread would include the following considerations:

Participants felt that patients would appreciate the ability to model on peers as demonstrated in the network 'patientslikeme' (www.patientslikeme.com). To witness patients or patient testimonies from patients with comparable conditions or pathways using a PHR could facilitate uptake and spread.

Participants were worried that PHR should augment and not replace human touch and capabilities. Information about a condition or patient questionnaires about concerns and pain can be made available prior a personal conversation and facilitate a focus on complex and difficult questions. Personal contact, the ability to examine a patient physically, or to hold a hand if a patient is sad or anxious are key to a trusting relationship between patients and healthcare professionals.

Participants suggested the need for a compelling value proposition that would convince patients and clinicians to start using PHRs. PHRs can be used for a large number of functions many of which can be undertaken without a PHR. Many PHRs don't have a function that is unique and at the centre of patients' and health care professionals' interests and thus so compelling that the usage would become a 'must'.

Conclusions

Patient-held records in hospital are, at best, a complete change in the way that we deliver health care by enabling patients to become an equal partner and be in control their own data. At worst, patient-held records may increase the amount of information for patients and clinicians with little added value or may disadvantage less computer literate patients. ■

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