Royal College of Physicians | Health Informatics Unit

Personal health record (PHR)
User insights

Final report
Executive summary
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Prepared by

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The Royal College of Physicians
The Royal College of Physicians (RCP) plays a leading role in the delivery of high-quality patient care by setting standards of medical practice and promoting clinical excellence. We provide physicians in over 30 medical specialties with education, training and support throughout their careers. As an independent charity representing more than 30,000 fellows and members worldwide, we advise and work with government, patients, allied healthcare professionals and the public to improve health and healthcare.

NHS England
NHS England exists to create the culture and conditions for health and care services and staff to deliver the highest standard of care and ensure that valuable public resources are used effectively to get the best outcomes for individuals, communities and society for now and for future generations. NHS England empowers and supports clinical leaders at every level of the NHS to make genuinely informed decisions. Central to their ambition is to place patients and the public at the heart of everything they do.

NHS Digital
NHS Digital is the trusted national provider of high-quality information, data and IT systems for health and social care. NHS Digital collects, analyses and publishes national data and statistical information as well as delivering national IT systems and services to support the health and care system. The information services and products are used extensively by a range of organisations to support the commissioning and delivery of health and care services, and to provide information and statistics that are used to inform decision-making and choice.

The Health Informatics Unit
The RCP Health Informatics Unit (HIU) aims to improve patient care. It provides clinical leadership for the development and implementation of standards for the structure and content of care records to achieve interoperability between computer systems in different care settings. The HIU advises on and promotes the implementation and use of safe and effective new technologies and it promotes the professionalisation of clinical informatics and the development of career pathways for those wanting to specialise in this field.

Acknowledgements

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Finally, we would like to thank NHS England for commissioning and supporting the development of this work, and NHS Digital for facilitating the publication of the report.

Contents

Executive summary

This report presents the findings of a study to better understand the needs of service users in relation to personal health records (PHRs) and the implications of these findings for providers, clinicians and commissioners. The study was commissioned by NHS England and carried out by the Royal College of Physicians (RCP) Health Informatics Unit (HIU). The purpose of the study was to explore and gain a deep understanding of the experiences, needs and aspirations of citizens in relation to PHRs and how these shape views and expectations for PHRs, and related actions.

The study methodology entailed:

- qualitative data gathered during nine focus groups and 27 interviews
- qualitative data analysis using framework analysis
- use of the insights to synthesise user journeys using the Integrated Patient Storytelling (IPS)[i] method
- review of relevant grey and academic literature.

For the focus groups and interviews, views were sought from people with various long-term conditions including diabetes, younger-onset dementia, depression, cancer, ulcerative colitis, renal failure and liver failure. Views were also sought from carers of people with autism, cerebral palsy, Down's syndrome, dementia and mental ill health.

In addition to this report, six user journeys have been developed in the form of audio recordings, journey matrices and narratives. These were developed by a multidisciplinary team using the IPS method, which applies oral storytelling techniques to anonymised qualitative data gathered from patient interviews and focus groups. These user journeys provide powerful insights into how people experience PHRs. A copy of the matrices can be found at Section 4.9 of the full report.

The full report sets the context for the research project; outlines the methodology; presents findings from the literature review and empirical research; and makes recommendations for PHR developers and implementers and recommendations for future research.

1.1   Definition of a PHR

NHS England recently adopted the ISO/TR 14292 definition of a PHR, where a PHR:

> *is a representation of information regarding, or relevant to, the health, including wellness, development and welfare of that individual, which may be stand-alone or may integrate health information from multiple sources, and for which the individual, or the representative to whom the individual delegated his or her rights, manages and controls the PHR content and grants permissions for access by, and/or sharing with, other parties.*
>
> *Health informatics – personal health records: definition, scope and context*
> ISO Technical Report: ISO/TR 14292. First edition, 2012

The definition of a PHR that this project used can be found at Section 2.6 of the full report.

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[i] © Prue Thimbleby

1.2   Summary of findings

Table 1: Summary of findings

Motivations to adopt a PHR	Take control of health and improve health
	Advocate for change in current service or treatment
	Able to share information
	Convenience, eg check test results from workplace Save time and resources
	See what is said about them Hold professionals to account
	Aid person-centred care and communication
	Support, eg instructional videos on how to meet a personal care task or memory aid
Barriers to adopting a PHR	Lack of awareness and understanding of what a PHR is and how it can support users
	Reluctance from health and care professionals to engage with a PHR
	Data security concerns, including data use by the private sector
	Worries about coercion to share records with others
	It will induce or increase anxiety
	Preference for face-to-face service
	Inaccessibility, ie lack of technology or skills, resulting in a second-class service for those without the resources to take advantage of PHRs
Factors that influence decisions to adopt a PHR	Trust in care provider and care professional(s)
	The experiences that the user has had of health and social care services
	Patient activation level; that is an individual's knowledge, skill and confidence for managing their health and healthcare
	Exposure to PHRs
	Family encouragement

Benefits to having a PHR	Self-management and monitoring of health and wellbeing, taking control of one's health
	Convenience
	Access to up-to-date information
	Ability to record and celebrate progress
	Better communication with health and social care professionals
	Better and more appropriate care and support
	Realise person centredness
	Reduce the need for repetition of information
	Reassurance and reduction in anxiety
Negative experiences of using a PHR and unmet needs	Lack of historic records
	Overwriting of previously entered information
	Not having access to full medical records, eg records not being updated or lack of interoperability between care organisations
	Inability to interpret data
	Lack of portability , ie PHR not available on a mobile device
	Health information provided is not relevant to the user
	Not realising what a PHR can do and how it works
	Functions not working and problems with login
Support needs	Developing computer literacy skills
	Support at PHR adoption and initial use
	Social group workshops can be helpful
	Ongoing support should be available to ensure that, when their health and care needs change, services users know how the PHR can support them and how to use it

1.3   Summary of conclusions

1   Service users are more likely to report experiencing tangible benefits from, and a high level of satisfaction with, their PHR where:

- the service user has a long-term condition
- the PHR is designed to meet an unmet need or address a 'pain point' for the service user in the health and social care they currently receive; for example, where:
    - the PHR allows the user to access test results sooner than the traditional care model, or in a place that is more convenient to the service user
    - service users receive answers to questions asked of healthcare professionals faster than they would using the traditional care delivery model
    - service users (especially those who have had a poor experience of health and social care) can use the PHR to monitor the activities of professionals in relation to their care and see what is written about them
- PHRs provide tools that the service user finds useful to monitor and manage their condition, such as a disease activity score
- service users are involved in the design, implementation and ongoing evolution of PHRs
- PHRs are introduced around the time of diagnosis
- health and social care professionals are engaged with the PHR.

2   Service users' motivations to adopt and use a PHR are linked to their current health and care goals; for example, to use the PHR to capture data to advocate for a change in treatment, or to self-monitor and manage a condition. An individual's pattern of PHR use will change over time and is influenced by factors such as condition type and disease activity, patient activation level, and experiences and frequency of contact with care services.

3   PHRs can be effective tools to empower service users to take greater control over their health, support person-centred care and, in some cases, transform for the better a person's experience of their care. PHRs can help those who experience communication difficulties to be involved in decisions around their care. Multimedia functions are especially beneficial to those who have communication difficulties.

4   Service users reported negative experiences with PHRs and unmet needs that were strongly linked to poor design, implementation and support, and unmanaged service user expectations.

5   There was no evidence of an appetite among those who do not have a long-term condition to use a PHR to promote a healthy lifestyle.

1.4   Summary of recommendations

1   PHRs are only one tool within a wider healthcare delivery model. The PHR and its implementation need to be in sync with the wider service. For example, a PHR will support person-centred care best if it forms part of a person-centred service.

2   Those who are developing and implementing PHRs should understand the needs and 'pain points' of users across the service and tailor the PHR to help resolve these. This will encourage adoption of the PHRs. Those who are motivated to take control of their health need little encouragement to adopt the PHR, so implementers need to design PHRs and implementation plans to meet the needs of those who are less motivated to adopt them. User testing should also be carried out with this 'reluctant' cohort.

3   Implementers need to support users to think through, in practical ways, how their PHR can improve their health, wellbeing and care, and demonstrate the benefits at the start of the user journey. This will help users to see the potential of the PHR to support their health and care. User expectations should also be managed carefully.

4   Ongoing support should be available to ensure that, when their health and care needs change, services users know how the PHR can support them. For PHRs to reach their potential, health and social care professionals need to be fully engaged on an ongoing basis.

5   PHRs are a new technology and are very likely to change rapidly if they are to not be superseded by future developments. Care must therefore be taken to ensure that any PHR development is future-proofed and that initial investments can be built on incrementally.

6   The findings of this report should not be used as a substitute for iterative person-centred design. Good practice relies on iterative design and specific PHRs must be evaluated, improved and evaluated again. The methods used in this project, eg the IPS method to create user journeys, can be used to inform and help iterative design.

1.5   Recommendations for future research

It is clear from the extensive literature on PHRs and the empirical work reported in this document that PHRs are complex, so effective PHRs need to use insights from many disciplines, especially health and digital literacy, behaviour change, risk communication, information design and sociotechnical systems. Further research adopting a mixed method methodology in all these disciplines should benefit the developers and users of PHRs.

Thirteen specific research questions, for those funding work on and researching PHRs, can be found in Section 7 of the full report.