

Personal Health Records: Understanding the Factors that Contribute to Creating Value and Practical Use by Patients and Citizens

Irina Osovska

PhD Student, University College London,
222 Euston Road, London NW1 2DA, UK
irina.osovskaya@gmail.com

ABSTRACT

Personal Health Records or Patient Portals (electronic records tethered to healthcare systems and allowing patient access), are recognised as a promising mechanism to support greater patient engagement, yet questions remain open about the best way to encourage adoption of patient portals and what factors might contribute to sustained and meaningful use. A review of the literature is ongoing, with qualitative data collection planned.

KEYWORDS

Personal Health Records, PHRS, Patient Portal, Patient Activation, Patient Engagement

1 INTRODUCTION

Ever since the Access to Health Records Act 1990 in the UK patients have had the statutory right to access to their medical records. Under the Data Protection Act 1998, doctors believe that all NHS patients have a legal right to apply for access to health information held about them. This includes NHS or private health records held by a GP, optician or dentist, or by a hospital.

“NHS Five Year Forward View”^[1] and the “National Information Board’s (NIB) report Personalised Health and Care 2020: A framework for action”^[2] set out a vision for greater adoption of digital technologies, including Personal Health Records (PHRs), to empower patients and promote self-management.

PCHRs (Personally Controlled Health Records), Personal Health Records (PHRs) or Patient Portals are referenced in literature in many forms from patient held paper-based records to fully EHR tethered patient controlled health records. These terms are often used interchangeably and frequently overlap in their purpose and utility.

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the Owner/Author(s). Copyright is held by the owner/author(s).

DH'17, July 2-5, 2017, London, United Kingdom.

ACM ISBN 978-1-4503-5249-9/17/07.

DOI: <http://dx.doi.org/10.1145/3079452.3079484>

Functionally and utility of PHRs varies greatly but several systems in the reviewed literature referenced functionality such as ability to view medical records such as diagnosis, list of medications, laboratory results, send messages to physicians and share own medical records with carers.



Figure 1: Patients Know Best personal health records system

2 RESEARCH SCOPE

The research focuses on how PHRs (Patient Health records) users (patients and carers) use these online systems to make sense of their own health condition(s). The research is investigating the potential of how the availability of PHRs (such as Patients Know Best) combined with other systems, Social Networking and data sources such healthcare tracking devices can influence self-care choices and how ready and willing the patients are to actively use such systems and data, to make sense of their condition and share personal health data with others.

During this study, I am reflecting on the role of clinicians and other healthcare professionals in user adoption and implementation of PHRs, evidence of benefits to patients and citizens. I believe that there is a need to better understand the information on certain user groups, digital features and capabilities that should be prioritised for the highest impact and benefit. My hypothesis is that there will be certain factors that affect adoption (separating adoption, adherence and continued

use) and elements or functionality of PHRs that promote activation as well as engagement barriers (e.g. making sense of the data available in PHRs, basic IT skills and how patients make sense of the information and data when they get it in PHRs).

3 METHODS

The following methods are used in this research:

Systematic literature review:

The systematic review is focusing on how the use of PHRs impact on patient activation and patient empowerment. Studies that are of most interest need to have an element of primary data collection from patients, carers and clinician perspective that primarily cover the best way to engage patients in managing their health and empowering them to make decisions.

Search in EMBASE, Medline, PsycINFO, CINAHL, Pubmed resulted in 1,678 of papers, out of which 157 were selected for initial review (abstract only) and 77 for further analysis. The final selection was limited to RCTs and resulted in a total number of 15 papers. I am currently conducting meta-analysis of these papers and findings will form part of my PhD thesis.

Primary research (Phase 1 – IBS Clinic, Luton & Dunstable hospital):

Approximately 20 patients and 5 clinicians will be enrolled at the Luton and Dunstable IBS clinic (Patients Know Best implementation in 2013).

Selection criteria includes a reasonable standard of English, access to smartphone or computer with internet connection, registered to use PKB or any other PHR at least 6-8 months prior to the study and use of the PHRs at least 2-3 times a month.

Once the study participants group is set up, the study will begin with face-to-face semi-structured interviews, followed by diary keeping (2-3- records a month) and 30min Skype phone calls (introspective/ recollection). Patient data will be triangulated with PKB usage data from the same or other (anonymised/ average) users. Data will be coded to determine common themes and analysed.

Primary research (Phase 2 – multi-condition):

North and West London NHS trust (PKB rollout from 2015). Details are still to be confirmed.

4 RESULTS SO FAR AND DISCUSSION

Following several systematic reviews and projects commissioned by the NHS National Information Board (NIB) in 2016, there appears to be an opportunity to gain a better understanding of how PHRs are being used by patients and what practical value such systems have in patient's daily life.

If patient health records are to become the norm, then there needs to be better understanding of the factors that contribute to creating value and practical use of PHRs.

Literature review has demonstrated that patients' interest to access and update own health data is growing but the ability to use patient portals is often influenced by personal factors including age, education level, health literacy and health status. National PHR adoption strategy and healthcare providers' endorsement appears to be one of the fundamental drivers in PHR adoption. As the patient-facing features of PHR portals are still evolving, redesigned care pathways to incorporate the use of PHR technology, where appropriate, will be fundamental in creating a sustainable environment for patient portal use. According to Irizarry et al ^[3], adoption by patients and endorsement by providers will come when existing patient portal features align with patients' and providers' information needs and functionality.

For most citizens, the use of patient portals is likely to be occasional and therefore the ability to access the system (e.g. single entry point, secure single sign on), intuitive and user centric design and single view of own health records (interoperability) will be essential in bringing the anticipated benefits of PHRs at scale.

REFERENCES

- [1] "NHS Five Year Forward View", <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
- [2] "National Information Board's (NIB) report Personalised Health and Care 2020: A framework for action" <https://www.gov.uk/government/news/introducing-personalised-health-and-care-2020-a-framework-for-action>
- [3] Irizarry T., DeVito Dabbs A., Curran C.R., 23rd June 2015 "Patient Portals and Patient Engagement: A State of the Science Review", JMIR, doi: 10.2196/jmir.4255