Personal health record (PHR)
User insights

Final report
January 2017
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Prepared by
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Clare Clement, Harold Thimbleby, Shiva Sathanandam and
Paul Rastall on behalf of the Health Informatics Unit.
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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 this report.
1 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)\(^1\) 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.

This 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:

\[
\text{is a representation of information regarding, or relevant to, the health, including wellness, development and welfare of that individual, which may be stand-alone or may integrate health information from multiple sources, and for which the individual, or the representative to whom the individual delegated his or her rights, manages and controls the PHR content and grants permissions for access by, and/or sharing with, other parties.}
\]

Health informatics – personal health records: definition, scope and context

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

\(^1\) © Prue Thimbleby
1.2 Summary of findings

Table 1: Summary of findings

<table>
<thead>
<tr>
<th>Motivations to adopt a PHR</th>
<th>Take control of health and improve health</th>
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<tbody>
<tr>
<td></td>
<td>Advocate for change in current service or treatment</td>
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<td></td>
<td>Able to share information</td>
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<td></td>
<td>Convenience, eg check test results from workplace</td>
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<td></td>
<td>Save time and resources</td>
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<td></td>
<td>See what is said about them</td>
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<td></td>
<td>Hold professionals to account</td>
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<td></td>
<td>Aid person-centred care and communication</td>
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<td>Support, eg instructional videos on how to meet a personal care task or memory aid</td>
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<td>Barriers to adopting a PHR</td>
<td>Lack of awareness and understanding of what a PHR is and how it can support users</td>
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<td></td>
<td>Reluctance from health and care professionals to engage with a PHR</td>
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<td></td>
<td>Data security concerns, including data use by the private sector</td>
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<td></td>
<td>Worries about coercion to share records with others</td>
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<td></td>
<td>It will induce or increase anxiety</td>
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<td></td>
<td>Preference for face-to-face service</td>
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<td></td>
<td>Inaccessibility, ie lack of technology or skills, resulting in a second-class service for those without the resources to take advantage of PHRs</td>
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<td>Factors that influence decisions to adopt a PHR</td>
<td>Trust in care provider and care professional(s)</td>
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<td></td>
<td>The experiences that the user has had of health and social care services</td>
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<td>Patient activation level; that is an individual’s knowledge, skill and confidence for managing their health and healthcare</td>
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<td>Family encouragement</td>
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<td>Benefits to having a PHR</td>
<td>Self-management and monitoring of health and wellbeing, taking control of one’s health</td>
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<td></td>
<td>Convenience</td>
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<td>Access to up-to-date information</td>
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<td>Ability to record and celebrate progress</td>
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<td>Better communication with health and social care professionals</td>
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<td>Better and more appropriate care and support</td>
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<td>Realise person centredness</td>
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<td>Reduce the need for repetition of information</td>
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<td>Reassurance and reduction in anxiety</td>
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<td>Negative experiences of using a PHR and unmet needs</td>
<td>Lack of historic records</td>
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<td>Overwriting of previously entered information</td>
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<td>Not having access to full medical records, eg records not being updated or lack of interoperability between care organisations</td>
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<td>Inability to interpret data</td>
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<td>Lack of portability, ie PHR not available on a mobile device</td>
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<td>Health information provided is not relevant to the user</td>
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<td>Not realising what a PHR can do and how it works</td>
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<td>Functions not working and problems with login</td>
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<td>Support needs</td>
<td>Developing computer literacy skills</td>
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<td>Support at PHR adoption and initial use</td>
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<td>Social group workshops can be helpful</td>
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<td>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</td>
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</table>
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 this report.
2 Introduction

2.1 Overview
NHS England commissioned the RCP HIU to undertake a study to better understand the needs of service users in relation to PHRs and the implications for providers, clinicians and commissioners. This report presents the findings of that study.

The focus of the study is on service users’ views and experiences. It explores the experience, needs and aspirations of those using health and social care services in relation to their access to digital PHRs (including records access and digital tools for health and care needs), and the extent to which these are being met through PHRs and similar digital services eg patient portals into electronic health records (EHRs). It also explores the perceptions and expectations towards PHRs of those who are not currently accessing health and social care services.

2.2 Background and rationale
NHS England is an executive non-departmental body of the Department of Health. It plays a key role in the government’s vision to modernise the health service, as described by the Health and Social Care Act 2012.

The RCP HIU contributes to safe, high-quality patient care by driving, leading and enabling greater use of new technologies to support information and communication in care provision. The HIU works with and for patients, clinicians, managers, policymakers and key opinion leaders in health and social care.

The NHS Five year forward view and the National Information Board’s (NIB) report Personalised health and care 2020: a framework for action set out a vision for greater adoption of digital technologies, including PHRs, to empower patients and promote self-management. It is anticipated that this will improve patient outcomes and contribute to efficiency gains in the health and care services. The ambition is that records access by patients should be extended to include all care settings and the ability for patients to write into their own record by 2018.

This project is one of three work packages that were identified under the Citizens Access to Digital Records (CADR) programme.

Another of the CADR work packages, the landscape review of PHRs undertaken by the RCP HIU in 2016, identified that, while there has been small-scale use of electronic PHRs in some care settings and by some clinical commissioning groups (CCGs), citizen uptake has been relatively slow. PHRs are currently used mainly by specific patient or citizen groups, especially those with long-term conditions, who require regular monitoring and contact with health and care services. There was evidence of patient expectations not being met, particularly related to the limited content of the record being made available to patients and the inability to bring together records from different care settings.


2.3 Aims of the project
The aims of this project, as set out in the NHS England grant specification, were:

- to develop a better understanding of PHR relevance to service users and the conditions that contribute to their adoption, as well as to identify the factors that discourage uptake
- to develop a better understanding of service users’ needs for PHRs and the implications for providers and commissioners.

2.4 Desired outcomes
The desired outcomes of this project, as set out in the NHS England grant specification, were:

- an improved understanding of service user motivation and needs, and to identify which of those needs are fulfilled by existing PHR developments and which needs remain unmet
- an improved understanding of the role of clinicians and other health and social care professionals in service user adoption and implementation of PHRs
- an improved understanding of how PHRs can impact the patient journey, and implications for both citizens and their carers, as well as service re-design implications for those who are implementing PHRs
- evidence of benefits to citizens
- information to help inform how service user experiences can be improved, including how to engage and support them
- information to help inform whether certain user groups and or digital capabilities should be prioritised to achieve the highest impact and benefit
- an improved understanding of the core requirements for the PHR design and user friendliness; that is, the smallest feature set that makes the PHR product a benefit to the end users and worth their investment in time and effort.

2.5 Objectives of the project
The objectives of this project were:

- to capture the views and experiences of service users who have encountered a variety of digital services and PHRs in the UK, primarily in England
- to capture the needs and aspirations of service users who use health and care services in relation to their access to digital services (including access to digital tools for health and care needs)
- to capture the extent to which the needs of service users are being met through PHRs and similar digital services eg patient portals into PHRs
• to capture the perceptions and expectations of those who are not currently using health or care services in relation to the availability, accessibility and concerns about digital health and care services
• to identify activities that support citizens’ adoption of PHRs and issues and barriers to use, and to make recommendations
• to present findings from the project in a report, making recommendations for further research including topics and the most suitable methods.

2.6 The definition of ‘personal health record’

At the time this study was undertaken, NHS England was using the following definition of PHRs:

*Digital tools that allow a citizen to interact with health and social care services, have access to the clinical content in their record, capture, record, and if they wish, share their own data with clinicians and others.*

*Personal health record (PHR) – Service user insights grant specification*

NHS England, 2015, p7

Please see Section 8.1 for a description of a PHR that was shared during data collection with participants who were unfamiliar with PHRs.

Service users were defined in this project as: citizens, patients, carers, parents and the families of those receiving health and/or social care.

NHS England has subsequently adopted the following definition, 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*


2.7 Structure of the report

The remainder of this report is divided into five sections.

• Section 3 identifies and justifies the methodology adopted in this research.
• Section 4 presents the findings from the primary research that was undertaken and includes matrices from six user journeys that were created from the data.
• Section 5 critically reviews academic and grey literature in light of the primary research findings.
• Section 6 presents conclusions and recommendations.
• Section 7 identifies recommendations for further research.
3 Methodology

3.1 Research design
Qualitative research methods were adopted because they are particularly well suited to the investigation of personal experience, individual perception and belief meaning systems\(^1,2\) and can enable researchers to clarify patients’ and clinicians’ understanding of practice and patient needs.\(^3\) In line with this study’s aims, the focus was on people who had used PHRs and those who may use them. The views of health and social care professionals were also sought, to gain further insight into the support required for patients who are adopting a PHR.

3.2 Sampling
The study employed a non-probability purposive sampling strategy to ensure capture of a wide range of views and experiences in relation to PHRs. Targeted participants included frequent and infrequent health and social care users (with and without experience of using PHRs), and clinicians and social care practitioners (with and without experience of using PHRs). Participants were sought to reflect different genders, a range of ages and ethnicities, and experience of a range of conditions. Participants were recruited to the study via voluntary community and sector groups, PHR suppliers and through contacts at the RCP HIU.

3.3 Research process
Pilot study
A pilot phase was undertaken to test aspects of the research design, to identify design issues and to allow for necessary adjustments before the main research was conducted. The purpose of the pilot phase was to identify the most suitable methods and tools for gathering appropriate information to address the project objectives, within the project constraints. Lessons learned from previous studies identified the following areas for attention during the pilot phase: developing and testing the description of a PHR for participants who are not familiar with the concept; testing that the methods and tools being used for data collection are suitable; and determining effective methods for recruitment. In addition, initial scoping of the project identified that further work was needed to clarify the participant subgroups and numbers.

Therefore, the specific objectives of the pilot phase were:

- to clarify the number of participants and subgroups; this informed the participant framework
- to test the suitability of the research approach and methods
- to identify effective recruitment approaches
- to test the draft protocols for information collection
- to test the suitability of the project’s description of digital PHRs with participants who have never used PHRs.

Learning from the pilot phase was incorporated into the main study, as were the data collected.
Data collection
The study used interviews and focus groups. In order to elicit participants’ own views and opinions while ensuring that data capture adhered to study aims and objectives, a semi-structured interview approach was adopted, supported by pre-defined interview and focus group schedules. Both types of data collection were conducted in a way that not only enabled the main topics to be covered but also allowed for participants to iteratively explore and discuss their beliefs, expectations, concerns and experiences of using a PHR and the ways they might use it that may not necessarily have been covered within the pre-defined topics.

Data were collected on the demographics, health conditions and impairments, digital capability, and use of assisted technology of participants.

Data collection was conducted over 5 months, starting on 3 February 2016 and completing on 21 June 2016. Primary qualitative data were gathered by two researchers through nine focus groups and 27 semi-structured interviews (25 face-to-face and two via telephone). Interviews lasted between 30 minutes and 2 hours, with focus groups lasting between 40 minutes and 1 hour (each involving four to ten participants).

Health and social care professionals were interviewed to gain further insight into the support required for people to adopt and continue using PHRs. Six health and social care professional interviews were conducted.

Prior to the interviews and focus groups, participants were given an information sheet that outlined the purpose and scope of the project, what their involvement would entail and how their anonymity would be safeguarded. Participants signed a consent form and gave permission for the interviews and focus groups to be audio-recorded.

Recordings were transcribed for analysis purposes using a professional transcription service and were uploaded to NVivo 10 (qualitative data analysis software) for coding.

3.4 Analysis
Transcripts were analysed using framework analysis to develop a thematic template that linked data with study aims and objectives. Framework analysis is a semi-structured approach that, like generic thematic analysis, uses coding to conceptualise and classify research data. One of the researchers involved in data collection (an experienced qualitative researcher) initially coded the transcripts and developed a unified framework that reflected essential and incidental themes and their linked categories. As each transcript was analysed the researcher’s knowledge increased and excerpts from transcripts were added to the framework as appropriate (coded). Both researchers then worked together to agree a final framework, which was reviewed by a third member of the study team and agreed. Involving a number of researchers in the development and agreement of the framework validated the process and ensured that major themes retained their nuance and detail. The analyst monitored the process to ensure data saturation (when no new information or themes
emerge) and the team agreed that saturation had been reached following completion of all transcript analysis.

### 3.5 Development of user journeys

The user journeys were developed using Integrated Patient Storytelling (IPS). IPS is a method of applying oral storytelling techniques to data gathered from patient interviews and focus groups. Many people’s stories are integrated into a single story.

The output from the IPS process is a recording of a constructed patient telling their story. The story they tell is informed by analysis from multiple patient interviews and focus groups. The recording can be used as audio, transcribed as text or have images added to create video. By combining many patients’ experiences as a single story, the aim is to convey generic truths in a way that communicates quickly and effectively to any audience.

The user journeys were developed by a multidisciplinary team made up of a clinician, a qualitative researcher, a community storyteller, a health informatics programme manager and a health informatics project manager.

### 3.6 Literature review

**Databases searched**

Literature on PHRs was searched on online databases including PubMed, CINAHL, MedLine and Google Scholar. Searches were carried out to the end of April 2016.

Searches were carried out using Medical Subject Headings (MeSH) terminology in the above databases, eg ("patients"[MeSH Terms] OR "patients"[All Fields] OR "patient"[All Fields] OR "personal"[All Fields]) AND ("health"[MeSH Terms] OR "health"[All Fields]) AND ("records as topic"[MeSH Terms] OR ("records"[All Fields] AND "topic"[All Fields]) OR "records as topic"[All Fields] OR "records"[All Fields]).

In addition to the electronic databases, UK-based PHR projects were searched using search engines to identify published literature.

In some instances, UK-based project details have been collected from websites and presentations at regional/national conferences. References from the initial literature search were also reviewed for identification of further sources of literature.

**Types of studies that were included**

Systematic reviews, randomised controlled trials (RCTs), case control, cohort, cross-sectional studies as well as other descriptive studies have been included in the literature review. Although the systematic reviews are classified as a high level of evidence, case studies and reports were included to cover a wider range of studies and especially those from the UK.
Inclusion and exclusion criteria
Most of the literature that was included were studies or projects based in the UK. However systematic reviews included studies from other countries to cover a larger evidence base, since the vast majority of the literature reports on work carried out in the USA.

PHRs have been distinguished from record access, and records have been classified as being PHRs if:

1. patients and carers enter the data, allowing them to monitor their conditions
2. healthcare professionals are able to monitor the data remotely or view data during a consultation.

Studies that do not meet the above criteria have been excluded from the literature review.

Data extraction and analysis
A form was designed to collate the data that were extracted from the included studies using predetermined measures for analysis. In addition, data regarding the study date, country, population demography and design of the PHR system were collected to add context to the results.

Search results
A total of 32 articles have been included in the literature review including: 12 systematic reviews encompassing RCTs and other publications mostly from the USA, the UK and European countries; two literature reviews; two Australian studies on PHR design and evaluation; and 17 other studies from the UK, which included specific PHR projects (eg eRedbook, Patients Know Best, Myhealthlocker, Renal PatientView and My Diabetes My Way). Examples of social care records (matching the search criteria) have also been included in the UK-based studies.

4 Findings from empirical research
This section presents the main findings from the empirical research under the following headings.

4.1 Description of study participants
4.2 Service users’ motivations to adopt a PHR
4.3 Factors that influence a decision to adopt a PHR
4.4 Barriers to adopting a PHR
4.5 Benefits of using a PHR
4.6 Interaction of patient journey and PHR use
4.7 Unmet needs and negative experiences using a PHR
4.8 Support required for adoption and ongoing use.

Sections 4.2–4.8 are divided into two parts. Part one presents a table summary of the empirical findings with signposts to the complete findings, which can be found in the appendix at Section 8.2. Part two provides a commentary on the main findings.
4.1 Description of study participants

The study had 88 participants, including:

- those who currently use PHRs, those who formerly used PHRs and those who have never used PHRs
- citizens who have at least one long-term condition\(^{ii}\) and those who do not have a long-term condition
- carers and parent/carers of those who have a long-term condition\(^{iii}\)
- clinicians and social care practitioners whose service users use PHRs
- clinicians and social care practitioners whose service users do not use PHRs
- those who were previously excluded from research; for example, social care users, members of families where at least one parent or carer is in the armed forces, and those who have experience of the criminal justice service and street homelessness.

The numbers of participants in the specific cohorts were:

- 41 recruited to the ‘people with long-term conditions’ cohort
- 36 recruited to the ‘carer’ cohort
- 5 recruited to the ‘neither carer nor has long-term condition’ cohort
- 3 social care practitioners and 3 healthcare practitioners.

Demographic information on participants

- 45% male, 55% female
- age range from 21 years to 84 years
- 76% white British
- 8% Asian/Asian British
- 8% black/African/Caribbean/black British.

For more information on participant demographics, please see Appendix 8.2.1.

\(^{ii}\) Participants with long-term conditions include those who have experience of at least one of the following: mental illness, ulcerative colitis, substance misuse, diabetes, liver failure, renal failure, arthritis, sight impairment (blind), young-onset dementia, cancer, high blood pressure and Crohn’s disease.

\(^{iii}\) Participants who are carers and parent/carers provide care for someone with at least one of the following: autism, mental illness, cerebral palsy, failure to thrive, Down’s syndrome or an unspecified genetic condition.
## 4.2 Service users’ motivations to adopt a PHR

Table 2 provides a summary of the empirical findings related to service users’ motivations to adopt a PHR. For the complete findings on this topic, please see Section 8.2.2.

**Table 2: Summary of the empirical findings related to service users’ motivations to adopt a PHR**

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Explanation</th>
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<tr>
<td><strong>Take control of health and improve health</strong></td>
<td>• To enable people to take control of health records, health conditions and care with the aim of improving health and wellbeing.</td>
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</table>
| **Advocate for change in current service or treatment** | • Use the PHR to gather evidence on quality of service, eg the number of cancelled appointments and impact on health, and provide feedback as a means to bring about change.  
• Use the PHR to track over time the effect of treatment in managing symptoms and its use at consultations to support a request for change in treatment. |
| **Ability to share information**              | • Share health records in an efficient and secure manner with healthcare professionals who do not have access to complete records, to reduce the risk of inappropriate treatment and the need to give a full history at each appointment.  
• Facilitate common goals and shared understanding between service users, families/carers and healthcare professionals.  
• Share health records with the family/carer so that they can communicate with healthcare professionals when the individual is unable to. |
| **Convenience**                               | • Reduce the need to visit GP practices and hospitals, saving time and money for service users and the NHS.  
• Remove the need to telephone to make appointments.  
• Reduce the need to take time off work to attend appointments.  
• Save individual fees that are currently charged to access paper records.  
• Make appointments more efficient and effective through access to full records. |
| **‘See what is said about them’**             | • Check that ‘accurate’ information is recorded in the record.  
• Track and monitor that healthcare professionals have done what they said they would do.  
• Allow for more transparent, accurate, accountable and, therefore, responsible record keeping, thereby supporting greater transparency in care and support. |
<table>
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<tr>
<th>Subtheme</th>
<th>Explanation</th>
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</table>
| An aid to person-centred care and communication | • Help the service user to be seen as an individual and not a set of symptoms, conditions or problems, which would lead to better care and experience of care, and reduce stigmatisation of service users.  
• Use videos to demonstrate the symptoms and needs of service users in a non-intrusive and effective way.  
• Support collaborative decision making through co-producing health and care plans.  
• Involve those with communication difficulties in their care through the use of multimedia PHRs. |
| Support and memory aid                       | • Keep track of medical history and medication.  
• Facilitate access to other people who are in a similar situation, to help the patient to understand their condition and implications of treatment options.  
• Use videos as an instructional tool for carers, schools and support workers on the needs of a child or vulnerable adult.  
• Carers and family could use the PHR to monitor service user’s symptoms and identify when they need support. |

• Overall, there was an appetite among participants to adopt a PHR; this was strongest among those who have experience of a long-term condition or those who are caring for someone with complex needs. Motivations for adopting were varied and multifaceted and were often related to service delivery model and approach; the relationship between the healthcare professionals and service users; approaches to health self-monitoring and management; and implications for resources of the service user and NHS.

• Motivations cut across three core areas: better health and wellbeing outcomes; enhanced experience of health and social care services; and greater control over health and wellbeing. Here motivations were closely aligned with user goals. Some motivating factors focused on the possibility of using PHRs to influence the model of care, such as aiding a person-centred care approach. Other motivating factors were directed at resolving specific limitations or weaknesses in the current model implementation, such as poor interoperability of health records or delay in transfer.

• Parent carers of children with complex needs and those with experience of mental ill health were enthusiastic about the potential for a multimedia PHR to aid communication. The ability to make and share videos and recordings with others with relative ease opens up the possibility to those with communication difficulties to share their health needs in a way that suits them, so that they can be part of the decisions around their health. Participants believed that a multimedia PHR is set up to ‘prompt(s) a different conversation’. It provides a different lens with
which to see a person: ‘it’s a different way of seeing what a person likes or dislikes or needs might be’. Also highlighted was the potential for those who ‘struggle with communication’ to use the PHR as an effective advocacy tool. They can communicate their needs clearly using videos, pictures and journal entries and start a two-way conversation.

- Those who do not have a long-term condition focused on the convenience that comes with a PHR’s transactional functions, such as booking appointments and access to records. While they could see the benefits for those with long-term conditions in adopting the more sophisticated tools, for them the trade-off between cost and benefit did not meet the threshold for adoption.

4.3 Factors that influence a decision to adopt a PHR

Table 3 provides a summary of the empirical findings related to factors that influence a user’s decision to adopt a PHR. For the complete findings on this topic, please see Section 8.2.3.

Table 3: Summary of the empirical findings related to factors that influence a user’s decision to adopt a PHR

<table>
<thead>
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<th>Subtheme</th>
<th>Explanation</th>
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</table>
| Trust in care provider                        | • Good relationships with health and social care professionals can positively influence a service user’s likelihood to engage with a professionals’ recommendation to adopt a PHR.  
• Poor relationships with health and social care professionals can positively influence a service user’s motivation to take control of their health and reduce the frequency of appointments, and thus to adopt a PHR. |
| Prior experience of health and social care    | • Mismanaged care in the past positively influences citizens’ motivation to adopt a PHR.                                                   
• Experience of a complex and rare condition can positively influence motivation to adopt a PHR, where the service user has encountered reluctance from new care teams to treat them without speaking to the principal care team.  
• Experience of poor communication across services can positively influence a service user to adopt a PHR. |
| Patient activation level                      | • Service users who are more motivated to self-manage and who have the skills and knowledge to do so are more likely adopt a PHR.                |
| Exposure to PHRs                              | • Those who have previous positive experience of some PHR functions are more open to adopting new functions.                                  |
| Family encouragement                          | • Family encouragement can have a positive influence on adoption of a PHR.                                                                |
People with higher patient activation levels were more likely to adopt a PHR and be able to clearly articulate how they would use it and what difference it would make. They saw a PHR as a vehicle for gaining greater ownership over their health. This group described access to their health records as ‘their right’:

*But the ownership thing, I think, that’s the one thing that, you know, that we all feel that we can own our own condition, our problems, and want to have that ownership, so we want to be proactive about it, and this provides a very good platform for us to do that.*

It is interesting to note that two of the five factors identified as influencing a user’s decision to adopt a PHR are related to health and social care provision, and that these can have a positive and a negative impact on a user’s decision to adopt a PHR. A participant described the consequences of not having access to his wife’s notes when discussing her care with a new consultant before her electronic health records had been transferred.

*... when we moved down here, the information didn’t get passed and the consultant in Lincolnshire said [her medication] was way too high, took her off it, put her on something lower which resulted in her unfortunately attempting suicide.*

### 4.4 Barriers to adopting a PHR

Table 4 provides a summary of the empirical findings related to barriers to adopting a PHR. For the complete findings on this topic, please see Section 8.2.4.

**Table 4: Summary of the empirical findings related to barriers to adopting a PHR**

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Explanation</th>
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</table>
| Lack of awareness and understanding | • Ambiguity among users around the meaning of the term ‘personal health record’. Not only is the term not self-explanatory but it is frequently misinterpreted as meaning access to electronic health records only, which immediately limits users’ thoughts around what a PHR can do.  
• Lack of knowledge among some health and social care professionals around what a PHR is, even when their clients/patients use a PHR. |
| Reluctance from health and care services | • Anticipated reluctance from health and social care professionals in the adoption and use of PHRs.  
• Past experience of the reluctance of professionals to allow access to records.  
• Concerns that it will increase professionals’ workload by increasing consultation time and frequency. |
| Increase in professionals’ workload |                                                                                                                                                     |
| Data security                | • Risk of data security breach and subsequent inability to regain control of who sees the health record.                                           |
• Lack of confidence in the NHS to keep data secure.
• Lack of trust in ‘the system’ and people.

Data use
• Concerns over use of data to monitor and for surveillance.
• Concerns that data are sold to private sector.
• Concerns that errors in records are widely circulated.
• Concerns that data will be used by insurance companies and employers.

Anxiety
• Not wanting to be reminded of past illnesses (‘opening wounds’).
• Over concerned and pre-occupied with measuring things.
• ‘Anchoring’ whereby users misinterpret new conditions on existing data or older conditions and become anxious.

Replacement of face-to-face service
• Loss of the ‘human’ element of healthcare, where the option of a face-to-face appointment is lost.

Two-tier system and inaccessibility
• Those without the resources (computer or language skills or access to technology) will have disadvantaged access to health and social care.

Pressure to share records
• People who are susceptible to coercion by partners, family or carers, will be pressurised into allowing access to their PHR.

• Many barriers to adoption were related to concerns over data security, the consequences of a data breach and the loss of control over personal information. Participants reported that they did not believe that the NHS was able to keep their records safe.

    Well today, this morning on BBC News they were talking about health data and how secure is it, and are the insurance companies in the future ... So they’re questioning, okay, all this big data is being gathered so ... But in future what security is there that the insurance companies are not going take this data when you apply for insurance for your house, your car, whatever, health ...

• While trust in the NHS as a whole around data was low, some participants reported that reassurance from their clinician that their data were safe would lower their concerns. It is worth noting that familiarity with a PHR that holds less-sensitive data could also build confidence in the system. Having alerts sent to a phone when the PHR was accessed could also lower concerns. Participants also wanted control over what information was on the PHR and who had access to it. Some participants wanted a second level of security for sensitive information, such as sexual health history.

• Another barrier to adoption was around participants feeling anxious about seeing their health record. Some thought that it might be overwhelming emotionally to see how unwell they had been in the past.
to access my records and read what’s written about me. I think if I read that I’d probably be disturbed by some stuff and I would just think about that ... the past and it would open more wounds and memories of stuff because I really don’t want to know what’s written about me.

- Others were concerned about the use of medical devices attached to PHRs, where people become preoccupied with measuring things. A further barrier was around misinterpretation of data, due to lack of knowledge on how to interpret them, or a predisposition to interpret data in a certain way.

- In addition, some participants were concerned that the introduction of a digital tool with facilities for online messaging would lead to a reduction of face-to-face contact with clinicians, which they valued. For some participants this was a reality. In a related barrier, some participants were concerned that the introduction of a PHR would lead to a two-tier system. This would be exacerbated where the PHR used overly complex language or layout.

> We’ve all got tablets and smartphones and that. I haven’t even got a mobile phone you see. I’m the archetypal Luddite. I’m a sort of carer for my mum who’s in her late 80s now. She doesn’t even know what the internet is. The thing that concerns me perhaps wrongly or rightly is that I can see, if you go down that road you’re going [to] end up with first and second class patients.

### 4.5 Benefits of using a PHR

Table 5 provides a summary of the empirical findings related to benefits of using a PHR. For the complete findings on this topic, please see Section 8.2.5.

#### Table 5: Summary of the empirical findings related to benefits of using a PHR

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Explanation</th>
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</table>
| **Self-manage and monitor health and wellbeing, Take control of health** | • Use to track symptoms and health behaviours over time, and to identify triggers and modify behaviour.  
• Increase in self-reflection skills, greater understanding of their condition and how to manage it. Reflect on whether they should seek help from professionals.  
• Contribute to records and feel more in control.  
• Upload own material to support wellbeing, eg quotes, photos, music and videos.  
• Use reminders for medication and therapy. |
| **Convenience**                        | • Medical devices linked to PHR save time.                                   |
| **Access to up-to-date information**  | • Better informed and easy to update.                                       |
| Ability to record and celebrate progress | • Log and share success stories with family and care team. This is important for parent carers of children who have complex needs. |
| Supported communication with health and social care services | • Enhanced confidence to engage with healthcare professionals.  
• Care team is more accessible through the messaging service.  
• Feel better prepared for appointments having reviewed electronic health records and other data on the PHR, eg symptom trackers.  
• Feel listened to when data from the PHR are presented at consultations. |
| Better and more appropriate care and support | • Bridge the gap in delay of records transfer to new health and social care providers, minimising the risk of inappropriate care.  
• Use data in the PHR to advocate for increased self-identify and effectiveness of current treatment, and to identify opportunities for improvement.  
• Use data to help support collaborative decision making around the level and type of support needed.  
• Provide professionals with the information they need to do their jobs. |
| Realised person centredness and empowerment | • Use videos to help the service user to be seen as an individual and not a set of symptoms, conditions or problems, leading to more engaged carers and a better experience of care.  
• Use videos to demonstrate the symptoms and needs of service users in a non-intrusive and effective way.  
• Use videos to support independence through capturing what a service user can do for themselves.  
• Ensure that those with communication difficulties can be involved in meetings about their care through using a multimedia PHR.  
• Share the PHR with colleagues to help them better understand needs and thereby support continued employment. |
| Reducing the need for repetition | • Time in appointments is saved.  
• Stress and anxiety around forgetting a key part of the patient’s history is removed.  
• Appointments do not start on the negative listing of what a person cannot do. |
| Reassurance and reduction in anxiety | • Fast access to test results reduced anxiety.  
• Fast response to messages between appointments reduced anxiety.  
• Reassurance that the messaging service is available if needed.  
• Identifying patterns in past recovery was reassuring when a service user encountered a ‘blip’ in test results. |
• Benefits and key functions are closely aligned with motivations. Significant benefits related to realised empowerment, greater control over health and wellbeing, successful partnership working with care providers and reduction in or elimination of ‘pain points’ from traditional service delivery.

• Some participants provided tangible examples of how they had used their PHR to track symptoms and behaviours over time to identify triggers for ill health. They were able to use this information to identify and implement behaviour change and monitor the result. The PHR helped them to develop self-awareness and self-confidence. Others looked back on results from past episodes of illness and subsequent recovery, to find reassurance when they received disappointing test results.

Another participant took his medication chart and symptom chart to his doctor and used it to support his successful request to lower his medication dosage.

> How I was feeling from day to day, whether I was feeling better, worse than the day before and I could see what some of the triggers were which tripped off my moods.

> A very, very, very good system and it’s a way of helping people ... to monitor their depression, their anxiety, their sleep, weight gain, blood pressure, alcohol intake or anything they want.

• Users of social care and their carers were the most enthusiastic proponents of PHRs (both users and non-users). They identified specific frustrations in their experience of current services and described how a PHR could/did support them and those for whom they care.

These users of social care and their carers are engaged with a large number of professionals across many services. This can contribute to logistical and administrative challenges as they try to navigate through appointments and processes in an environment where services and systems sometimes have poor communication. They would value a PHR that provides a mechanism to both record and track appointments and actions by professionals, and they would value a multimedia PHR as an aid to communication with and between services.

Users or those who care for them often feel like they are defined by their conditions, a feeling that is exacerbated by the need to repeat at every appointment their symptoms and limitations. The use of videos allowed users to demonstrate in an efficient and effective way who they are as individuals, and their aspirations and support needs. Some of these users have long-term, ongoing contact with services and it is important to them that they are treated as an individual and not as a ‘condition’. Furthermore, they believe that a person-centred approach supported by the PHR leads to better care and outcomes through a shared understanding. This sentiment was echoed, albeit to a lesser extent, by those who access hospital services for acute and episodic illnesses.
Also, for our situation, our son has quite complex needs and if you just read all his medical files and his lists of disabilities, it’s a very dark picture and you actually can very, very easily underestimate him. And without really understanding, not only where he needs support, but knowing what he can do, because if you don’t fully understand what somebody can do, you can fully disable them.

- Many people used PHR functions to access traditional services in a new way, which reduced or eliminated service user pain points. For example, participants like the speed with which they received test results and the convenience of not having to visit a hospital or GP practice. They also liked the convenience of being able to check online when they last had vaccinations and booking appointments online. These functions were particularly attractive to those who did not have frequent contact with healthcare services. Others were pleased to have access to up-to-date information about themselves or their condition.

The fact that I can use it and it is there has lowered my levels of stress about my condition ... I think that it has made it more timely, in particular, and for me that’s a big issue ... my level of anxiety about my condition is reduced when I am able to sort things out and quickly.

4.6 Interaction of the patient journey and PHR use

Table 6 provides a summary of the empirical findings related to interaction of the patient journey and PHR use. For the complete findings on this topic, please see Section 8.2.6.

Table 6: Summary of the empirical findings related to interaction of patient journey and PHR use

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of use</td>
<td>- Frequency of accessing the PHR may be monthly, weekly, daily or across multiple months. It can vary for the same person over time.</td>
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<tr>
<td></td>
<td>- Frequency of access is needs driven and is not related to satisfaction with the PHR.</td>
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<tr>
<td>Patterns of use</td>
<td>- Where a participant is in their illness or recovery journey affects patterns of use of a PHR. Different cohorts who are at different points in their journey access the PHR at different times, at varying frequencies and for different purposes.</td>
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<tr>
<td></td>
<td>- For many, PHR use is linked to presence of symptoms or need to access health information, such as test results.</td>
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<tr>
<td></td>
<td>- Those with mental ill health are more likely to use the PHR in the long term to promote wellbeing.</td>
</tr>
<tr>
<td>Introduction</td>
<td>- Introduction of a PHR close to the time of diagnosis is preferred.</td>
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</table>

• Participants’ use of their PHR differed depending on their condition type and disease activity, where they were in their health journey and their experience with the PHR. Participants who do
not have a long-term condition or those with a long-term condition that is in remission and does not require monitoring are not motivated to use a PHR. Use is limited to ad-hoc access to undertake transactional activities or check records for administrative purposes eg vaccination history for holidays and medical history for insurance/mortgage. As identified earlier, while use of the PHR at this stage may be limited, access helps to increase familiarity and may reduce concerns about risk.

*if you are just healthy then you don’t, I don’t think everyone will use it because there is no … and especially for young people … what are the benefits? Like, just leave me alone. I don’t want to think about it.*

- For those with a long-term chronic condition that requires monitoring, access to a PHR with functionality to track symptoms, access to information about their condition and the ability to message their care team is preferred close to the time of diagnosis. It is at this point that the PHR was reported to be of greatest use to this cohort. It is worth noting that introduction to the PHR should not be at a time when the user has received significant news – good or bad. Frequency of use is related to severity of symptoms/patterns of flare-up. However, satisfaction with the PHR is not related to frequency of use. And even when this cohort are not using the PHR, they are reassured that it is there when they need it.

*It’s not something I would use so long as I am well. I would be pleased to use it if I went into a longer period of relapse so then it would be useful … if I ever needed it then I would make the time to do it.*

*But I don’t really use it as I say, only when I’ve got to check up to see what comes through with the (test) results.*

- For those who access social care or mental health services and use a multimedia PHR, PHR use can be daily or weekly on an ongoing basis as they use the PHR to support their health and wellbeing through uploading helpful tips and reflections. Others use it to upload videos or photos to share achievements among friends and family (protecting the confidential health information). In this situation, the PHR is much more than a health record.
4.7 Unmet needs and negative experiences of PHRs

Table 7 provides a summary of the empirical findings related to unmet needs and negative experiences of a PHR. For the complete findings on this topic, please see Section 8.2.7.

Table 7: Summary of the empirical findings related to unmet needs and negative experiences of a PHR

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Explanation</th>
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<tbody>
<tr>
<td>Lack of historic records</td>
<td>• Historic test results missing, impacting on the ability to track their condition over time.</td>
</tr>
<tr>
<td>Overwriting of previously entered information</td>
<td>• Functions storing data from the latest entry each day only, when the user instead wants to track more than once a day.</td>
</tr>
</tbody>
</table>
| Records not being updated and not having access to full records | • Care plans and other key documents not added to the PHR by professionals.  
• PHRs not containing full medical history. |
| Unable to interpret data                      | • Test results being presented to the user as a clinician would see them, with no guidance. The user not having the knowledge or expertise to read the results or meaningfully interpret them. |
| Lack of portability                           | • Some PHRs cannot be successfully viewed on handheld devices.               |
| Health information not relevant to the user   | • Health information is too generic, not covering the user’s experience of their illness. |
| Not realising what a PHR can do and how it works | • The user assumes that information entered into the PHR is seen by professionals and acted upon. |
| Functions not working and problems with login | • PHRs are launched with ‘hold’ buttons that the user can see, for functions that are yet to be developed. For example, a feedback button that when clicked took the user through to an error/blank page. |

• Negative experiences with PHRs were frequently related to unmet expectations, often from underdeveloped or incomplete functions. Such experiences were aggravated by a lack of prior knowledge of the limitations of the PHR and poor communication about them from the services that were delivering them. It is important to note that a poor experience with a specific PHR function led some participants to stop using their PHR.

*I think because it was such an early stage, it was still quite bare in places. There were things that obviously they’d set up that they were intending to add to it at a later date that didn’t*
have functionality at the time. For example, there was a tab that said ‘send us your feedback’ but there was nothing there.

I’ve sort of kept a paper diary. It’s not uploaded to anything.

- A key function for users is access to up-to-date and complete records. Prior to login, many participants with PHRs had expected their complete medical records to be on their PHR. Some of these participants reported that their records were incomplete: historic data were missing or their records were not up to date. For others, their records section was a ‘data dump’ and documents were not presented in an ordered or searchable fashion. One of these users reported other functions that were partially complete or not working as she needed. One participant noted that some of her records, before a specific date, had been deleted without prior warning and she now keeps a back-up of her PHR contents.

- Others noted that the information on test results in their PHR was difficult to interpret or that information on their condition was not relevant to them. The former could lead to increased anxiety at a time when anxiety levels might be raised anyway, or to accessing poor-quality information on the internet. It was important to users that information is tailored to them and not a ‘copy and paste’ of what the doctor reads, especially if the user needs medical expertise to understand it. Condition management literature should be relevant to the users. One participant said that the information provided on her condition was not relevant to her experience of her symptoms. She felt disappointed, which impacted on her overall impression of, and engagement with, the PHR.

  now I understand how these things work but I could understand if somebody was just presented with that and thought: What do these mean? How do I go? What do I do?

- In addition, some participants were unaware of the functions that were available via the PHR, or whether the information they uploaded was looked at by others. This was especially true for those who used their PHR intermittently or experienced a change in their health which prompted use of a function that they had not used before. This is a risk to the health of the service user and services, especially where the PHR represents a move to a remotely supported self-management model of care.
4.8 Support required for adoption and ongoing use of a PHR

Table 8 provides a summary of the empirical findings related to support required for adoption and ongoing use of a PHR. For the complete findings on this topic, please see Section 8.2.8.

Table 8: Summary of the empirical findings related to support required for adoption and ongoing use of a PHR

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition from clinician management to shared decision making and self-management</td>
<td>• A change in the model of service delivery requires support for users that encompasses how to use the PHR and how to self-manage. Not all service users will be ready for this transition.</td>
</tr>
<tr>
<td>Computer literacy</td>
<td>• Computer skills training and access to technology.</td>
</tr>
<tr>
<td>Require ongoing support</td>
<td>• Users pay particular attention during induction to how to meet their needs from their PHR at that time. Additional support is welcomed by some users when their needs, and therefore their use of the PHR, change or if they had not used the PHR for a long period of time.</td>
</tr>
<tr>
<td>Social group workshops are helpful</td>
<td>• Those who have long-term conditions that impact on their quality of life valued the workshops (in some cases more than they expected to).</td>
</tr>
<tr>
<td></td>
<td>• For those with conditions where low motivation is a symptom, ongoing face-to-face support encouraged ongoing use.</td>
</tr>
<tr>
<td>Introduction and guidance needs</td>
<td>• Introduction and guidance needs to be easy to understand.</td>
</tr>
</tbody>
</table>

- The majority of participants, users and non-users, focused on describing support needs at the point of adoption. Support needs were discussed in the context of the user’s needs from the PHR at that time. Most users were given a face-to-face introduction to their PHR; for some that included a workshop but for others it was a quick chat and a leaflet.
- Needs vary depending on the PHR and the characteristics of the users. For example, some participants required information technology (IT) training and access to devices, such as a laptop or tablet. Others, including those with mental ill health and those experiencing low motivation, needed ongoing encouragement and support to use the PHR. This cohort reported long-term use of the PHR.

 users are desperate to take control of their own recovery plans but if you’ve been someone who’s been using the services for a long time and have been brought up in a tradition which
is very much about ... you tell me what’s wrong doctor, then it’s quite difficult for them to
switch overnight.

So I’ve done it at home, but I quite like the social, having to walk out and meet people ... I
mean, the social contact I think is quite important.

• Participants paid particular attention during workshops to the functions that they needed to use
at that time. As referenced earlier, some participants reported a change in what they needed
from the PHR over time and that they did not know how to get those needs met.

    I mean going through it in the consulting room is totally different to doing it yourself.

• Ongoing support is especially important where a PHR is being employed to support a change in a
care pathway from face-to-face consultation to remote self-management. Users who experience
new symptoms and challenges may not be aware of how the PHR can support their new needs
or how to ask for support.

4.9 User journeys
Six user journeys were developed from the data. Each journey covers PHR use in a different scenario.
# Jo’s journey matrix

Jo, aged 49, is an inpatient at a psychiatric hospital, she was admitted after she attempted suicide 3 months ago. At discharge, she is offered a support package that includes access to a community mental health support group that meets weekly, a care coordinator called Gary, counselling and access to a personal health record (PHR), which she calls the ‘app’. She is also prescribed an antidepressant. Jo is unemployed at the time of her discharge.

<table>
<thead>
<tr>
<th>1. Introduction to the PHR (day 1)</th>
<th>2. Preparation for adoption (week 2)</th>
<th>3. Adoption and early use (weeks 2 to 5)</th>
<th>4. The PHR as a tool for self-reflection (week 5 to year 3)</th>
<th>5. Using the PHR to aid advocacy and maintain wellbeing (years 4 to 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doing</strong></td>
<td><strong>Thinking</strong></td>
<td><strong>Feeling</strong></td>
<td><strong>Pattern of PHR use</strong></td>
<td><strong>Satisfaction with the PHR</strong></td>
</tr>
<tr>
<td>Leaves psychiatric unit</td>
<td>I want to get better.</td>
<td>Anxious</td>
<td>Not applicable</td>
<td>High</td>
</tr>
<tr>
<td>Moves back into her flat</td>
<td>I can’t see how to get better.</td>
<td>Sad and uncertain</td>
<td>Once</td>
<td>High</td>
</tr>
<tr>
<td>Taking medication</td>
<td>‘The doctors know what is best for me.’</td>
<td>Motivated to get better</td>
<td>Weekly at sessions</td>
<td>Low</td>
</tr>
<tr>
<td>Shopping and cleaning</td>
<td>‘The app could be a good thing.’</td>
<td>Surrounded by daily confusion</td>
<td>Daily at home, and review at weekly sessions</td>
<td>Medium</td>
</tr>
<tr>
<td>Seeks her care coordinator</td>
<td>‘It looks simple enough to use.’</td>
<td>Motivated to use the PHR when she is given a laptop</td>
<td>It varies: between five times a week and five times a month, depending on how she’s feeling</td>
<td>High</td>
</tr>
<tr>
<td>Stays in her flat a lot</td>
<td>‘I won’t remember how to use it.’</td>
<td>Mostly feels the same as she has since discharge</td>
<td><strong>Encouragement to adopt it, but not pressure</strong></td>
<td><strong>High</strong></td>
</tr>
<tr>
<td>Attends a weekly support group</td>
<td>‘I couldn’t do this on my own.’</td>
<td>Nervous before the first session</td>
<td><strong>Face-to-face introduction to the PHR</strong></td>
<td><strong>Encouragement to use the PHR</strong></td>
</tr>
<tr>
<td>Logs on to the app</td>
<td>‘I need support.’</td>
<td>Goal of ongoing support with the PHR</td>
<td><strong>Face-to-face support</strong></td>
<td><strong>Face-to-face support</strong></td>
</tr>
<tr>
<td>Watches how the BP and weight functions work</td>
<td>Mood questionnaire makes me think about how I am feeling today.</td>
<td>Motivated to use the PHR when she is given a laptop</td>
<td><strong>Laptop</strong></td>
<td><strong>Laptop</strong></td>
</tr>
<tr>
<td><strong>Anxious</strong></td>
<td>‘I am working hard to get better.’</td>
<td>Still feels the same as she has since discharge</td>
<td><strong>Support of the wider care team, including the care coordinator</strong></td>
<td><strong>Support of the wider care team, including the care coordinator</strong></td>
</tr>
<tr>
<td><strong>Sad and uncertain</strong></td>
<td>‘I can see that on weeks that I drink lots I feel worse, so I take a break from wine for a while.’</td>
<td>Low on the day of the group session and goal of support and encouragement from the group leader and other members</td>
<td><strong>Care plan uploaded to the PHR</strong></td>
<td><strong>Care plan uploaded to the PHR</strong></td>
</tr>
<tr>
<td><strong>Motivated to get better</strong></td>
<td>‘When I have low mood and I see the mood diary has a red sad face it tells me nothing; I know I feel bad. Why doesn’t it tell me something to help me feel better?’</td>
<td>Frustrated that the care plan isn’t uploaded, and frustrated with Gary, the care coordinator, for not uploading the care plan</td>
<td><strong>Communicate the realistic capabilities of the PHR; what it is designed to do</strong></td>
<td><strong>Communicate the realistic capabilities of the PHR; what it is designed to do</strong></td>
</tr>
<tr>
<td><strong>Sometimes tired and confused</strong></td>
<td>‘I wish someone else could see how I am feeling.’</td>
<td>Most days she feels like the future will be better and that she can cope with daily-to-day activities</td>
<td><strong>Mood up and down</strong></td>
<td><strong>Mood up and down</strong></td>
</tr>
<tr>
<td><strong>Surrounded by daily confusion</strong></td>
<td><strong>Passed on to have identified triggers and to be learning what can keep her well</strong></td>
<td>Before her GP appointment, she is nervous but prepared</td>
<td><strong>Passed on to have identified triggers and to be learning what can keep her well</strong></td>
<td><strong>Passed on to have identified triggers and to be learning what can keep her well</strong></td>
</tr>
<tr>
<td><strong>Feeling</strong></td>
<td><strong>More in control</strong></td>
<td>After the GP appointment, she is proud and more in control of her own health and healthcare</td>
<td><strong>More in control</strong></td>
<td><strong>More in control</strong></td>
</tr>
<tr>
<td><strong>Pattern of PHR use</strong></td>
<td><strong>Sometimes alone</strong></td>
<td>Able to advocate for change in treatment</td>
<td><strong>Sometimes alone</strong></td>
<td><strong>Able to advocate for change in treatment</strong></td>
</tr>
<tr>
<td>Not applicable</td>
<td><strong>Still frustrated that the care plan isn’t uploaded</strong></td>
<td>Before her GP appointment, she is nervous but prepared</td>
<td><strong>Still frustrated that the care plan isn’t uploaded</strong></td>
<td><strong>Able to advocate for change in treatment</strong></td>
</tr>
<tr>
<td><strong>Satisfaction with the PHR</strong></td>
<td><strong>High</strong></td>
<td><strong>Medium</strong></td>
<td><strong>High</strong></td>
<td><strong>High</strong></td>
</tr>
<tr>
<td><strong>User’s needs for the PHR</strong></td>
<td><strong>Encouragement to adopt it, but not pressure</strong></td>
<td><strong>Support of the wider care team, including the care coordinator</strong></td>
<td><strong>Tracking health behaviours and symptoms over time</strong></td>
<td><strong>A PHR that works on a smartphone</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Face-to-face introduction to the PHR</strong></td>
<td><strong>Care plan uploaded to the PHR</strong></td>
<td><strong>Positive messages from others on the PHR for when she’s feeling low</strong></td>
<td><strong>Multimedia capability to add own resources to help maintain wellbeing</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Clear, realistic information about the PHR that is easily digestible</strong></td>
<td><strong>Communicate the realistic capabilities of the PHR; what it is designed to do</strong></td>
<td><strong>Someone else, a professional or a friend, to access the PHR when she’s feeling down</strong></td>
<td><strong>Control over who has access to the PHR, including which professionals</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Reassurance that the PHR does not replace face-to-face support and the support group will be ongoing</strong></td>
<td><strong>Ongoing support</strong></td>
<td><strong>Ongoing support</strong></td>
<td><strong>Ongoing support</strong></td>
</tr>
</tbody>
</table>

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Josh and Michelle’s journey matrix

Josh is 8 years old. He is kind and generous and he has a good sense of humour. Josh has autism and epilepsy. They are not who he is—they are a part of him. His autism means that he cannot communicate in the same way as his brother, Ben. His mum, Michelle, aged 36, has had what feels like a long struggle to get Josh’s voice heard and to get both Josh and her family the support that they need. This struggle is ongoing as Josh grows and his needs change. It is compounded by the family’s frequent moves due to his dad’s job. Michelle has not worked since Josh was born, but she will get a part-time job at Josh’s school when he is 10 years old.

<table>
<thead>
<tr>
<th>Doing</th>
<th>Preparation for adoption (week 3)</th>
<th>3. Adoption and early use (weeks 3 to 7)</th>
<th>4. The PHR as a communication tool (week 8 to year 6)</th>
<th>5. The PHR as a person-centred tool (years 7 onwards)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Introduces Josh to his new care team and books appointments</td>
<td>• Attends an introductory workshop on the PHR, attended by parents and professionals</td>
<td>• Explains the PHR to the family, practices uploading videos</td>
<td>• Continues to add videos to the PHR</td>
<td>• Watches video uploaded at school</td>
</tr>
<tr>
<td></td>
<td>• Visits Josh’s epilepsy clinic</td>
<td>• Shares videos with Josh’s care team</td>
<td>• Visits the epilepsy clinic because Josh is having more seizures</td>
<td>• Moves house</td>
</tr>
<tr>
<td></td>
<td>• Meets with the school to discuss Josh’s care</td>
<td>• Corrects errors in Josh’s record</td>
<td>• It’s nice to see Josh’s brother Ben involved, helping him work the PHR</td>
<td>• Meets Josh’s new health and care teams</td>
</tr>
<tr>
<td>Thinking</td>
<td>The PHR sounds like it could help.</td>
<td>‘I can use this. It is so easy to upload videos and documents.’</td>
<td>‘The video is a great way to set the school know how Josh communicates and how to care for Josh when he has a seizure.’</td>
<td>‘I am learning about Josh from the PHR too’</td>
</tr>
<tr>
<td></td>
<td>‘I have to redo over and over again the most painful parts of my child’s life. Why can’t they have access to Josh’s records already?’</td>
<td>‘This can develop around Josh; his skills, aspirations and needs. I can help to give him a voice through the videos.’</td>
<td>‘The school needs to watch this video and there is no excuse for them to not look after Josh properly when he has a seizure.’</td>
<td>‘I am prepared. This time you will have the full picture before you meet Josh and change his treatment.’</td>
</tr>
<tr>
<td></td>
<td>‘Why can’t they see Josh as an individual? How can they know what he is capable of if they don’t see him?’</td>
<td>‘I can use this as something that will help me to work with Josh’s education, health and care professionals to get him what he needs.’</td>
<td>‘I can see this as a way to set the school know how Josh communicates and how to care for Josh when he has a seizure.’</td>
<td>‘I can see it. They see Josh as a person, not a file. They are getting to know him.’</td>
</tr>
<tr>
<td></td>
<td>‘I wish the new doctor hadn’t lowered Josh’s medication. I know that he will have more seizures. How can I communicate his needs better?’</td>
<td>‘It’s nice to see Josh’s brother Ben involved, helping him work the PHR.’</td>
<td>‘Josh was much calmer during this appointment. The PHR really helped the doctor to know how to be with Josh.’</td>
<td>‘This is so different to last time; Josh is participating in his care meeting.’</td>
</tr>
<tr>
<td></td>
<td>‘The PHR sounds like it could help.’</td>
<td>‘Josh is much calmer during this appointment. The PHR really helped the doctor to know how to be with Josh.’</td>
<td>‘I know exactly how many seizures Josh had had and when. The doctor saw them on a graph—a language he understands.’</td>
<td>‘We’re working together for Josh.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Satisfaction with the PHR</th>
<th>Pattern of PHR use</th>
<th>User’s needs for the PHR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sad</td>
<td>Medium</td>
<td>Not applicable</td>
<td>Josh to be seen as an individual and not an illness in the PHR</td>
</tr>
<tr>
<td>Angry</td>
<td>High</td>
<td>Daily</td>
<td>Josh’s achievements, needs and aspirations to be recognised</td>
</tr>
<tr>
<td>Frustrated</td>
<td>High</td>
<td>From several times a week to daily</td>
<td>Engagement from the wider care team with the PHR</td>
</tr>
<tr>
<td>Scared</td>
<td>High</td>
<td>From several times a week to daily</td>
<td>Communication tool</td>
</tr>
<tr>
<td>Relieved to hear about the PHR</td>
<td>High</td>
<td></td>
<td>Multimedia capability</td>
</tr>
</tbody>
</table>

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Frank’s journey matrix

**Frank’s journey matrix**

Frank, aged 70, is retired. He has had prostate cancer. Prior to diagnosis, he had been having symptoms for a while but he was being treated for chronic urine retention. Although he was dissatisfied with his care up until the point of diagnosis, he is very happy with the care that he received from the urology cancer team. Frank has finished his treatment and as his follow-up appointment he is offered the opportunity to have his care managed remotely with the support of a personal health record (PHR).

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### Doing

<table>
<thead>
<tr>
<th>1. Introduction to the PHR (day 1)</th>
<th>2. Preparation for adoption (day 2 to week 3)</th>
<th>3. Adoption and early use (weeks 12 to 14)</th>
<th>4. Accessing test results (6 months to year 2)</th>
<th>5. When circumstances change (year 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attends his first post-treatment appointment to find out whether his treatment has been successful. if his appointment with a nurse who explains about the PHR.</td>
<td>Tries unsuccessfully to set up the PHR account at home. if his appointment with a nurse who explains about the PHR.</td>
<td>Has a blood test at his GP practice to test his prostate specific antigen (PSA) level. if his appointment with a nurse who explains about the PHR.</td>
<td>Has a blood test at his GP practice to test his prostate specific antigen (PSA) level. if his appointment with a nurse who explains about the PHR.</td>
<td>Starts to feel pain in his back. A few weeks later, he completes the MOTC and records that he is feeling back pain.</td>
</tr>
</tbody>
</table>

### Thinking

- **Will my results be good or bad?**
  - "My test results are good. Great! But what does that mean for me?"
  - "I haven’t had time to digest my results - I am not interested in talking about the PHR. I can’t take it in."
  - "I’m not a condition, I’m a person. I like meeting with my consultant. Why are you fobbing me off?"
  - "Getting test results at home rather than coming to the hospital will be handy. I will try it."

- **This is too complicated to set up. I have the lengthy manual on one screen, the PHR website on another screen and I am trying to flick between the two. I give up, they can fix it at the workshop.**
- **The workshop is really well run. It was great sharing experiences with others.**
  - "I am in a similar situation; they understand. I am too embarrassed to talk about the side effects of treatment with my family."
  - "I must remember how to complete my health questionnaire (MOTC), get test results and look at records. These are what I am really interested in."

### Feeling

- **Anxious**
- **Fobbed off by the care team**
- **On his own**
- **Accepting**

### Pattern of PHR use

- **Not applicable**
- **Twice**
- **Three times in 3 months, linked to his PSA test schedule**
- **Regular but infrequent, linked to his PSA test schedule**
- **Regular but infrequent, linked to test schedule**

### Satisfaction with the PHR

- **Low**
- **High**
- **Medium**

### User’s needs for the PHR

- **Do not introduce the PHR during or immediately after an appointment when the patient is expecting or receives significant news – good or bad**
- **PHR accounts set up by care team prior to use by patient or a simple set up process that can be explained in a short leaflet**
- **Help button**
- **Working with other users to discuss how the PHR can support patients**

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### Tim’s journey matrix

Tim, aged 56, had high blood pressure that is exacerbated by stress. He is a kitchen designer, and he had an accident a few years ago that left him unable to work for a number of months. This coincided with the financial crash and he lost his business. It was at this time that Tim was told that his blood pressure was high. He continues to see his GP regularly to have his BP monitored and he experiences no physical symptoms. He also monitors his BP at home.

He finds the trips to the practice inconvenient and costly in terms of the time away from work. Other than having high blood pressures, Tim feels that he is in excellent health. Tim’s GP practice offers him a BP monitor that will link results directly into his GP record.

<table>
<thead>
<tr>
<th>1. Introduction to PHR (day 1)</th>
<th>2. Preparation for adoption (day 1)</th>
<th>3. Adoption and early use (to week 4)</th>
<th>4. Recording BP and weight (weeks 3 to week 6)</th>
<th>5. Security concerns (week 4 onwards)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doing</strong></td>
<td><strong>Thinking</strong></td>
<td><strong>Feeling</strong></td>
<td><strong>Pattern of PHR use</strong></td>
<td><strong>Satisfaction with the PHR</strong></td>
</tr>
<tr>
<td>Attends his GP to have his BP taken</td>
<td>“I can’t believe I am here again to get my blood pressure taken – that is another 2 hours off work.”</td>
<td>Fed up with having to take time off work to visit the GP to have his BP taken</td>
<td>Not applicable</td>
<td>High</td>
</tr>
<tr>
<td>Agrees to be part of a pilot using a BP monitor at home that sends results directly to the GP patient record</td>
<td>“It’s the new ‘app’ – it’s excellent.”</td>
<td>Felt that there is an alternative to GP appointments</td>
<td>Not applicable</td>
<td>High</td>
</tr>
<tr>
<td>Given a BP monitor</td>
<td>This looks so easy... I’ll just turn it on and go.”</td>
<td>Happy with the new BP monitor</td>
<td>Happy with the new BP monitor</td>
<td>High</td>
</tr>
<tr>
<td><strong>Pattern of PHR use</strong></td>
<td><strong>Satisfaction with the PHR</strong></td>
<td><strong>User’s needs for the PHR</strong></td>
<td><strong>Control over what information is held on the PHR</strong></td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td>High</td>
<td>Design PHRs to solve a problem for patients in current service provision – Tim doesn’t want to visit the GP practice to get his BP taken</td>
<td>Design PHRs to solve a problem for patients in current service provision – Tim doesn’t want to visit the GP practice to get his BP taken</td>
<td>High</td>
</tr>
<tr>
<td>Happy with the new BP monitor</td>
<td>High</td>
<td>Minimal instruction needed in this case on how to use a PHR</td>
<td>Minimal instruction needed in this case on how to use a PHR</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Present test results in a way that is accessible to patients: what does it mean and what patients should be looking out for</td>
<td>Present test results in a way that is accessible to patients: what does it mean and what patients should be looking out for</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provide information on which professionals are looking at the PHR and when</td>
<td>Provide information on which professionals are looking at the PHR and when</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Choose when to use the PHR to contact the team and when to have a face-to-face consultation at the GP practice</td>
<td>Choose when to use the PHR to contact the team and when to have a face-to-face consultation at the GP practice</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Messaging function</td>
<td>Messaging function</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Record weight</td>
<td>Record weight</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reminders</td>
<td>Reminders</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Control over what reminders are sent and how frequently</td>
<td>Control over what reminders are sent and how frequently</td>
<td>High</td>
</tr>
</tbody>
</table>

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Brenda’s journey matrix

Brenda, aged 53, runs a cosmetics company and she employs five people. She has rheumatoid arthritis and has lived with it for 20 years. She is under the care of a rheumatology team. At her latest appointment, Brenda was happy to say that she had been keeping well. When she was leaving her nurse, Mark, asked whether she wanted to try a new online personal health record (PHR).

<table>
<thead>
<tr>
<th>1. Introduction to PHR (day 2)</th>
<th>2. Preparation for adoption (day 1)</th>
<th>3. Adoption and early use (week 1)</th>
<th>4. Unmet expectations (month 8)</th>
<th>5. Further disappointments (month 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doing</strong></td>
<td><strong>Thinking</strong></td>
<td><strong>Feeling</strong></td>
<td><strong>Pattern of PHR use</strong></td>
<td><strong>Satisfaction with the PHR</strong></td>
</tr>
<tr>
<td>• Attends routine appointments with the rheumatology team</td>
<td>• This is right up my street. It will help me to keep track of my symptoms.</td>
<td>• Impressed</td>
<td>• Not applicable</td>
<td>• High</td>
</tr>
<tr>
<td>• Has a meeting after an appointment with Mark, a nurse, who introduces her to her PHR</td>
<td>• I wonder what they’ve written about me over the years.</td>
<td>• Curious</td>
<td>• Not applicable</td>
<td>• Low</td>
</tr>
<tr>
<td>• Reads a leaflet given to her by Mark on her way home from the appointment</td>
<td>• This will be easier than trying to keep my own paper records.</td>
<td>• Relieved there appears to be a straightforward login system</td>
<td>• Frustrated that the system does not allow her to do what she feels she was promised it could</td>
<td>• Low</td>
</tr>
<tr>
<td>• Logs into her PHR after work – it takes her 20 minutes</td>
<td>• It’s always been to learn about what else I could be doing.</td>
<td>• Annoyed that it took so long to log in</td>
<td>• Annoyed that her records aren’t complete</td>
<td>• Low</td>
</tr>
<tr>
<td>• Looks up her medical records</td>
<td>• It will be handy to access what I need when I am travelling for work or on holiday.</td>
<td>• Frustrated that she cannot interpret her results fully</td>
<td>• Frustrated that she cannot find research tailored to her condition</td>
<td>• Low</td>
</tr>
<tr>
<td>• Looks up her test results</td>
<td>• “Why isn’t this working? I know how to use a computer; there are too many tabs.”</td>
<td>• Disappointed that the symptom tracker does not allow her to record her symptoms more than once a day</td>
<td>• Disappointed that the symptom tracker does not allow her to record her symptoms more than once a day</td>
<td>• Low</td>
</tr>
<tr>
<td>• Works from home because she experienced a flare up</td>
<td>• “Why am I wasting my time? The morning symptom entry is deleted when I complete the evening entry.”</td>
<td>• Urged to be told her needs around the symptom checker are not a priority</td>
<td>• Disappointed that the symptom tracker does not allow her to record her symptoms more than once a day</td>
<td>• Low</td>
</tr>
<tr>
<td>• Completes the symptom checker twice per day</td>
<td>• “How do I know which one is mine?”</td>
<td>• Inconvenienced by keeping a paper record of symptoms in the morning</td>
<td>• Low</td>
<td></td>
</tr>
<tr>
<td>• Looks up the research section of the PHR</td>
<td>• “Err, where are my records from the last hospital I attended? They said my medical records would be available, not ‘some of them’ – is it just my records that are incomplete or is it the same for others too?”</td>
<td>• Not listened to</td>
<td>• Low</td>
<td></td>
</tr>
<tr>
<td>• Checks the blood test results tracker</td>
<td>• “What is the point of feeding back — my needs aren’t a ‘priority’.”</td>
<td>• Angry that her test results have been wiped without her consent</td>
<td>• Low</td>
<td></td>
</tr>
</tbody>
</table>

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Sugra’s journey matrix

Sugra, aged 17, is at college when she first starts to get diarrhoea. She is so embarrassed by it that at first she doesn’t tell anyone. Eventually she visits her GP, who refers her for an endoscopy. The appointment is sent through the post. Her mum opens the letter. Sugra has told her mum so many times not to open her post. Her mum still does it though – and she worries. Her mum insists on coming to the appointment with Sugra, which leaves Sugra even more embarrassed. After the endoscopy, the consultant gives a preliminary diagnosis of ulcerative colitis. At a follow-up appointment, also attended by her mum, the nurse takes Sugra to one side and introduces her to the PHR.

<table>
<thead>
<tr>
<th>1. Introduction to PHR (day 1)</th>
<th>2. Preparation for adoption (day 1)</th>
<th>3. Adoption and early use (day 2)</th>
<th>4. Gaining independence (day 2 to week 4)</th>
<th>5. Taking charge (week 4 onwards)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doing</td>
<td>Thinking</td>
<td>Feeling</td>
<td>Pattern of PHR use</td>
<td>Satisfaction with the PHR</td>
</tr>
<tr>
<td>Attends follow-up appointment</td>
<td>I wish my mum wasn’t so involved in my appointments; I know it is because she is worried, but... At least now I know what is wrong with me, what does that mean for me? Will I be able to have a normal life? This is embarrassing, I don’t want anyone to know. The PHR looks good, I can better control who sees my records and appointments.</td>
<td>Nervous about what she might find out: Will it help to answer her questions?</td>
<td>Not applicable</td>
<td>High</td>
</tr>
<tr>
<td>Has a consultation with a nurse who introduces her to the PHR</td>
<td>I am a bit scared about what I might find out. How are others living with this? I have so many questions.</td>
<td>Grateful for the help button: Pleased it is confidential; empowered by access to medical records; Pleased that communication about her is secure</td>
<td>Once</td>
<td>High</td>
</tr>
<tr>
<td>Logs in that evening</td>
<td>I can’t really remember how this works, but the help button is useful. It is reassuring to get information on my condition using the PHR; I’m so pleased that I don’t need to rely on leaflets which my mates might see. I know what medication I am on and what my care plan is; I feel in control of this.</td>
<td>More in control: Comforted by information on the PHR; Reassured by the Fast Response Team; Likes not having to wait for appointments to contact nurses</td>
<td>Three times per week, as she reads up on her condition and gets used to how it works</td>
<td>High</td>
</tr>
<tr>
<td>Logs in to the PHR</td>
<td>I am feeling really ill; I can’t wait 2 weeks to see my doctor. The messaging service was great; the nurse responded so quickly.</td>
<td>Easy — for the symptom checker when she is unwell</td>
<td>Daily — for the symptom checker when she is unwell</td>
<td>High</td>
</tr>
<tr>
<td>Uses the help button to navigate</td>
<td>The messaging service was great; the nurse responded so quickly.</td>
<td>Helps in control: Comforted by information on the PHR; Reassured by the Fast Response Team; Likes not having to wait for appointments to contact nurses</td>
<td>Easy — for the symptom checker when she is unwell</td>
<td>High</td>
</tr>
<tr>
<td>Views her medical records and health information</td>
<td>The messaging service was great; the nurse responded so quickly.</td>
<td>Helps in control: Comforted by information on the PHR; Reassured by the Fast Response Team; Likes not having to wait for appointments to contact nurses</td>
<td>Easy — for the symptom checker when she is unwell</td>
<td>High</td>
</tr>
</tbody>
</table>

Please note that the user journeys are based on a constructed patient telling their story. They are an amalgam of real patients or existing PHRs. The journeys have been created from an analysis of nine focus groups and 27 interviews with PHR users, former users and non-users to illustrate their thoughts, experiences and needs. The user journeys are grounded in qualitative data.
5 Literature review

This section outlines the main findings from the literature and reviews them in light of the findings from the primary data. The full literature review can be found in Section 8.3.

5.1 Benefits of having a PHR

• The literature demonstrates positive outcomes for PHR users related to experience of healthcare, partnership working with care professionals and health efficacy. Patients reported that PHRs were making them act on information, which increased their sense of empowerment and their motivation and prompted positive behaviour change. This supports the finding from the primary data that was collected.

• Evidence of the extent of benefits to users from PHRs is mixed. Differences are reported across studies. Studies differ on the type of condition that the PHR user has and the type of benefit being measured. For example, a systematic review found health benefits associated with PHR use for patients with diabetes. Similar health benefits were not found in studies with people with cancer and idiopathic thrombocytopenic purpura (ITP – an autoimmune disease). Participants in the primary research did not identify improved health as an outcome of PHR use when asked specifically about this, with the exception of those with enduring mental ill health.

• Findings of benefits in qualitative studies have not always been replicated in RCTs. There is discussion in the literature around whether an RCT is the most appropriate design for the evaluation of PHR interventions, as wider contexts cannot be captured in trials. There is the suggestion for multimethods research to understand the user perspective and impact.

• The literature shows a paucity of research among social care users. One Australian study did report that chronic disabled patients view a PHR as a way to help them to communicate with unfamiliar healthcare providers, an area in which they reported lacking confidence. Participants reported that the PHR would also help them by improved ‘storing’ and ‘sharing’ of health information. Additionally, the primary research found that a multimedia PHR can be important to support effective communication for those with communication difficulties or those with disabilities who access multiple services.

5.2 Factors that influence PHR adoption and use

• The qualitative methodology employed in the primary research and the relatively low number of participants, combined with the diversity of participants, makes it impossible to draw conclusions about patient demographics and PHR adoption and use.

• From the literature, the evidence of the relationship between age and gender and the decision to adopt a PHR is inconclusive.

• There was strong evidence in the literature between greater deprivation and failure to complete first login and early lapse. Greater deprivation was associated with substantially reduced
probability of continuing PHR use at 6 months, but subsequent attrition rates were similar in all deprivation groups.

- Engagement of professionals in the PHR was seen as a pivotal factor in a person’s likelihood to adopt the PHR. There is evidence that even where healthcare professionals find PHRs beneficial to themselves (to communicate with other healthcare professionals and patients), there is low involvement and lack of interest due to concerns about inducing anxiety in patients and creating additional workload for themselves.\textsuperscript{10} Again, this theme was echoed in the primary data.

5.3 Barriers to adopting a PHR and negative experiences

- Barriers to adopting a PHR and negative experiences with a PHR focused around lack of awareness of what a PHR can do and the negative impact on engagement where a PHR is not being embedded into the healthcare system. Barriers relating to low IT proficiency and data security concerns were identified.\textsuperscript{14,16} These themes also emerged from the primary data collection.
6 Conclusions and recommendations

This section presents the conclusions from the research and the recommendations that relate to the development and implementation of PHRs. Detailed recommendations relating to design and implementation can be found in Appendix 8.4 and the user journeys in Section 4.9.

1 There is an appetite among citizens to adopt a PHR, especially in those citizens who have long-term conditions who experience tangible benefits from adopting a PHR. There is no evidence of an appetite among those without long-term health conditions to use a PHR to promote a healthy lifestyle.

2 Motivations for adopting a PHR are linked to user goals, ie PHRs were seen by users as a tool to support them to meet a predefined goal such as a change in treatment. Barriers to adoption are based mainly on perceived implications of PHRs that can be mitigated through development and implementation, eg fear that PHRs will replace all face-to-face consultations.

3 Patterns of PHR use are influenced by user factors that change over time, eg condition type, disease activity, patient activation level and contact with services.

4 PHRs can be effective tools to empower service users to take greater control of their health, support person-centred care and, in some cases, transform for the better a person’s experience of their care. They can allow those who find it most challenging to be involved in their health and care to take an active role.

5 PHRs are complex, so effective PHRs need to incorporate insights from many disciplines, especially health and digital literacy, behaviour change, risk communication, information design and sociotechnical systems.

6 PHRs are a single tool within the wider healthcare delivery model that is experienced by the user. Those who are developing and implementing a PHR should therefore understand the needs and ‘pain points’ of users across the service and tailor the PHR to help resolve these. This will encourage adoption of PHRs.

7 The aims of each PHR and the implementation model should reflect the wider service delivery model. For example, a person-centred PHR will work best in a service that also adopts a person-centred model.

8 It is important that service user expectations are managed. Developers need to have clear aims and objectives for a PHR before development, and to evaluate its success against them.

9 Those who are motivated to take control of their health need little encouragement to adopt a 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.
10 Ongoing support should be available to ensure that those with changing needs are aware of how the PHR can continue to support them and to ensure that they know how to use it.

11 PHRs should be developed around the needs and ‘pain points’ of individuals as they interact with services, and not a particular illness or condition.

12 Multimedia functions enable better communication and are especially beneficial to those with communication difficulties.

13 Implementers need to support users to think through, in practical ways, how their PHR will impact on their health and wellbeing, 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.

14 For PHRs to reach their potential, health and social care professionals need to be engaged with the PHR and willing to support its implementation and use.

15 A user group representative of the wider user population should be involved in the development and implementation of PHRs.

16 The findings of this report should not be used as a substitute for iterative design. Good practice relies on iterative design and specific PHRs must be evaluated, improved and then evaluated again. The methods used in this report can be used to inform and help iterative design.

17 Although this report highlights the value and centrality of user-centred design, six user journeys is a small sample for many purposes. More of the same Integrated Patient Storytelling (IPS) should be developed, using participant sampling criteria that are appropriate to the intended use of PHRs.

18 PHRs are a new technology and are very likely to change rapidly. Care must therefore be taken to ensure that any PHR work is future-proofed appropriately and that initial investments can be built incrementally.

19 This report is based on qualitative research with patients and current and potential PHR users. In addition, expert review is essential to consider issues such as security; technical developments (like open source and healthcare app developments); user error management; user interface design guidelines. These are critical issues that users per se are unlikely to have insightful views on.
7 Recommendations for future research

Further research that adopts a mixed method methodology into health and digital literacy, behaviour change, risk communication, information design and sociotechnical systems should benefit the developers and users of PHRs.

For those funding work on and researching PHRs, more specific research questions include:

1. **How do service users trade off the perceived benefits of PHRs** (eg more rapid contact with clinicians via a digital channel) **versus the perceived disadvantages** (eg fewer face-to-face contacts)?

2. **How can you motivate people to use PHRs in a sustained and constructive manner**, to help prevent and manage illness and prevent exacerbations? The ‘people’ here especially includes those who feel healthy and also social care professionals and clinicians, whom seem to underuse PHRs.

3. **How can you best introduce people at various disease stages to a PHR?** For example, is a paper leaflet, a website (with or without multimedia) or a face-to-face workshop more effective or cost-effective?

4. **What is the ‘minimum viable product’ for PHRs for users who are at varying disease stages?**

5. **How can you improve the usability of PHRs**, especially to overcome barriers related to occasional use? Such barriers include login (where forgetting the login process or the password/username is more likely) and navigation, as well as the technical terms (eg names of tests and meaning of the results) used in many PHRs.

6. **How can you efficiently support the users of PHRs in a context sensitive way?** Do automated technologies such as Cortana (a virtual personal assistant created by Microsoft), web chat or forums have a role here?

7. **How can you organise and represent the data that PHRs contain to improve retrieval and understanding**, by both patients and clinicians? For example, there is evidence that clinicians overreact to variations in disease activity markers, wishing to intervene unnecessarily. This can be seen in the wider context of the alarming influence of alternative graph formats on clinicians’ intention to intervene in childbirth. This means that PHRs could increase, rather than decrease, health system expenditure, so should prompt a programme of work exploring the influences of alternative tabular and graphical PHR data formats on patient and clinician understanding of disease activity and willingness to intervene. It also reminds us of the need for an ongoing programme of work around how patients perceive, learn and understand the language used by clinicians: which words or phrases alarm the public and which do they ignore or misunderstand?

8. **What words and phrases do the public commonly use or recognise to describe important signs and symptoms?** While clinicians learn classical descriptions of diseases (eg ‘constricting chest pain radiating to the arm or neck, accompanied by nausea or dyspnoea’), patients rarely use these words or phrases. Experienced clinicians learn which expressions people do use, and can adapt their language accordingly. However, patient language varies by generation and by region,
so for example ‘nausea’ in the south east of England is called ‘feeling seedy’ in the west of Scotland. With the growth of PHRs and self-triage tools, we need a large-scale research programme to capture patient language and correlate it with future diagnoses and outcomes – the Human Phenome Project.23

9 How can you design PHRs so that they capture and communicate data (including videos or images) that will evoke in professionals the patient’s preferences and personality, in addition to the conventional coded data?

10 How can you triage user requests via a PHR for clinical support or advice, to minimise NHS resource use and maximise patient safety and satisfaction?

11 How can a PHR act as a patient-centred multiprofessional care pathway, linking patients, friends and families with health and social care professionals working in a variety of settings, without excessively burdening the service user?

12 Do users really wish to record and review their data in a PHR at all, or would they prefer the PHR to be hidden behind a digital health toolkit? This toolkit would be tailored to their needs, preferences and context using a back-end PHR, but would focus on supporting specific tasks that the user wishes to achieve (eg book an appointment or test; report a suspected drug side effect; undertake annual screening for disease complications; review disease activity and share this with others; and explore the impact of medication adjustments on future risk of complications). In this scenario, the PHR would still exist but would disappear into infrastructure (a web service) behind a variety of visible user-focused services and functions (apps). These would access data from the PHR and capture and validate data to record in it.

13 What are the medium- and longer-term impacts on patient and clinical outcomes and NHS resource utilisation of shifting people with long-term conditions to use of a PHR? For example, are the findings of a past US study showing an increase in patient resource utilisation and A&E admissions during the year following access to a PHR repeated in the UK?

14 What are the specific needs from a PHR for those who have specific conditions?
8 Appendices

8.1 Description of ‘PHR’ circulated during primary data collection

The purpose of a personal health and care record (PHR) is to help you to manage and maintain your health and wellbeing.

A PHR is a digital tool (website or app) that supports the sharing of information between your health or social care team and you. The service user or nominated carer has control over what is in the PHR and who it is shared with.

Content may include some or all of your GP or hospital notes, your results, care plans or additional information to help you to understand and manage your health needs. You typically access a PHR via the internet, either via a computer/tablet or some types of phone.

A key feature of the PHR is that it allows you to interact with your health or social care service and contribute to your records. Should you give permission, it will allow those who care for you to do this as well.

To be a PHR, it must allow you to do more than simply access the health or social care record created and held by your health or social care team, book appointments and renew prescriptions.

In general, PHRs may allow you to do a number of things, including the following:

• view all or part of your electronic health or social care records
• enter data to update your electronic health or social care records
• record health and social care information eg blood pressure readings, how you are feeling, your symptoms or problems and/or things you may want to discuss at an upcoming appointment
• request repeat prescriptions
• make appointments
• securely message and receive messages from your health or social care team
• make links with other service users
• provide feedback on the health or social care service that you receive.
### 8.2 Primary data collection complete findings

#### 8.2.1 Study participant demographics

Table 9: Participant type by age

<table>
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<tr>
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Table 10: Participant type by gender

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### Table 11: Participant type by ethnicity

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### Table 12: Participant gender by ethnicity and age

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8.2.2 Motivations for adoption

This section describes and analyses what motivates people to use PHRs, why they want to use a PHR, and how they perceive PHRs would benefit themselves and others.

Taking control of and improving health

Participants described PHRs as a way to take control of their records, their conditions and their care with the aim of improving their health and wellbeing. PHRs were seen as a vehicle for ‘taking control over what’s happening’ and having ownership.

*I’d love it personally ... I think it’s helping the patient to take control of their own health.*

*I’d say it’s a valuable tool if you want more control in monitoring your health and having a say in your treatment. It’s a good system to use.*

Participants believed they were not taken ‘seriously’ by healthcare professionals and would not be listened to, because they were young or had a history of alcohol or drug misuse. The PHR would be a way of providing information that was easily accessible and would allow them to take ‘control’ and ‘ownership’ of their condition and their care. They felt the health and social care services should put more trust in them to do this.

*The ownership thing, I think, that’s one thing that, you know, that we all feel that we own our own condition, our problems, and want to have that ownership, so we want to be proactive about it, and this provides a very good platform for us to do that ... the health service needs to trust that we can take ownership of our own health.*

Participants also wanted access to their records as a way of ‘being kept in the loop’, which enabled them to have a sense of control over what was happening around them and to them, and to be more involved in their own care.

*That’s kind of what I wanted to get out of it most, I would say, more than anything else, I wanted to be kept in the loop about my own healthcare ... kept aware of what the plans and results were ... I know I have the right to view them, so to have them automatically uploaded*
when they were created felt empowering ... it’s just being better informed ... rather than just turning up to an appointment and ticking a box, I feel more involved in my own care ... the PHR has helped me do that.

Losing control can be a big issue for those who are ill or vulnerable and therefore gaining and maintaining control is important.

A lot of people ... when people are ill ... the lack of control, losing control, is such a big issue.

However, participants highlight that taking control and making decisions without a healthcare professional can be detrimental (for example, someone adjusting their own medication, self-medicating or self-treating inappropriately), and caution against people taking control and making decisions without consulting a healthcare professional.

Advocating for change in service or treatment
Participants would want to use a PHR to provide evidence for a change in service or treatment they are receiving. PHRs would be a way of recording experience with services and providing feedback and recommendations from the patient’s perspective which could result in, for example, setting up new services to meet needs.

If we were able to provide feedback, we’d be able to say how important it is and all of those voices would be able to be captured. So you know, the appointment’s been cancelled for the third time because the clinic’s been cancelled ... Now if that’s been recorded by the patients and their impact and you know, what does this mean on your life, then the people higher up are going to be able to read that without having to have six patients in the room, and be able to actually read case studies and go: ‘Oh, this service is not meeting standard at the moment’, and look at what the impact is and look at what the cost of that is, because actually it’s an immunodeficiency area, so if we’re not seen by the clinic then we’re more likely to be put on to antibiotics and you know, other things that are costing the NHS, and so that has an impact on costings, where if it’s not being captured, it can’t proceed.

Participants could also use the information from the record to advocate for services; for example, using symptom tracking and medication data as ‘evidence’ to support a request for a change in medication prescribed. Also, participants could share care plans or consultant letters to show the level of service that was previously provided and to advocate for equivalency.

Linked in with advocacy is a PHR’s ability to act as a communication tool, especially for people who may ‘struggle with communication’. Due to the PHR’s ability to be person-centred through input from the patient and the ability to share that input with others relatively easily, it is well placed as an advocacy tool. Users of the multimedia PHR can communicate their needs and questions using videos, pictures and journal entries. Participants believed that the way the multimedia PHR is set up ‘prompts a different conversation’. It provides a different lens with which to see a person: ‘it’s a different way of seeing what a person’s likes or dislikes or needs might be’.
Sharing information

Combatting limitations in current healthcare and facilitating better and more appropriate care

Participants saw potential benefits in being able to share efficiently and securely their health and care information. These benefits included facilitating awareness of their health status such as conditions, medications and management plans in order to reduce health risks of not having access to this information.

Having the efficient flow of information would significantly, you know, reduce the risks, the health risks that we’ve all experienced if we’re having shared care between different hospitals. Facilitate a two-way street.

A number of participants saw value in having centralised records that could be accessed and shared by different healthcare professionals to enable accurate and important knowledge to be known and appropriate care to be delivered. For example, in an emergency situation where the patient is not able to communicate their condition and needs, healthcare professionals having access to records could be ‘life-saving’.

Where you might have had like an epileptic fit on a train. Somebody’s called an ambulance, you’ve had an epileptic fit. I mean you’ve took medication in the morning, you taking too much medication might do damage. So they know at what time you supposedly take your medication .... Do you know what I mean because this is going to help maybe save lives isn’t it?

I think for me there it’s saying, you know like ... I’m like allergic to certain kinds of antibiotics and stuff like that and I can’t remember the names of these antibiotics and I think if when you’ve like say been taken to hospital and they’re going to treat you – so it should be they can access that straightaway and it should be flagged up that you’re allergic to that ... potentially saving your life and if they prescribe that they could kill you.

In situations where access to the PHR is ‘locked’, a way of opening it in specific circumstances is needed, where the patient cannot give permission and care or treatment may be compromised. One suggestion was to have a nominated clinician who would be able to open the record and relay relevant information or allow sharing with others. An example of this is a participant who suffers from non-epileptic fits and used information on her mobile phone to communicate her needs. A PHR could be used in a similar fashion.

Most recently I had a fit. I have non-epileptic fits, and I had a fit at a Tube station. And I was like, ‘Okay, I know I’m gonna have a fit in a minute. What the heck am I supposed to do?’ And they’re not scary, ‘cause they’re not like convulsion fits – they’re just like absences more than anything else – but I was like, ‘What happens if someone notices that I’m gonna have one?’ And then I spotted a police officer, so I handed her my phone with ... I’ve got an iPhone that’s got, you know, the health section, and just pointed to the description of what my fits are and what you have to do, and then just sat down. And then she stayed with me and was talking to me and was really lovely, and then I came back to and I was like, ‘Okay, sorry. Sorry for all that. Thank you. Thank you.’ And she was like, ‘That’s a really, really good way of dealing with that ... Because, like, if you’d just been on the floor, I would probably have called an ambulance’, and there wasn’t a need for that, because it was only a couple of minutes and then I was fine again, but in that time she would have called an ambulance. So it was really useful to have something there to be able to hand over.
Participants believed it is important to not only share records with health and care professionals but with family members, partners and carers as well. Reasons for this included ensuring that someone would be able to convey the information in the absence of the patient being able to and communicating their ‘journey’ and needs such as how they need to be supported; this was particularly valued in those who accessed social care.

*Particularly acting on your behalf if you’re incapable for any reason.*

Participants also felt that sharing records with others, such as professionals or family members would:

*bring a fresh pair of eyes to see it if I’ve forgotten something there and I find it’s always better.*

Sharing information could also facilitate common goals and shared understanding; for example, in parents of children with complex needs who would benefit from schools having access to and the ability to enter information into a PHR.

*I just said, I remember well when I received the video of [my son] bringing the snack to the table, just being so surprised at what school have come up with something new to try with [my son] that I hadn’t thought of first and it really ... it was a learning thing for me as well about we’re always learning. You know, I may be the expert on [my son]but everybody working with [my son], also know [my son]in a different context and by everyone sharing the best practice and the best result, that has to be good for [my son].*

*So if you have common ownership within a platform, a common platform with both sides having access to it, you will be able to point to the doctors the right section within those records.*

The PHR could allow immediate access across locations which could be beneficial to those who travel or move around a lot.

*I am comfortable with the fact that if I present to a sick bay in Scotland, they will have access to all the records that I have generated in Portsmouth today.*

**Convenience**

Participants believed that having a PHR would be more convenient; it would reduce the need to visit GP surgeries and hospitals and remove the need to make appointments via telephone, which is often inconvenient and frustrating. Convenience meant different things to different people; for example, being able to communicate with healthcare professionals via the PHR was welcomed by those who worked and found it difficult to get to appointments during working hours.

*It’s a matter of convenience isn’t it this process to make appointments from home and to order from home, the prescriptions and all ... I feel it’s a matter of convenience rather than overloading the system by phoning or going in person and putting prescriptions in. You could just key into your health provider saying I need that or I need an appointment and get it done that way so I feel that some of it is more of a convenience for the patient.*
the hassle of getting that phone call ... playing phone tag for 2 days ... there are just so many processes for everyone ... just making troublesome things easy ... I’d just jump at it.

Another participant who had used other medical devices saw the value in having scales that linked to his record to facilitate monitoring of his weight.

the blood pressure monitor thing is just so easy to use now, it’s just so great, the company also makes a set of scales that update the app as well ... they are a bit pricey at the moment ... I’ll buy it because it would be lovely for me to stand on the scales as well and be able to have that collected on my phone ... the barrier is the cost ... much easier.

PHR functions such as appointment scheduling and ordering repeat prescriptions would be ‘handy’ mainly due to the convenience of it:

‘I think that’s a big inconvenience so you have a system like that in place, where you can book appointments or repeat prescriptions online, save you having to go out’.

This would be particularly useful for older people who struggle to get to their GP surgery: ‘they’re struggling in on a really windy night to see their GP ... you know when they could have stayed at home and ... just switched on the laptop’.

One participant would also value the PHR to not inconvenience others:

I would be able to do it when I wanted without inconveniencing anybody ... seemed appealing ... discreet and easy to do anywhere.

In terms of accessing the PHR, participants value ease of access, mobility and speed and would want to see the PHR in a form of an app or accessed through an app, preferably one they could access through their mobile phones, as being more convenient to use.

If it’s an app, it’s a lot more accessible, a lot faster ... it’s just a lot better on a phone.

It’s just there in your hand and it’s much easier to convey information.

Seeing what is said about them

Participants would want to be able to access records to view their medical history, view what information the doctor has about them as well as what has been written about them. Reasons for this include wanting to keep track of their medical history as well as a need to check that ‘accurate’ information is recorded and that doctors have accessed and read this information. Having access to records would also serve as an auditable record that could hold professionals to account: a ‘permanent record’ whereby patients could keep track and monitor responses or lack thereof (‘a one-stop-shop’). Participants believed that patients being able to keep an eye on records would force professionals to be more transparent, more accurate, more accountable and therefore responsible for what they write. They would need to provide ‘evidence’ and ‘qualify statements’.
Participants wanted to see more transparency in their care and support, and seeing their records would ensure this.

Participants expressed a desire to be able to ‘challenge’ what is written about them or their children, such as incorrect or irrelevant information: they want to be able to give their side of the story and a reply function would be of benefit. Some participants would want to change information that they deemed to be incorrect or that they did not want to be on their records. However, not all participants believed that records should be altered by patients, as a complete and accurate ‘untouched’ record should be available.

If you have got access to all those records, medical records, at least you could keep an eye … there has to be transparency and maybe people are going to be, maybe it’s going to force professionals to be a bit more responsible and a bit more and work a bit harder to actually, to be accurate and get the accurate data because it’s going to more transparent it’s going to be more available.

Saving themselves and the NHS resources

Participants were motivated to use PHRs to not only save themselves money and time but also to save the time and resources of the NHS.

When wanting access to paper records, participants have had to pay a fee to do so and they believe that having free access to a PHR would remove this cost.

Participants would save time by not having to visit hospitals and surgeries for test results and information that they could gain from their PHR.

Really not having to go backwards and forwards to the hospital, it saves a heck of a lot of time, so you have got time on your side on that one thing really.

The NHS would also benefit from ‘less appointments and fewer longer appointments for some people’. The sending of information electronically would lessen the impact on clinic time and resources.

Rather than the doctor rushing around – ‘Oh, 2 minutes’ left on the appointment – I’ve got to see the next patient’ – you know, that sort of thing, because that’s what they do, you know. They’re always, like, they’re always looking at the time, because you’ve got 10 minutes per appointment and most of the time the appointments run late. Like last time, recently, I’ve had an appointment for 40 minutes, and I didn’t intentionally have an appointment for 40 minutes, but it just happened, like, and I’m surprised that she didn’t tell me to go away, like, kind of thing … But the thing is, like, she had, like, four people running late, so if I had the opportunity to just write everything down in [the PHR] and she can just see it, rather than me sitting there explaining it and explaining it, she could have easily have seen another four patients rather than spending 40 minutes with me. Not that I’m not grateful, but you know … yeah.

Last year [my son] was having an assessment to be fitted for a new wheelchair, and before the occupational therapist came around, I actually did a video of [my son] when we were out walking in his wheelchair at different angles, so that the occupational therapist would be able to see in terms of the wheelchair, what it was like for size, because [my son] would not understand if a professional came home and said can you just sit in the wheelchair because I
just want to measure you up? That wouldn’t make sense to [my son]. If he gets in the wheelchair, it’s for a walk. So I did the video and when the occupational therapists came around, they had a look at the video and said yes, it’s clear he needs a bigger wheelchair. So it not only saved time for the assessor but most importantly for me, it saved unnecessary stress for [my son].

One participant believed that PHRs would not be time-consuming for health professionals and highlighted that, if clinicians spend less time in the office updating patient notes, there would be more patient contact where information can be directly entered into the record. This would be beneficial in community care settings.

The amount of time I saved by having my son’s [PHR] at the tap of a button ... I don’t know how I would have got through it all without it.

Participants believed that by sharing information electronically through PHRs and having centralised access, they would save themselves and the health professionals time and effort during appointments. It would make healthcare appointments more efficient by not having to wait for records to be ‘sent over’, as well as reducing the time the patient needs to get their story across, which in some cases was quite complex and ‘quite a long story’.

Well for example I recently went for an X-ray and I had to wait a whole week before I saw the GP but if I had been able to access those results and I’ll be able to go and see her and know what to ask her about it but as it is she just said to me, it’s not this or not that and I think we should go forward whereas I would have done some research on all that and gone with my right questions to ask and also I think it would have saved me time because now I feel I’ve got to go back with asking those sorts of questions you know because in the 5 minutes you’re given, you can’t think of everything as you’re being given those results and for me it’s a case of being prepared for what I want to know.

Wanting person-centred care

Being seen ‘as a person’ not a condition, a diagnosis or a number was important to participants, particularly those with social care needs.

I think doing it that way would give it more of the story, so if people do want to go with it, they are seeing you as a human instead of just all these little labels that they like to give you.

They believed that a PHR would provide a holistic ‘lens’ through which professionals could see them.

it’s a different way of seeing what a person’s likes or dislikes or needs might be.

For those with drug and alcohol abuse backgrounds, this holistic lens could ‘reduce the risk of stigma’ through professionals being more informed about the person.

And similar things like ... I think it was the same doctor ... I don’t see her anymore ... going in and me saying ‘you know I haven’t felt this anxious since I’ve stopped drinking’. ‘Oh you sound like a right alchi’. ‘Well actually I am an alcoholic in recovery’. You know, it would break down that ... I felt really bad after that ... you know I thought it was a bit of a sweeping statement but, but reduced the risk of that stigma.
And they always look ... I mean for me personally ... they always look at the negative side of everything. You know I was always branded this bad girl. You know. Still am and actually I'm not a bad girl, you know and then you think about moving away from all of that.

Encompassed within a desire for person-centred care was the need to be involved in decision making and person-centred planning, which participants believed could be supported with PHRs. For example, through sharing information about previous medication history and their personal experiences and wishes, participants could be involved in decision making around their care.

Sort of, like, if they saw from our previous experiences and previous medication and we had access to that and said, ‘Oh, yeah, this worked; this didn’t work’, then we could easily say, ‘Yeah, we want that again, because that worked for us’, or ‘We don’t want that again, ‘because it didn’t work for us’. So having that decision-making power, for us, is quite important.

Parents of children with complex needs felt that the multimedia PHR was an ideal tool to involve their children in their own care and decision making, which is something that had proved difficult in the past due to the non-engaging paper format of reviews and reports.

[My son] would always be invited to his annual review. He would come in to the room, he would stay for 1, maybe 2 minutes and walk out. The environment wasn’t inviting for [my son]. It was a group of people, sitting around a table with lots of papers ... So for me it was more looking at the tool and seeing it was an opportunity for me to be able to involve my son more in his decisions. But initially it was about having a tool where I could store pictures and videos, so I could share my son’s personality and what was important to him.

Parents of children with complex needs also felt that the multimedia PHR would be of benefit in developing and delivering care and support plans at stages such as transitioning between schools or health and social care settings.

I looked at the product and thought that there was scope to use it for person-centred planning and because my son was coming up to his Year 9 annual review, and I knew lots of different people would be coming in to his life, I didn’t think the paper format of everything about my son was going to give those new people a good insight into who he was as a person.

Being able to co-produce health and care plans was also important to those with mental health issues and a complex background (for example, experience of mental ill-health and the criminal justice system) who had not been able to take an active role in their own care. The PHR would provide a way for them and those supporting them to work with professionals and services to produce a person-centred plan.

An element of co-production, because I have to have an element, because up until now really everything has been dictated to me. That is not a two-way conversation and if I want to have a two-way conversation, my side of things has to be voiced and the [PHR] is one way where people that don’t have very much of a voice at some point in their life, are able to have more of a two-way conversation by having their story.
Gaining an additional source of support

Use of a PHR could act as a support mechanism for users in a number of ways. These include users supporting themselves and being supported by others. Participants believed that, if information was monitored on the other end, ‘things could be flagged up’ and acted upon, which would act as a safeguard.

*If a patient wasn’t very good at communicating or had gone off the radar a little bit and were using [the PHR], if their scores did go to the bad side ... then hopefully it would flag up.*

Others believed that the PHR could act as memory aid, for example in those who have dementia, by logging conversations with consultants and reasoning behind decisions and logging important events in the calendar such as appointments. It would also allow the user to write a diary to remember ‘who she is and what’s she’s about’.

*I believe it to be an excellent idea, especially in the world of dementia early onset of Alzheimer’s. Because I would be able to tap into my account online and be able to see what I’ve been doing what my ... what the doctors have said, what my medication is. And then I can always print if off, keep a copy for myself and if any health professional asks me about my health I have it in front of me. I know exactly what’s going on.*

The PHR could also support the patient to organise thoughts and activities for example in those with mental health issues who find this difficult.

*Because I would be able to tap into my account online and be able to see what I’ve been doing what my ... what the doctors have said, what my medication is. And then I can always print if off, keep a copy for myself and if any health professional asks me about my health I have it in front of me. I know exactly what’s going on.*

Participants felt that having access to others who are in their situation or who have had similar experiences would help them to feel more supported and would be a way of gleaning information. This could be via an online forum. For example, one participant said that if she had had access to someone in her position when she was considering surgery for her condition, she would have been better informed.

*I didn’t know anybody with a colostomy. I could have spoken to people online perhaps with ... living with an ileostomy, which I did many years later.*

Participants believed that the multimedia PHR could be used as a training tool, which would not only save time and resources for services but would enable better care for children’s needs in an accessible and engaging way. For example, one participant said that the method for fitting her son with a shin splint could be recorded and then shown to the ‘people who to actually care for him’.

Inability to articulate what they would use PHR for

For some participants who had not experienced using a PHR, primarily those who considered themselves to be ‘healthy’ and therefore did not see a need for a PHR, it was difficult for them to envisage what it would be used for.
8.2.3 What influences people in making a decision to use a PHR?

Trust in clinician

Good relationships with healthcare professionals led to service users engaging with a clinician’s recommendation to use a PHR, as well as an obligation to give it a try. One participant found that having a good relationship with her current healthcare team was an important factor in trying the portal. She does not have ‘a lot of confidence in the medical system’ but she has built confidence and trust in her current team: ‘more than just a doctor–patient relationship … friendship … so yeah I think it made a difference that he recommended it’.

However, those who have poor relations with clinicians and lack trust in them would also be motivated to adopt a PHR, so that they can see what is written about them, take control of their care and avoid going to see the doctor. This was seen in participants who were accessing and having bad experiences with primary care.

> It would increase my confidence, this sounds awful, I’ve no confidence in my GP whatsoever.

> I don’t see my GP unless I really have to, because I know it’s a waste of time.

Prior experiences of healthcare

Participants described both positive and negative prior experiences of healthcare, including limitations in current practice which impacted on their views of PHRs and whether they would adopt it. A number of participants had experienced fragmented care, discontinuity of care and experienced poor communication across services, including those who moved around the country. Due to records not being transferred across services, participants found themselves subjected to repeated re-investigation of conditions and treatments that had already been addressed by previous clinicians.

> Well they don’t have any of that type of information so all the information, when I moved from north Yorkshire down to Lincolnshire, none of that information got passed down effectively, so we had to start the process all over again, getting everything and start talking back through the stuff again and again and again, which made it exacerbate even longer and took the process on quite long.

These issues led to a number of instances where care was delayed or inappropriate care was received by participants, their children and partners, which was ‘stressful’. Some participants said that, clinicians who did not have records to refer to, or ‘did not believe each other’, insisted on reinvestigating and changing treatment to align with what they thought was appropriate at the time or, in some instances, they refused to treat participants until they had consulted the original clinician. Examples of this include one participant whose wife experienced poor mental health and frequently engaged with mental health services. When moving as part of his job, the participant experienced ‘catastrophic’ consequences of such a lack of communication:

> That specific thing was, from my wife’s point of view, quite catastrophic the fact that that information wasn’t passed down. When she was in a secure unit in north Yorkshire she got put on the highest form of antidepressant which was above the normal governing guidelines, the consultant there decided to do it, but when we moved down here, the information didn’t get passed and the consultant in Lincolnshire said it was way too high, took her off it, put her
on something lower which resulted in her unfortunately attempting suicide and then she ended up in another secure unit for quite a long period of time, so that could have had a catastrophic sort of knock-on effect there.

Another participant, who had complex needs as a result of a rare condition, was refused treatment at an emergency department, until the original consultant could be spoken with. This resulted in delayed treatment and the participant experiencing further complications, which she still lives with.

‘Oh, well, we don’t know how to treat this, because you’re different’, and they can’t do anything ... ‘Oh, can’t touch you! Need to call your consultant first’... So recently I dislocated ... well, I locked my knee with my hypermobility, so my muscles went into spasm and it locks, like, backwards in a flexed position, and the A&E consultant refused to manipulate it back because I said, ‘Oh, normally they yank it back in place’, which is to me what they do. Like, I’m on gas and air and as high as a kite. How am I supposed to know how they do it? Like, I’m not with it. And he refused to touch it because of my other complications, and he was just too scared, and actually, if he’d fixed it there and then, I wouldn’t have had the damage that I’ve now got ... so that’s really frustrating.

These participants believed that, if they had had a PHR, their information could have been communicated between services. This would enable continuity of care which in turn would have resulted in them receiving appropriate and timely care. They would therefore be motivated to adopt the PHR.

Experiencing mismanaged care in the past would also influence citizens’ motivation to adopt a PHR. This was the case for one participant who, as a result of such experiences, realised that she needed to ‘take control’ and that PHRs would help her to avoid using the health services and enable her to self-manage:

I have a genetic joint condition, and, because they didn’t know a lot about genes when I was younger, my care was mismanaged, which has reflected on what has happened to me as I’ve got older and I recognised some years ago that if I didn’t take control of my condition, the profession was probably going to kill me [laugh]. [I was] being treated by different consultants at different hospitals and being given medication by different consultants, the same medication with different labels, so I was being over-dosed. And then in an A&E I was accused of trying to commit suicide. So it was at that point I thought I’d better take control. So I became a self-manager before it was fashionable to be a self-manager. I stay away, as far away as I can from the medical profession and I deal with it myself, and this would help me to do that.

PHRs can be used to address limitations of current service provision by facilitating effective information sharing across services, thus improving patient care.

It seems to be no communication between hospitals and doctors. You know they don’t even get the letter from a hospital visit for about 3 months afterwards and a simple record for the person they are dealing with would be able to go in and look up and say oh yeah you went to hospital for so and so and you did such and such and they put you on this or whatever would seem to me to be a very good thing.
It feels like they don’t talk to each other very well. I registered at a new GP surgery a few months back, because I moved home, and I didn’t need an appointment for a couple of months. And when I did go in, they said, ‘We haven’t received anything from your old GP, or from the hospital or anything. We’ve got nothing’.

A centrally held PHR that different professionals and services can access would enable the flow of information and address communication issues, resulting in better service provision and appropriate care for patients.

They need to be able to know what’s wrong with a patient straightaway. If I’d gone into that doctors’ surgery feeling extremely unwell and barely able to walk and I’d collapsed on the floor, they wouldn’t have had a clue what was wrong with me, because they hadn’t got any of my details … So, in that respect, if I’d taken in an iPad, or if I’d logged onto their computer, or if I’d printed off the documents from my PHR and said, ‘Look, this is what’s been agreed’, then they would have been much better informed. But it felt like they didn’t know what to discuss with me. There was no communication.

Patient activation levels

Levels of patient activation would have an influence on whether people would adopt a PHR. Those people who were more engaged with and more able to self-manage (those who are more ‘activated’) would be more likely to engage with PHRs than those who are less activated.

But the ownership thing, I think that’s one thing that, you know, that we all feel that we own our own condition, our problems, and want to have that ownership, so we want to be proactive about it, and this provides a very good platform for us to do that.

I would say that it’s somebody that’s interested. I think there’s a couple of things. You have to be interested in your condition. You have to want to understand everything, what’s going to you, so I think that’s important because some people bury their head and say ‘I don’t want to know, I’m not going to go down that route, others say okay let’s find out what we can do. What does this involve?

It had just been interest and being motivated to do so, because that’s the sort of person I am.

One participant who had bad prior experiences with the health service was actively self-managing to avoid putting the responsibility for her care on the health service. For this reason, this participant was very interested in adopting a PHR.

Those who are less activated may require additional support to become more engaged and motivated to self-manage before they adopt a PHR.

Exposure to PHRs

Those who had previously been exposed to PHRs, for example to monitor blood pressure, saw the benefits of using them and were therefore more open to using other PHRs or expanding the use of the one they had for more functions and areas of health and wellbeing.

Family encouragement

Family members played a key role in whether the PHR was adopted. Participants described instances where at first they were resistant to using it, but they were then convinced by others. For example,
one participant who was initially introduced to the PHR to monitor his cancer did not want to use it and wanted his care contact to remain the same. His wife encouraged him to use the PHR not only for the convenience of not visiting the hospital but also to give up appointment time that could be given to someone in greater need. This participant took up the PHR:

Err well I don’t like technology, especially computers themselves, I’m a bit reluctant to do it really, but then my wife said to me well if you keep going to the hospital, you’ve got to get there and you don’t like going to hospital and you’ve got to hang around possibly, not that I did have long to wait anyway but she said you’re doing somebody else out of an appointment which is necessary for them and not for you, so and that’s why I went on to the computer.

8.2.4 Barriers to adoption

Lack of awareness and understanding

Lack of awareness and understanding of the term ‘personal health record’ was prevalent among those who had not experienced PHRs. Most had not heard of it before and were not aware that people could access PHRs. They displayed uncertainty about what having a PHR means and they lacked understanding of what it could mean for them.

Personally haven’t heard of it as in a normal part of my everyday life.

I suppose I found the title slightly misleading, because of course you used the word record, which implies, to me, history, rather than being a kind of interactive er, or well, a more, I don’t mean immediately interactive, but it will allow actions to take place, plus also message and receive, which is, which is more interactive than I would have guessed from the title of records.

Those who had experience of using PHRs reported healthcare professionals not being aware of what a PHR was and what it could do. This was frustrating to users who valued using their PHRs and recognised the benefits, and it was distressing to those who relied on the PHR. Examples include a parent whose health nurse did now know what his child’s PHR was and, as the participant gathered, had no desire to find out what it was either. This was frustrating to the parent, who preferred to see objective information about his child logged against graphs and parameters in electronic format.

Other participants had met resistance from healthcare professionals who they felt did not have the time and inclination to learn about the patient’s PHR because they saw it ‘as a flash in the pan’. Others found their own use of the records was inhibited by health and care professionals; for example, one user who wanted and felt that he needed his care plan to be uploaded to his PHR found himself without access because his care coordinator did not upload it:

The only thing I would say is my care coordinator was asked three or four times to upload my care plan and that was never done.
Health service issues
Participants anticipated resistance from healthcare professionals in the adoption and use of PHRs. This would be due to already ‘high workloads’, being ‘too busy’ and participants ‘have no confidence that it’s going to work’. They would want different services, such as GP practices and hospitals being able to share/communicate to ‘transfer it onto their system’: ‘a key requirement for us is that information can move with you’. Participants doubt that systems could be integrated, as different localities have different systems: ‘I mean in the future one would hope that they will talk to each other’.

Participants highlighted that introducing PHRs may increase doctors’ workload by extending appointment time and frequency due to patients becoming over anxious about what they see in records or not understanding it and wanting clarification from their doctors.

Some participants anticipated resistance from healthcare professionals who would not want to relinquish control. Should PHRs become a reality, they would perform a form of ‘role reversal’ where healthcare professionals are less relied on to provide information and keep records updated; they would struggle with letting go and passing ownership and control to the patients and would question the authenticity and validity of the information provided.

If it’s been written by the parents, it’s obviously rubbish and we don’t need to read it.

Denied access to records
There was a sense of bureaucracy and red tape with access to records, even though participants see it as their ‘right to access and view their own records’. Participants anticipate resistance to them being able to access records and to view what is written about them, and some have experienced being denied access.

I think there’s a lot of bureaucracy with our health records. I think even when ... on occasions when you have asked about the health records, it’s very much like: ‘No, you can’t access your health records. It’s all confidential and you’re not allowed to know about yourself.’ And it’s just like: ‘Well, it’s about me. I should have the right to know about what’s going on with me.’

Data security
Data security was a consideration for many, but not all, participants. Of those for whom it was a consideration, the consequence of a data security breach was an issue. Participants had a lack of trust in the NHS being capable of keeping their records safe and secure, mainly as a result of being exposed to negative media stories about data security but also a result of having bad prior experiences with their data not being kept safe as a result of ‘system integrity and human error’, which meant that they remained sceptical.

There was another BBC programme where they took literally teenagers, 19–20-year-olds, and they took them and asked them to hack into all these really top sites, and they just went in 20 minutes.

It’s the whole security thing, who has access, you know people can upload stuff, can they just kind of, you know can somebody just take it away and I don’t feel confident about some of these things.
It’s not just the government, but large corporations to sensitively and carefully handle data ... I would be worried about my sexual health information being digitised and shared ... I just wonder where that stuff goes.

How safe is it for being hacked on a personal computer? Having just had my personal computer hacked. Whether or not they would, the hackers would be interested in my medical records. But they might be if they’re being paid by the drugs companies or something, yeah, so that might be a bit of a concern.

A participant recalled when their records were merged with someone who has the same name, resulting in each being able to see the other’s information; this experience had put them off using PHRs.

When my records got amalgamated with somebody who had just one letter different in her Christian name and they merged us, we have a totally different date of birth, address and it just, I suppose electronic stuff is only as good as the operators or whatever so that’s not a big security, well I suppose it is, I mean I had her address and everything, you know to hand then but I mean it’s, it’s open to sort of a little bit of, not necessarily abuse, intentional abuse, but that’s just mistakes, it’s human error and it probably doesn’t happen every day but ...

Other participants, particularly those with complex histories, found it hard to trust people and systems. As a result of their past experiences and negative media stories, these participants were very cautious about the security around PHRs as well as being monitored through surveillance.

Coming from like where we’ve come from, you know we find it very hard to trust people to start with ... whatever we’ve got now or whatever somebody knows about us, we want that kept safe.

It’s just a collation of data against you ... we’ve already got eyes in the sky all over the gaff, do you know what I mean, so what do they want? Do they want just to say right let’s microchip us and let’s go?

Everything on the news saying ‘such and such has been hacked’.

The big companies that pay a lot ... million pounds in security ... they can’t keep it safe.

Other participants voiced concerns over not just the NHS but also schools and other organisations holding their information safely. Parent participants were reluctant, for example, to share medical information with schools because they felt that schools had poor security in place and they had little faith that their child’s data would be held safely and securely. Parents also highlighted situations where, because of security concerns, schools were not open to PHRs, which resulted in parents not being able to use this tool and the child not receiving appropriate support.

However, data security is not always a barrier to use; some participants were aware of data security issues but accept that appropriate measures are in place and, because of these measures, will use PHRs. This acceptance is more pronounced in those who use PHRs as, having experienced the safeguarding and security around the PHR, they are more comfortable with it.
And that measures were in place, for example, the, you know, all the usual passwords and things. And that the information was in a trusted, secure network, which would mean that it wasn’t going to go missing or get sold on, or anything like that, so I felt I was happy to link my own medical record with this PHR, so that I was able to go into it myself, and they could go into it. So, I had to authorise my team to be able to view what I was saying and I trusted my clinicians to know what they were talking about … . It felt very much like they took confidentiality of the documentation very seriously.

Plus, my God, I go in my GPs and I see the amount of security they have even to get onto their computer system. They’ve got things, they’ve got cards that go in, they’ve got passwords. No system is unbreakable but it was at least of the level of my local bank, and so for me I felt okay about it.

A little worried about the security but that seems fine.

Views and fears over data security also depended on the life stage a participant may be at; for example, a participant who had finished her working career was less worried about other people finding out about her information. She was aware of current worries over security of health data but, having been ‘treated with respect’ and coming from a time when ‘patient confidentiality was not at all an issue’, she has faith in the system.

There’s no one to be affected by what might come out about me … so I don’t worry about my records … and being at the end of my working career, for example, I don’t have to worry about employers finding out anything … if you can trust internet banking, then you would hope that you could trust a National Health Service portal.

Data use

Related to data security was the concern over data being used for purposes other than healthcare. This concern was raised by those who do not use PHRs, but it was not raised as an issue by PHR users. Participants feared others such as insurance companies or drug companies gaining access to their information, and it being released or ‘sold’ from the PHR to such companies.

Well today, this morning on BBC News they were talking about health data and how secure is it, and are the insurance companies in the future … So they’re questioning, okay, all this big data is being gathered … But in future what security is there that the insurance companies are not going take this data when you apply for insurance for your house, your car, whatever, health …

I’m also worried that drug companies might be able to access, or people that could be a part of a, you know being able to use they’re drugs and that’s another worry for me.

And I know certainly my GP sells anonymised information to God only knows who she sells it to, I’ve no idea, and that does make me feel uncomfortable … That they have to ask my consent to do anything with my information, other than use it for my care.

But what they were saying is this information is then recorded and it is recorded in an official record, and you’re inputting that information and then what happens if you make a mistake or how can that information be used in the future? Whether it’s for job applications or whether it’s for insurance or mortgages or whatever.
In order to negate these security and data use barriers, participants need to build trust and familiarity through experience of using such systems, perhaps with less sensitive health issues first so that they ‘feel comfortable that the information is secure’ before extending their use of the PHR. Participants believe that this would lead to a ‘calculated risk’ in terms of comparing security concerns with convenience (ie with making their life easier).

*It’s got to be very, very, very confidentially.*

In order for people to trust these systems, the ‘NHS or provider will need to prove that they have the highest level of security’. But it must also retain easy access and usability:

*I would expect to have robust security but easy access.*

Having alerts when someone accesses the record, with a log of who, when and what they do, would also help to mitigate these concerns.

*You know ... and I wouldn’t have ... having a link sent to my phone to see if that was ... you know someone was trying to log in. You know I had to then go on and sort it out but I think something like that maybe would build people’s trust and confidence.*

Having a choice about whether or not to share their record and which aspects of their record was an important point for participants. Also, participants thought that having an electronic record provided additional security for them to control what gets shared; participants suggested having different ‘zones’ and ‘levels of security’ for what they deemed to be ‘sensitive’ and ‘non-sensitive’ information. For example, sensitive information was more likely to be related to mental health and sexual health, and non-sensitive information would be related to allergies, height and blood pressure results.

*I wouldn’t want my weight and exercise and general health stuff next to my deepest darkest secrets. They’ve got to be separate for me, otherwise I wouldn’t log it.*

*I don’t care who sees my thyroid data or my blood pressure data.*

Having control over their own record, including what is shared and with whom, is a key factor for many participants when making the decision to adopt a PHR. Without this control, people are unlikely to adopt a PHR. Participants were uncertain about who owned the records and therefore who had responsibility for keeping the records safe. They also demonstrated uncertainty around permissions settings within a PHR (ie who would give permission for access) and they highlighted how this could become complicated and difficult to navigate.

**Anxiety and not wanting to see records**

Not all participants would want to see their records, and they envisage that others would feel the same way. They raised concerns over users feeling undue anxiety and distress, and some questioned whether participants should indeed have access to their records. Accessing records could result in users accessing distressing or ‘overwhelming’ information about themselves and their conditions,
and could result in them becoming anxious and worried. This could arise as a result of users not being in a position to emotionally handle the information that the PHR provided. For example, participants spoke of mothers and other relatives who ‘probably couldn’t handle what the records say’. Others could take the information that they access and search the internet and other sources for more information: becoming a ‘Google doctor’ and ‘self-diagnosing’ and self-treating inappropriately. This could also cause undue anxiety because participants are not accessing appropriate services to interpret and discuss information such as test results and symptoms.

*I can see the problem that if you’re not careful you end up by being your own doctor and you look at it and think [a particular result] was 3.8 last year and now it’s 3.6. What does that mean and it might mean a lot and it might mean absolutely nothing. It might be within the, you know, the variation you expect anyway so you might sort of frighten yourself for nothing.*

Well there’s lots of people who self-diagnose themselves with all sorts of things and then worry themselves to death because they go through all sorts of symptoms. They go through lists and say I’ve got that, got that, got that. Oh that means I’ve this and that means and actually yes, it’s maybe nothing to do with and there’s an element in which you can worry yourself unnecessarily when actually there may be for exactly the set of symptoms that you think that you’ve got, there may be a perfectly much less worrying explanation.

You’ve only got to Google something on the internet haven’t you to discover that you’ve got a brain tumour.

*Some people might be too anxious and they’ll be checking everything and has the doctor really done that and they’re checking against Google ... I can see people taking the diagnosis, looking at it, putting it into Google, see what symptoms come up, [and thinking]: ‘is the doctor right or is Google right’, ‘am I missing out on the right treatment?’*

Other participants were concerned about those who use medical devices attached to PHRs. They felt that people could become overly concerned and pre-occupied with measuring things and, again, this could result in undue anxiety.

*Concern sometimes though is that if you are constantly taking your blood pressure and constantly recording it.*

Participants highlighted the risk of ‘anchoring’, whereby users misinterpret new conditions as a result of viewing data on existing or older conditions and they do not seek appropriate help or they become anxious.

*There’s always a risk of anchoring. So because you know what has happened to you in the past and, you know, you know too much about it, and when you do experience something new, but you would have anchored it from your previous experience that, ‘Oh, you know, it could just have been because of that that I’ve done’, because you don’t understand it so well, rather than seeing it from a new perspective, an independent perspective, that, ‘Oh, you know, maybe this could be a new symptom I’ve experienced, or the cancer might have come back’, or like, you know, things that may not necessarily relate to the past experience. There’s a risk that you assume that it’s the same as previously, and you just ignored it, so that the risk of anchoring would be there by knowing too much ...*
Those participants with complex histories would prefer not to see records for fear of ‘opening up wounds’, which could result in further upset and anxiousness and worry in users.

> to access my records and read what’s written about me. I think if I read that I’d probably be disturbed by some stuff and I would just think about that … the past and it would open more wounds and memories of stuff because I really don’t want to know what’s written about me.

However, some participants acknowledged these issues and concerns and saw them as barriers to using PHRS, but they felt that it was important to remain informed because it is ‘important to know what to expect and where you’re going’.

**Replacement of a face-to-face service**

Participants feared that the introduction of PHRs or ‘face-time’ would replace face-to-face consultations and support from health and social care services. While they welcomed the convenience of not having to visit the GP surgery or hospital to communicate with their doctors and/or received test results, they strongly believed that a ‘human’ element of care should be retained. One participant praised the ‘very rapid communication … it’s terrific’; however they felt that it cannot replace the ‘one-to-one conversation’ that would allow more in-depth discussion and a dialogue that may facilitate enhanced understanding. He felt that the patient would become ‘detached from the clinician’, and vice versa. This view was influenced by a positive relationship that the participant had with one of his consultants following surgery, where he felt that he was treated as a person and not ‘as a patient with a symptom’.

Patients should, if they choose to, still be able to make an appointment to see their doctor.

> Would want to have the periodic opportunity to say yes I would actually like an appointment with the consultant … especially if I could see the same person … because I’d have a conversation as opposed to an email.

> Because to be honest you can do things online, sometimes you need to have a face-to-face consultation with somebody rather than sending them an email or whatever that if you had concerns and they can read your body language and you can read theirs.

**Social justice**

Participants were concerned that having PHRs in place may mean that some people have disadvantaged access to health and social care. These would include people who are not computer literate, people who are less wealthy and do not have access to their own personal computers, as well as people who are less articulate and literate with the English language. Participants also highlighted trust issues that first-generation ethnic minorities have with technology and sharing information.

> In [my area] we have a very, very, very high Asian, Romanian, Polish, and a lot of them are not computer literate at all and I’ve been dealing with this, as I said, for 4 years and it’s very, very difficult to get them, perhaps they don’t want to do it. They’ve all got mobile phones but they do not trust this sort of system so they won’t do it in that respect. Whether they could
do it or not, they won’t do it because they think you could look at my records, you could look at my records even though you know in theory they can’t do it but the Asian population is very much against it.

Participants feared that a widespread introduction of PHRs would result in a two-tier system with, so-called ‘first-class citizens’, who are more computer literate and comfortable with technology and who own a personal computer, being able to articulate themselves through these means. This cohort would have a greater advantage to access better care and treatment through the use of PHRs. In contrast, ‘second-class citizens’ would be those who are less able to communicate and manage their health and wellbeing through these means and would therefore miss out on the best care and support. It was also felt that clinicians who support PHRs would favour people who are more likely to fall into the first-class citizen group.

We’ve all got tablets and smartphones and that. I haven’t even got a mobile phone you see. I’m the archetypal Luddite. I’m a sort of carer for my mum who’s in her late 80s now. She doesn’t even know what the internet is. The thing that concerns me perhaps wrongly or rightly is that I can see, if you go down that road, you’re going to end up with first- and second-class patients. You’ve got the patients that have got access on their smartphones to all this stuff. You’ve got people like me who haven’t got a mobile phone but I mean I go onto the internet via the library and people like my mum who haven’t got a clue what the internet is, so with the best will in the world I can see a modern young doctor is going to think this 88-year-old lady, I can’t do anything through the internet with her because she’s not on, she doesn’t understand it, well we’ll sort of push that off to one side you know. Maybe I’m wrong to think that but that is my concern.

those less wealthy, may not have access to personal computer and would have to access records through a public computer which would put people off using the PHRs.

It’s a political point is getting to a point where only the very sophisticated user can take advantage of it and then another generalisation the more sophisticated user is likely to be the individual who’s got all the advantages, who is advantaged anyway.

Participants also worried that access to PHRs would become chargeable to the user in the future, which contributed further to worries that only those who could ‘afford’ it would access the record.

therefore those who have got the ability to use and the ability to pay get the perceived advantages.

it would only be something that potentially the wealthy or the abled would be able to access.

There was also concern that some people, such as older people, could become isolated as a result of their care being managed electronically.

It also adds to the older people’s isolation.

Access to records by others
Whereas some people are happy and eager to share information with clinicians, family members, partners, spouses and carers, there are others who worry about such people having access to their
information and would not want to share their records. Examples include younger people who have had cancer and experienced mental health issues, and who worry about family interference and power of attorney concerns.

Yeah I definitely wouldn’t want any family members ever being able to access it ... that could be an issue when you’re a vulnerable young person with cancer ... therefore it becomes sort of like, power of attorney type things, and I wouldn’t want them knowing that. My mum has no clue over my mental health. She never will ... if you’re like from particular families where they’re just like, ‘You’re my daughter I’m entitled to know’, they don’t really care about you and you don’t really want them to know, so that’s another reason why I’d really like, I’d rather have stuff electronic, because I know there’s that security with your family not opening your letters or you post being lost and random housemates opening it and being ‘oh, what’s going on here? I didn’t know that’.

This concern highlighted a contention between what parents would want and what young people would want, which may cause conflict and act as a barrier to both groups adopting the PHR. Parents were keen to have access to their children’s records and, in some instances, they have attempted to work around processes that were put in place to protect access to the records. There was also discussion around the age that people should have control and responsibility for their own records, with younger people stating 16 years old or the age when the young person is diagnosed, and parents stating 18 years old (when they become an adult).

Other young people would not want their health professionals to have access to all of their records and would only want to share certain aspects of their history and not others such as mental health.

I wouldn’t have wanted all health professionals to be able to access that element [referring to mental health history].

Again there was contention between some participants who believed that only the patient or user should have access to their health records and others who felt that it is important and should be mandatory to have shared access with at least one healthcare professional.

Further examples of problems arising from access to records by others include those who have been involved in domestic abuse or who have controlling partners or family members. It was felt that access to records could result in information being used maliciously or to control the patient.

Concerns were raised more around access to ‘sensitive information’ such as mental or sexual health information; one participant particularly highlighted that he would not want his partner to see his sexual health history.

Accessibility
PHRs need to be easy to access and understand in terms of the content, layout and language that they use. Participants were concerned that PHRs should be written in ‘plain English’ and not contain any ‘jargon or acronyms’. Participants have a lot of experience of healthcare professionals using medicalised language which can result in patients not being able to understand what they are being
told, and they state that they would not use PHRs if they used such language. They also highlighted that people whose first language was not English would also struggle to read the records. Those who have experienced using PHRs emphasise the need for a simple layout, with one participant recommending a tile layout, which his newer PHR has.

8.2.5 Benefits from PHRs and key functions

This section presents the findings in relation to benefits from PHRs as reported by those who have experience of using PHRs.

Participants who had experienced using the multimedia PHRs spoke very positively about them and described the benefits that they reaped because the record revolutionised the way they manage their own and their children’s conditions and care/support.

I was asked to go on a pilot for [a PHR] and I have done and I haven’t looked back.

Managing and monitoring health and wellbeing

Being able to manage and monitor health and wellbeing was a major benefit for participants who felt that the PHR enabled them to effectively self-manage.

Participants were able to identify and track triggers over time. This allowed them to identify negative behaviours through the use of wellbeing monitoring tools such as mood scales and to correlate the negative behaviours with other measures such as a log of alcohol intake. These monitoring tools enabled participants to change behaviours and reduce their negative impact. One participant had been using his PHR primarily to record and monitor his moods each day and to identify what he calls ‘trends’ and ‘triggers’; for example:

How I was feeling from day to day, whether I was feeling better, worse than the day before and I could see what some of the triggers were which tripped off my moods.

This allowed him to have an enhanced awareness of his condition and how to manage it. The participant described his PHR as:

A very, very, very good system and it’s a way of helping people ... to monitor their depression, their anxiety their sleep, weight gain, blood pressure, alcohol intake or anything they want.

For example, he used his PHR to record his alcohol intake and he was able to compare his intake against what was healthy:

I was finding things stressful, I was tending to drink a lot so I was also like using it to monitor my alcohol intake and found my alcohol intake was way up compared to where it should have been ... what I did then I printed off a lot of new information, like the graphs and that, I took it to my doctor and I had a chat with my doctor and I said this is, this is my online health record, this is how I am feeling. So it was good to have something I could print off which I had done myself as a record to show him how I was actually feeling. He responded by referring
me for CBT [cognitive behavioural therapy] counselling which I found useful and he also referred me to other activities like social inclusion which was getting me out of the house to make me feel better.

Participants were able to track and share their progress and achievements with their care team, to help maintain wellbeing. Participants also valued being able to add motivational quotes and other inspirational and uplifting material such as photos, videos and music.

One participant reported using the multimedia PHR as a self-reflection tool, enabling self-management through reminders about triggers and what to do to avoid them or to manage the triggers if they occur. He also values using the multimedia PHR as an advocacy tool to tell his story, not only for himself but for others, and he has shared it with a number of people including his doctor, his GP and his workplace manager and occupational health department.

Triggers? Yes, like one of my triggers as I said was at the time I was getting a lot of correspondence from the Department for Work and Pensions and I was finding that really overwhelming but it was put on my care plan that if I should get anything from them, that I go to see a benefits adviser who works for Lambeth who will deal with it for me to ease the strain.

Convenience
Participants who used medical devices linked to their PHR found that logging and monitoring data was easier and more convenient, which they valued.

easier ... more portable ... is attached to the internet, so the readings go, obviously are registered, collated and sent to my doctor. So, it's very easy when I wake up in the morning, before I go to sleep at night to take my blood pressure and then fold it all up and put it in its box, it's extremely portable ... I save it and it's stored, and then it goes to me, I sent it to my doctor by email. I just press a button, it's all on the little app, so it's the combination of the app and the fact that it's recorded ... makes me like the new one.

Expediency
Participants welcomed the convenience of having access to electronic records. By having quicker access to test results and information about their condition, they were less anxious and stressed and they felt more in control and able to better manage their conditions. They liked ‘having the ability to have information at the touch of my finger tips and be able to use it’:

And you get a fast response to it, rather than waiting weeks and weeks for your simple question being answered by somebody.

The fact that I can use it and it is there has lowered my levels of stress about my condition .... I think that it has made it more timely, in particular, and for me that's a big issue. Timeliness has been something I would ... it's – my level of anxiety about my condition is reduced when I am able to sort things out and quickly.
Up-to-date information
To receive the best quality of care, participants believe that their health and care records need to be up to date. Those who have experienced using a PHR found that the electronic, easily accessible and flexible nature of the PHR allowed this to happen.

And the [PHR] is updateable all the time. I’m always adding things to it, especially [my son’s] achievements and it’s just a click of a button. You don’t have to wait around for the annual review or the next termly review for it to be updated on paper. So it’s here, it’s now, it’s present.

I think the fact that it’s an electronic version means it’s easier to update and it’s easier to keep doing it than the written plan because I find things change quite often.

Recording and celebrating progress
For participants who accessed social care or who had children with complex needs, the PHR was an important tool in recording, collecting, showing and celebrating progress. It was felt that the PHR should not only record negatives such as someone’s challenges or what they cannot do. For example, the multimedia electronic facilities afforded by the PHR enabled positives to be shared, including videos of a child reaching a milestone or achieving something that they no longer required support for.

Reports, documents and paperwork paint such a dark picture. Nowhere on a statement or an IEP [individual education programme] plan will it have what [my son] likes, what he enjoys, his achievements – it’s very sort of, he can’t do this, he can’t do that or he’s um ... wanting to ... that’s the next stage, that’s the next target for him but through the [PHR] and the videos and the input that us as parents and carers want to share with professionals and other people about our children, we show them the positive sides. That gets neglected in paperwork. As I said, we are showing the achievements and the successes so it’s very positive. Yes, it has to have some negative stuff on there, especially if it’s with regards to teaching or trying to educate people as to [my son’s] communication and what not to do, definitely not what to do with him because as [someone] said, he can feed himself but nowhere on a piece of paper will it say, under [my son’s] independent skills, will it say, oh he can feed himself because I want to show videos of yes he can do it, but he still needs the help and support. But the help and support isn’t written down on a bit of paper and can get overlooked.

However, in contrast, parents of ‘normally progressing children’ noted that they would only use the PHR for recording things outside of the norm, such as illness, and they would not use the PHR to record and log normal developmental stages and milestones. For example, a child’s first step would not be entered onto the PHR of these parents, but parents of children with complex needs would add their child’s first step to the record.

It is a health record and I don’t know that it’s necessary to have space to put those sorts of things (photos of milestone achievements). Now that may be different if you’ve got a child who has a bit of a developmental delay as you may have waited for years for them to crawl or to take a step in which case, actually, that’s probably significant from a health point of view.
Taking control of health
Through having access to their information and being able to add information to their records, participants feel more in control of their condition and care.

*I feel like I’ve got more control over my care, my medication. I’ve got a lot more control than before because before things were being written down just by my GP, my care coordinator and I wasn’t really able to put my own view on it but now I can go online every day, I can put in how I’m feeling, how much sleep I’ve had so yes, I feel it has made a difference.*

Others valued being able to view, track and monitor test results over time and felt that they could interpret results and reflect on whether they needed to seek assistance from their doctor. For example, one participant described seeing and being aware of ‘blips’ in her test results. Through checking her records, she was able to see that this had happened before without negative consequences and she therefore felt more in control.

*And then I try and work out: is it because, when I get to the office, I’ve got something tricky to do so I’m thinking about that? Or, if I’ve got a long difficult day, is it, you know? I’m trying to work out in my own head what is, what causes any blips there are … I know what spikes me … and then I just try to calm myself and talk myself out of it.*

Being able to view and monitor records also allowed participants to be prompted to seek out medical care; for example, through measuring and monitoring their own blood pressure one participant realised that their blood pressure was going up and therefore sought medical assistance.

Supporting communication with health and social care services
Participants reported feeling an enhanced confidence to engage with healthcare professionals and more accessible services. This was facilitated through activities such as messaging, asking questions and receiving responses.

*It’s [improved healthcare] been mainly because of the way I can communicate with my team, and the information I get out of it, but I would have been able to do both of those things without it. It’s just it was easier to do it through it [the PHR].*

Communication between participants and healthcare professionals was facilitated through daily logs of symptoms and health behaviours. For example, one participant brought a printout of his recorded daily alcohol intake and mood levels to a GP appointment. He was keen to use the record as validation of how he was feeling and what he was reporting to the doctors, as he believed that the doctor would be more receptive to this ‘concrete evidence’. He felt more prepared for his appointments and he felt that he had everything he ‘needed to back up my case with my GP’.

Facilitating better and more appropriate care and support
Having access to what is written in the PHR would also facilitate better care and access to services for participants’ children, particularly when dealing with new or additional healthcare professionals and providers. In some cases, the participants have struggled to provide ‘evidence’ of what previous
healthcare professionals have said, which can result in delayed or lower quality treatment for their children. Participants felt that having the record that they could login to and show to healthcare professionals would not only facilitate confidence in the health professionals that what the parent is saying is correct but would also ensure that appropriate care and access to services was provided for their children.

We ... [my son] got discharged from Great Ormond Street in February because he was 18 in May. Prior to that, [my son] had appointments once a year following his surgery. [My son] had about 10 years of surgeries at Great Ormond Street, and his last surgery he had when he was 11. So we had yearly check-ups on his hips and his walking etcetera. And since having the [multimedia PHR], what I did was take videos of [my son] walking with his ankle ... which are splints he uses on both feet and videos of [my son] walking without them because this is what the consultant was interested in. We only had one appointment, one opportunity for him to see [my son]. So if we got there and [my son] had been waiting too long or was upset and refused to walk, the consultant would not have seen how [my son] was doing. So we always had a backup plan with the [multimedia PHR]. So we had those up-to-date videos on there.

One participant used his PHR as a ‘sort of monitoring process where you can actually observe your moods over a period of time and I was thinking possibly that I might be able to optimise the amount of Lithium I’m taking, which I think I have done now’. In line with this, he used his PHR to record his medication and complete the mood scales, and through this he could observe the effect that the medication had on his ‘mental state’. The participant felt that he has more control over his medication and care. He also logged his blood pressure and made notes of anything ‘noteworthy ... arguments at the bus stop ... buying too many DVDs from Amazon’, which are all signs of mania. He usually entered information on a weekly basis with the support of his healthcare professional, but he had also accessed the PHR at home.

Videos within the PHR can also act as instructional tools; for example, demonstrating how to properly fit leg splints or how to change dressings. This enables people at the school of children with complex care needs to perform this task, which removes the need for physiotherapists to visit the school.

Nobody is waiting for visiting physiotherapists. We’re not taking up more professional time, because the information they need is all on the [multimedia PHR].

One participant reported receiving therapeutic benefit from using a PHR to plan and execute his care plan, including reminders for mindfulness and being able to reflect on his past and current experiences and state.

It was therapeutic. I wouldn’t have said whether it’s intended to be. I was deriving some therapeutic benefits whereas it’s only supposed to be measuring.

Creating a better working environment
A number of participants who work found that using their PHR to communicate their ‘journey’, their conditions and their needs helped create a better working environment. Through understanding the
participant’s needs, their colleagues were more accommodating and the participant was more able to continue to work. For example, one participant showed their multimedia PHR to their manager, which explained that being asked ‘are you ok?’ was distressing for them, and so their manager ceased to do this.

I’ve shared it with people at work and my deputy manager has a copy of my thing.

Realising person centeredness
Participants benefitted from having a PHR because it enabled person-centred care, through assisting with decision making and allowing the user to be seen as a person.

The multimedia functionality of the PHR enabled participants to use videos to show professionals the whole person: not just how the person may appear in a brief meeting or paper record but as they actually are. This was important to parents of children with complex needs, as they were able to show their child’s progress through videos and photos. They were also able to ensure that their children receive the correct support, as well as facilitating a more engaged response from professionals and services.

Yes, it’s crucial really because sometimes professionals and services can put children and young people with disabilities into boxes. So if you have a visual impairment, you will like X. If you have cerebral palsy, you will like Y. So they’re not really looking at the person as an individual. Also, for our situation, our son has quite complex needs and if you just read all his medical files and his lists of disabilities, it’s a very dark picture and you actually can very, very easily under estimate him. And without really understanding, not only where he needs support, but knowing what he can do, because if you don’t fully understand what somebody can do, you can fully disable them. For example, [my son] can drink out of a cup without support. But like anybody else, we can all learn to be lazy. One example I give is my husband puts the bins out each week for the dustbin men. But I know if I start doing it, that will become my job and he’ll learn to be lazy because I will do it for him. So young people and children with disabilities, they’re just like us. So if people are over supporting [my son], he would allow that and that would take away his independence. So it’s about understanding the importance for [my son] to be able to achieve and when you can see clips of [my son] doing certain things for himself and smiling and being happy, you can see it’s really important for him and that’s part of his personality. He enjoys achieving things and being able to do something for himself. Whereas on a piece of paper, you will only get the list of things he cannot do. By having videos, then for us, we feel that we have a better chance that he will be supported how he wants to be supported.

Because it’s not just about having everything that’s related to education and health and social care, it’s also about all the fun things and the days out that we do and the family times we have, having all that information as well on the [multimedia PHR]. It also makes [my son] not just this person with a disability, but it shows him as a son, a brother, a grandson, a friend and so people who see it then, they see him that way. They don’t see him as an individual. They see him as part of a family.

Reducing the need for repetition
Use of a PHR would remove the need for constant repetition: ‘I would like to be able to go to an appointment and not have to go through everything with [my daughter] sat next to me’. Another
participant said it would be: ‘less stressful … not constantly going over and over and over stuff’. It could also help to facilitate health and care professionals’ understanding of the child and their condition; for example, having information before an appointment could lead to improved and more efficient appointments, which would be especially beneficial considering the ‘short appointment times’. Participants saw value in the potential to use PHRs primarily to stop ‘having to go through everything all over again … they don’t have to keep telling a story time after time after time with different agencies’. The reasons for this were twofold; firstly it would make healthcare appointments more efficient by not having to wait for records to be ‘sent over’ and by reducing the time the patient needs to get their story across, which in some cases was quite complex and ‘quite a long story’. Secondly, having to repeat their ‘story’ was difficult, which could cause ‘anxiety problems when you’re trying to like bury them and move on from that’; ‘having to go through everything all over again … sometimes it’s not good, it’s just like opening up old wounds constantly. Whereas if it’s all there and they can have immediate access to it, it’s a lot better I think’.

[My son] has autism so he might not feel comfortable. That should be flagged up just so the doctor knows that ok [my son] is going to have trouble communicating or he is going to be fidgety, so he [the doctor] will be prepared … [and will] understand why [my son] is going to behave badly.

Participants said that having to constantly repeat themselves can be ‘depressing’. Having to repeat what their child cannot do is difficult, and a multimedia PHR would not only remove the repetition but would also allow a focus on the positives and allow parents to demonstrate these to professionals.

One of the values of this kind of thing is so that we are not repeating the same information time and time and time and time again, which is what we have to do … and with a complex needs child, you spend a lot of time doing that and it’s actually very depressing … there’s a mental health issue there because you’re always explaining what your child can’t do.

Realising empowerment
The participants were empowered simply by having access to their own records:

And I know that I have the right to view them [the health records], so to be able to have them automatically uploaded when they’re created felt empowering.

Participants also felt empowered as a result of being able to provide ‘evidence’. One participant recalled using a graphical representation of results from mood scales that could be correlated with medication adjustments, which he could use to enable a discussion with his doctor. The participant had sent these graphs to his doctor, to discuss at his appointment. This was very empowering, as the participant felt he had ‘concrete evidence’ to show to the GP and he negotiated his treatment which went against the psychiatrist’s prescribed treatment.

Parents of children with complex needs reported their children being empowered to be more involved in their reviews and decisions about care and support. One participant described how her
son was able to show videos that demonstrated how he communicates, thereby facilitating understanding of his needs among his healthcare professionals.

Since his Year 9 review, [my son] has been present at every single meeting that’s about him and he shows the relevant parts of his [multimedia PHR]. He enjoys the technology. He does need support, but he’s able to participate and show various clips and what we try and focus on is, we look at what is the purpose of this meeting? Now [my son] with the new SEN [special educational needs] reforms has an education, health and care plan. So outcomes are ... for [my son]. So what we do in the meeting is show video clips with regards to those outcomes, showing [my son’s] progress, so everyone can be really clear, has [my son] achieved this outcome or is he still working on it? [My son] is going to present some parts of his [multimedia PHR] at his annual review in June.

Reassurance
Participants felt reassured by being able to see what is written by doctors. They feel that seeing it written down in a record provides confirmation of the reality of what is happening, over and above what doctors have said. One participant said: ‘if it’s written down it’s a fact’. This was articulated by one participant who had not believed doctors who said not to worry about her concerns, as she felt ‘fobbed off’:

I think it would have been quite useful, because I, I felt like I was being fobbed off, but obviously they felt that there was no need, but they weren’t, they were trying to reassure me, rather than actually saying it like the last doctor. They were trying to reassure me, which made me more worried.

Other participants were reassured just by having access to records:

It’s just nice to know isn’t it.

Participants felt reassured through accessing results and logging information, producing graphs and being able to see trends and what happened before and after diagnosis, treatments and monitoring.

Expediency in accessing information and acting on this information (for example a diagnosis) was also reassuring. Participants felt that anxiety and worry were reduced by their being able to access test results earlier than would be possible without a PHR.

As I say, once I’ve gone for the test, it’s there within days really, 2 days, and that’s it, the information’s there, you don’t have to worry about what’s going on and beforehand you used to get notification from the doctor to have a blood test while that was perhaps within 7 to 10 days, but now on that PHR it’s there within 2 days, it might even be 24 hours ... you don’t have to sit about and worry what’s going on.

It’s convenient; it’s useful. It’s always available. I have found it reassuring, because there have been, for example, questions that I’ve asked, which, it was good to have an answer that clarified something. So, I was better positioned.
8.2.6 Interaction of the patient journey and PHR use

Where a participant was in their illness/recovery journey affected their patterns of use of the PHR, and different cohorts of participants would access the PHR at different times, at varying frequencies and for different purposes. Frequency of access may be monthly, weekly, daily or across multiple months, and is needs driven.

If I was monitoring, say blood pressure, which, thank god, is one thing I don’t need to monitor, if I was monitoring blood pressure, then yeah, that would be something I would do regularly. Um, my weight, I don’t need to log on to because for weight I just get my bathroom scales. Um, maybe, um, if I was having more regular blood tests I would perhaps look at that. But I think it would depend on what information I wanted. I can’t see me logging in every Friday night. I would be logging in as and when I needed it.

I think, and even, and that could be something which is as simple as, when did I last have my ears syringed? As simple as that, in terms of frequency. But that isn’t very often, that could be like 3 or 4 months so that would be an investigation I might do now and again, but that would be by the month. But if it was investigating, if we, if we were currently investigating what’s happened to me under a certain ailment, then that could be on a regular weekly, or in some cases of course, if it’s diet, then it could be blood pressure or weight daily. I think that would be driven by the investigation rather than just my casual interest.

So really it’s of no use to me. If for example my weight and blood pressure if they did fluctuate fairly regularly, I would use it for that but as they don’t and the times when they did I’ve got them in my head anyway, so those two parts of it are irrelevant now.

Those who have chronic conditions were more likely to use the PHR during flare-up periods, to identify and manage symptoms; although if the flare-up was only a short term issue, these people would only use it for a specific period.

It is managing acute episodes.

They would find it more useful to sort of manage their symptoms, and also be more aware of when they were starting to get ill again.

As one participant said, until she had a serious flare-up, she had no need to engage with the PHR because she had never been in the situation of having a flare-up and using the record in this way. However, she was reassured that ‘I would, if I became ill very suddenly be in a position to make contact with my clinical team immediately’ and in line with this, she ‘felt that setting it up when I felt well meant that it was there when – if – I needed it rather than waiting until everything went wrong’.

Some participants with acute illness (such as treated prostate cancer) used the PHR when they were discharged from hospital to access blood test results and monitor prostate-specific antigen (PSA) levels. They said that they were likely to use the PHR for a few years while they continued to be monitored for cancer reoccurrence.
One such participant, although having a PHR that had multifunctionality, did not use the PHR to its full potential because he did not see a need for it. He instead used the PHR to access and monitor PSA level blood results as well as completing a routine health questionnaire, which he calls his ‘MOT’. He did not use the PHR to check doctor appointment times and, although he was aware that information about his pacemaker was stored on the PHR, he saw ‘no other reason to go onto it’. The participant was not aware of any other functions, including whether or not he could access his medical records through the PHR. He did not use it for general health and wellbeing, and he only accessed the record occasionally (when blood tests are logged). The participant’s perception was that the ‘cancer has gone’ and he considered himself to be fit and healthy, so there ‘isn’t a need to worry about anything’.

But I don’t really use it, as I say, only when I’ve got to check up to see what comes through with the PSA results.

Participants with mental health issues and those who accessed social care were more likely to use a PHR longer term, across their life span, and had more intense interaction and use of the record to monitor and manage their conditions and wellbeing. For example, one participant accessed the PHR on a daily basis to complete mini mood scales and then again weekly to see graphs of trends in the scores over the week.

It depends what I’ve got to do. Sometimes I do it in the morning, other times I do it late at night but I always make sure that I do it on a daily basis.

People with complex health and social care needs were also likely to be life-long users of the PHR, with responsibility for record being transferred from the parent to their child as they get older.

If in future the child health record transitioned into an adult PHR, then yes I’d continue to use it and I would introduce the kids to it as they got old enough and give them the responsibility to say right, as you become 16 to 18, then yes it’s for you to look after.

Those who use PHRs to monitor the ‘normal’ growth or progression of children would only use a PHR for the first few years, as ‘immunisations get fewer, growth slows down and [you] wouldn’t use it once you’re out of the initial few years’.

In line with the differing needs and levels of engagement throughout the patient journey, the PHR needs to be developed to incorporate users’ changing needs. To achieve the greatest benefit, the PHR needs to be introduced near the point of diagnosis in order to maximise the likelihood of the user adopting the PHR and of it having a positive impact by enabling them to continuously update it with their progress.

One participant felt that she had moved beyond the point where a PHR would be helpful to her self-management of her chronic illness. She sees the benefits of a PHR for others but not herself: ‘it seems to have uses, but not uses for me’. There are a number of reasons for this viewpoint, including that she has already established an ability to self-manage (such as identifying triggers like
stress); she is able to communicate easily and quickly with her healthcare team; and she has a good understanding of her condition and herself. The participant is ‘very self-reliant’ and she describes herself as being a ‘control freak’. She believes that using the PHR would mean ‘admitting that I’m not managing ... I’m not in control ... I don’t know whether I see it as a sign of weakness’. Not feeling in control can be stressful and can act as a trigger to flare-ups. Other people who are perhaps ‘more reliant on the medical profession’ could benefit more from using a PHR. The same participant believes that the PHR would have been of more benefit if she had been introduced to it earlier on in her condition, particularly when she was being diagnosed:

It really was a dreadful time and it was the worst time of my life. I really thought I was going to have to die because I couldn’t live with this. Having access to something like that would have raised my confidence, I could have spoken to people online perhaps ... I think if I’d had that, I would have made a speedier recover I think, because I wouldn’t have been in the panic that I was in for so long.

She feels that she is ‘too far down the line’ for the PHR to really benefit her now. She does, however, feel that it is still important to ‘have it there’, as it would be important to have access to her records if she wanted ‘or needed’ it. If her current condition changed and she could no longer manage it, she would consider using the PHR, but she does not currently need it and she feels that she does not have the time needed to dedicate to it. Being too busy and not having time to do things is a trigger for her, but she believes that she would make the time to use the PHR if she really needed to:

It’s not something I would use so long as I am well. I would be pleased to use it if I went into a longer period of relapse so then it would be useful ... if I ever needed it then I would make the time to do it.

Participants who see themselves as ‘healthy’ said that they do not see a need for the PHR and would not use it, but if they were to become ill with a chronic condition would consider using it. They are aware that clinicians keep records, so they do not see a need for a PHR nor a reason why they would access it:

I feel like I wouldn’t need to keep that record on myself for my own use ... if I were to need it then I could obviously ask the doctor or something to get it from them but I don’t think ... I can’t see a reason why I’d need to access it myself ... I can’t think of a reason why I would.

Participants said they believe that without a specific motivation, such as managing an illness, people are ‘not going to be bothered’.

If you are just healthy then you don’t, I don’t think everyone will use it because there is no ... and especially for young people ... What are the benefits? Like, just leave me alone. I don’t want to think about it.

The participants’ reason for accessing the record impacted on the frequency and timing of their access of their records. Those who used the record to access test results, such as blood tests for PSA levels, would only access the record when they received an alert stating that the results were ready. Others accessed the records at specific times following appointments; for example, to see what had
been written and to gain access to letters from GPs. Others said that they log in to the record on a daily basis to monitor their mood and access information about triggers or reminders for mindfulness. The latter use was more commonly described by those who access social care for mental health issues. Also, more frequent access was reported by those who have children with health and social care needs.

*I always access it in the 2 weeks after my appointments. … I’ll go in a couple of times just to see my blood results are in there and my letter to my GP.*

Some participants were advised by their healthcare teams when to access the record, to ensure that support would be available if they needed it.

### 8.2.7 Unmet needs and negative experiences

#### A lack of historic records

A number of participants reported issues with not being able to see their historic records on their PHR despite knowing that doctors hold these records. They could not understand why they, as service users, could not access them.

*There’s only a year’s worth of blood results that you can produce from and I’m interested in my longer prognosis so I have to keep my own graphs at home … . Because I know, when I go to see my consultant, he has 6 years’ worth of my results up on screen, so why can’t I have them?*

*It doesn’t really show back far enough.*

Having access to historic records is important to participants, as they are keen to monitor their health and wellbeing over a period of time; they want to be able to compare before, after and during phases of illness.

*I would like to be able to see what my results were of my test and investigations right from the start of dementia.*

*If it allowed me to track my symptoms over time, especially over time, if it drew out a graph, rather than just showing me one entry a day. I would find that a lot more useful, because I’d be able to see trends and be able to analyse it a bit better.*

#### Overwriting previously entered information

Participants experienced difficulties when trying to enter multiple diary entries into their PHR. Despite being told that they would be able to track symptoms or diet across the day, they found that each new entry would overwrite the earlier one. One participant needed and wanted to track symptoms across the day to monitor her condition, but she was prevented from doing so. This proactive participant fed back this issue but she was told that fixing it was not a priority.

*There was this diary feature too – where if you entered more than one entry per day, it would supersede the earlier entry. So, you didn’t get a full picture of what it was telling you. So, for example, if you were putting in symptoms, and you put in one at none o’clock in the morning,*
and then another at three o’clock, the nine o’clock one would disappear to be replaced by the three o’clock one, which I found a bit annoying to be honest because I felt like, ‘Well, what’s the point in me adding anything?’ Because I can’t view it, and it’s not going anywhere, and it’s not showing me anything useful.

To mitigate this, the participant has taken to writing her diary out manually and she does not upload anything to the PHR.

I keep a sort of paper diary. It’s not uploaded to anything.

Records not being updated
A number of participants were frustrated that their records were not updated by doctors and support services. Participants believed that this delayed care and could adversely affect the monitoring of their condition.

Problems with logging in
A number of participants raised difficulties with logging in to their record. Some participants persevered but others abandoned the PHR. Some participants could have sought help from an identified source, but they did not.

So, he explained practical things like how to log in, and actually connect to it, which could be quite – there was a little bit of an issue with it, because it was run through Microsoft HealthVault, and because I already had a Microsoft account, it wanted to link that to the HealthVault, and I didn’t want it to do that, so, you know, you have to kind of get around all that sort of technical issue first.

Data interpretation
Some participants had experienced difficulties with interpreting test results, measures of BP and mood scales. This resulted in confusion and anxiety. It also resulted in the participant not being able to identify potential health issues and therefore not being able to seek out care and support. Participants would like to receive clear, visual information about how to interpret the results that are displayed; for example, one participant suggested that it would be helpful to develop ‘an information button that if you clicked on would open up another webpage and it explained what the numbers meant’:

Now I understand how these things work, but I could understand if somebody was just presented with that and thought ‘What do these mean’? How do I go? What do I do?”

A lack of portability
For convenience and immediacy of access to information, participants stressed their desire be able to access the PHR on a mobile phone using an app. However, a number of participants had experienced problems with accessing PHRs from their phones.

I suppose the main limitation which comes I suppose from expectations derived from everything else that’s going on is the mobile functionality. So it works very well on a computer. It works okay on a tablet. It does not work well on a mobile, and what that means
in terms of accessibility is that I need to ... with two young children, find time to sit down and boot up a computer to do it whereas, as we all know these days, if your phone is in your pocket, you whip it out and you’re just straight to the app or even if it’s on the website on a mobile version, it’s very easy to do now. I appreciate that it is easier said than done to create a mobile version of something that has got so many different sections to it, however in terms of limitations, that for me as a user in terms of if I was going to appointments, is a limiting factor, because you’ve got to take a changing bag with you. So to shove the [PHR] in, actually is no big deal. I’m not going to take my laptop to an appointment though, so in terms of using it and entering data, if I was able to do it on a mobile, then I’d go along ... I probably wouldn’t ... I probably would consider not taking the [PHR] and saying okay, I’ll just enter it straight in here. Whereas, you know, to need to do it on a computer, it then becomes a bit much faff to consider doing it in an appointment.

Health information and guidance not relevant to the participant’s particular condition
Participants were disappointed and frustrated that information about their condition contained in the PHR was too generic or was not appropriate to them. Participants wanted patient-centred, perhaps tailored, information that is relevant to them to be able to appropriately monitor and self-manage their health and wellbeing.

I don’t use the information section. It is too generic.

One participant, who had had her condition for a while and was actively self-managing it, reported feeling very disappointed when looking at the information on her record because it seemed to be ‘patronising’ and something that only someone without knowledge of their condition would want to look at.

Not realising what the PHR can do
One participant experienced undue anxiety and worry over symptoms that he worried indicated that his cancer had returned. While he completed his questionnaire and reported within it his concerns about his pain, he did not receive any response and he wondered whether the information was being accessed by his doctor. He was left wondering. What the participant did not realise was that he could have used the PHR to message his doctor to raise his concerns.

Lack of knowledge of where information goes and whether it is looked at
This case also highlighted a further issue which was prevalent in other participants; the lack of knowledge and understanding of where information goes and what happens to it. Many participants assume that information is accessed and acted upon but this is not always the case. This causes anxiety and worry in participants.

Not having access to full record from all care providers
Participants highlighted that not all PHRs contain all information from all services. Participants deemed this to be important to facilitate continuity of care. Participants experienced issues with services not being able to connect to other services and facilities; for example, only having access to hospital records and not GP or social care records.
**Functions not yet built or working**
Participants reported instances of functions being present on the PHR but not yet fully activated or working. One participant was not able to report that the feedback button was not working:

*I think because it was such an early stage, it was still quite bare in places. There were things that obviously they’d set up that they were intending to add to it at a later date that didn’t have full functionality at the time. For example, there was a tab that said ‘send us your feedback’ and there was nothing actually on the page … So I couldn’t say, ‘There’s nothing on your feedback page’, because I had no way of feeding back.*

**Expectations not being met**
Many of the participants were left disappointed and frustrated after being told about an ‘all singing and dancing’ PHR which then did not deliver on the promises. For example, one participant was told that she could write multiple entries into her record but she could not. Others had expected to find clear and organised information in the record but they found that it was just a ‘data dump’ with letters and other documents uploaded to the record without any thought about how users would access it. One such participant no longer used the PHR but he instead collected and organised all paper records and letters himself.

One participant was particularly disappointed with the PHR that professionals said would link to his health records but which did not, due to the system not being activated on the healthcare professional’s end. This was one of the main motivations for the participant to adopt the PHR but they decided not to continue with it for this reason:

*and the biggest part of looking to try and access my medical records – that doesn’t work for people; I can do it my end but other people can’t do it at their end, the professionals’, so therefore it’s of no use to me.*

When this participant was asked how he would sell the PHR, he said:

*I wouldn’t sell it to you. I wouldn’t want to get your hopes up that it’s something good when it’s not.*

**8.2.8 Support required for adoption and ongoing use of the PHR**

**Transitioning to self-management**
Participants voiced concerns that not all people would be willing and able to take control of their health and wellbeing as well as their records and that they would therefore require additional support. People who would not being able to take control included those who are in transition from being a patient to being a self-manager.

*Users are desperate to take control of their own recovery plans but if you’ve been someone who’s been using the services for a long time and have been brought up in a tradition which is very much about … ‘you tell me what’s wrong doctor and I’ll you know’, then it’s quite different for them to suddenly switch. You can’t expect someone to switch overnight from a position … well you’re no longer a patient, you’re now a service user.*
My concern would be with my educated head on is that there are people that do not have the capacity to be able to do that and to take that control and that they need assistance and they need help and would there be something put in place to help those people?

There is also a need for sensitivity around when the record is introduced; for example, one participant experienced difficulty with transitioning from being a patient to having the PHR as a perceived replacement support mechanism. This was not helped by his seemingly abrupt introduction to the PHR when he was still feeling quite vulnerable and wanted explanations and reassurances about his condition and the treatments he had undergone. He says it felt like:

Well that’s out of the way, now let’s talk about my [PHR] they forget about the person … it feels like being in the wilderness at times … a little more … measured explanation of this would have been better.

Computer literacy levels
Those who are less computer literate will require more support, and some people’s conditions or medication may make it harder for them to set up and use a PHR.

Some of the poor chaps there didn’t know how to use a computer, so they wanted to know how they sort of get someone to show them how to do the computer really.

Other groups who may need additional support when being introduced to and continue to use PHRs include people who have cognitive problems such as with organising information in their head; those whose medication may impair their cognitive function and understanding; and people who suffer from dementia and associated memory problems.

... due to their medication, what have you, it’s just going to be too complicated for them and they’re just not interested.

Requiring ongoing support
Participants may require ongoing support with using the PHR. Some participants identified that they understood and were able to use the record within the introductory setting, but not at home.

I mean going through it in the consulting room is totally different to doing it yourself.

Others needed to use the record at set intervals and for a limited number of activities, such as to access test results. There was a risk that if they encountered a new need, they would not know how to use the PHR for that new purpose. Similarly, there was the risk that they would forget what the PHR could do and how it worked during periods of infrequent use.

Ongoing support needs to be flexible; it needs to be available at different times and, in some cases, it needs to be pro-active on the part of professionals and services. Support can be provided in group settings, but some participants stressed the need for one-to-one support. Support can be provided online, by telephone or in person. The benefit of each option is dependent on the needs and expectations of the users. For example, those who are less computer literate would want more
tailored in-person support, as would those who have cognitive difficulties. One participant recommended an online ‘user guide, like an interactive training tool’.

One participant who was living with dementia described being introduced to the record. She could clearly see the benefits of the record in supporting her to manage her condition but after leaving the introductory session, she could not remember what to do. If this participant were to have ongoing support, she would be more likely to adopt and continue to use the PHR. This support would need to be proactive because, although the participant could identify someone that she could approach for additional support, she did not do so.

**Social group workshops are helpful**

Social group workshops were beneficial to users, particularly when they start to use the PHR. The social aspect of such support is particularly important to those with mental health issues and those who access social care. As one participant stated, the social element involved in setting up and maintaining his record within his local support group is the key to his use of the PHR and, if it were removed, he would cease to use the record:

> So I’ve done it at home, but I quite like the social, having to walk out and meeting people ... to me if [the PHR] was exactly as it is now but they said ‘Here you are. Do it at home every week’, that would just destroy a lot of it for me. To me that would take a social element out of it that would make it far less appetising and desirable really from my point of view ... I mean, the social contact I think is quite important.

**Introduction and guidance needs to be easy and understandable**

Introduction to the PHR needs to be facilitated with easy-to-understand information in a supportive environment: preferably visual information with ‘human’ support. Leaflets are helpful because users can then take the information away with them to refer to it at a later time. Those who engaged in the group workshops when they were first setting up the records valued the workshops and said that they would recommend them. The introduction to the PHR needs to outline simple processes, in order to encourage the user to adopt the PHR. For example, one participant described what would have been the ideal supportive introduction to using the PHR:

> for him to have sat me down in front of his computer and said ‘do this do that, do the other’ ... I would want to be taken through the programme not necessarily by my consultant, because it’s time-consuming, but by perhaps the nurse who was there at the time ... and then a leaflet of instructions to take with me ... I didn’t get any leaflets ... a password that I didn’t have to fiddle with and didn’t have to change and a telephone number for someone to ring up if I needed to, rather than, I cannot bear onscreen support. You know if I can’t get on screen, how the heck am I supposed to get the support? [laughs] ... yeah so access to a human being that I could talk to if I needed to.

Those participants who have experienced using PHRs and who were unsure or experienced difficulties at the start stressed that, with support and practice, they later became comfortable with using the PHR.
Health and social care professionals’ perspectives on the support that users require
Both health and social care professionals emphasised the need to support users when they are adopting the PHR. The support themes that they identified mirrored those identified by the users themselves: computer literacy skills and IT devices for those with limited or no experience using computers; workshops or one-to-one / face-to-face support for users where PHRs represent a change to the model of care delivery and result in a reduction in face-to-face appointments.

Similarly, healthcare professionals spoke of the benefit for users being in contact with other service users during these workshops.

Health and social care professionals did not emphasise the need for ongoing support for users or for regularly checking that established users were comfortable with using the PHR. There was an assumption that users would contact their care team if they had any questions or concerns, and many users did so.

Professionals who did not have direct experience of using a PHR reported that they felt users would need a higher level of support when they were adopting a PHR.
8.3 Full literature review
A total of 32 articles have been included in the literature review, including 12 systematic reviews encompassing RCTs and other publications mostly from the USA, the UK and European countries; two literature reviews; two Australian studies on PHR design and evaluation; and 17 other studies from the UK, which include specific PHR projects (e.g., eRedbook, Patients Know Best, Myhealthlocker, Renal Patient View, My Diabetes, My Way etc). Examples of social care records (matching the search criteria) have also been included in the UK-based studies.

8.3.1 Benefits of using a PHR and important functions
The studies report differing evidence of the extent of PHRs’ benefits to users. The studies also differed in terms of the type of condition that the PHR users had, the type of benefit being measured, the PHR functions that were available and the research methods that they used.

A systematic review that included 143 studies reported an increase in patient adherence and attendance to clinic visits from use of a PHR (four studies); better patient experience and satisfaction (16 studies); and better communication with healthcare professionals (13 studies). Evidence from eight studies indicated that PHR use may result in an improvement in patient safety, primarily through identifying errors in medication lists and adverse drug reactions.

A second systematic review found health benefits associated with PHR use in 16 of 23 studies, with most of the benefits being realised in patients with diabetes. There was no evidence of benefits in cancer, multiple sclerosis (MS) or ITP patients. Similar results were seen in a third systematic review that focused on PHR use in cancer care. In this review, RCTs did not demonstrate the positive outcomes from PHR use that had been seen in pilot studies and studies that employed a qualitative methodology. One study that was included in the literature review showed that, while no difference in satisfaction or communication was found with PHR use, patients did feel actively involved in their own care. The authors discussed whether the RCT is the most appropriate design for the evaluation of PHR interventions because the wider context of health professionals’ and patients’ attitudes, beliefs, preferences and satisfaction is often ignored in the trials.

A fourth systematic review found that, in terms of changes that resulted from PHR use, 67% (31/46) were positive across all self-efficacy domains: patient involvement (67%, 10/15), patient empowerment (78%, 18/23), and patient communication (38%, 3/8).

Table 13 summarises findings on the benefits of PHRs and the functions that service users used when realising those benefits.
Table 13: Findings on the benefits of PHR functions

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Benefits</th>
<th>Functions</th>
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<tr>
<td>Archer 2011&lt;sup&gt;25&lt;/sup&gt;</td>
<td>• Better communication with healthcare professionals</td>
<td>• Decision support to manage chronic illnesses&lt;br&gt;• Personal log to record symptoms&lt;br&gt;• Comparison of test results&lt;br&gt;• Links to educational websites&lt;br&gt;• Electronic newsletter&lt;br&gt;• Community events summary&lt;br&gt;• Online scheduling for routine appointments</td>
</tr>
<tr>
<td>de Lusignan 2014&lt;sup&gt;12&lt;/sup&gt;</td>
<td>• Patient adherence and attendance at clinic visits&lt;br&gt;• Better patient experience, satisfaction and communication with clinicians&lt;br&gt;• Preparing for the next consultation&lt;br&gt;• Identifying medication errors&lt;br&gt;• Adherence to medications&lt;br&gt;• Time-saving in terms of avoiding an in-person clinic visit</td>
<td>• Communication with clinicians&lt;br&gt;• Timely responses from clinicians&lt;br&gt;• Access to prescriptions and test results, and to arrange referrals and reschedule appointments</td>
</tr>
<tr>
<td>Hawley 2014&lt;sup&gt;26&lt;/sup&gt;</td>
<td>Ownership and feeling more in control of pregnancy&lt;br&gt;User perceptions of:&lt;br&gt;• increased reliability&lt;br&gt;• faster transmission of information&lt;br&gt;• reduced medical errors&lt;br&gt;• global access&lt;br&gt;• less duplication&lt;br&gt;• lower use of paper and improved legibility</td>
<td>• Links to educational resources&lt;br&gt;• An obstetric calculator&lt;br&gt;• User-friendly language&lt;br&gt;• Keeping sensitive information confidential</td>
</tr>
<tr>
<td>Nnabuko 2015&lt;sup&gt;27&lt;/sup&gt; eRedbook</td>
<td>• Control the child’s calories intake&lt;br&gt;• Sharing experiences with clinicians and family members</td>
<td>• Menu-planning game&lt;br&gt;• Forum&lt;br&gt;• Use of graphics and animation</td>
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<tr>
<td>Study ID</td>
<td>Benefits</td>
<td>Functions</td>
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| **Joined Up Leeds 2015**<sup>28</sup> | • Have more control over health and wellbeing  
• Identify and respond to problems sooner | • Sharing information with healthcare professionals  
• Actively tracking health measures |
| **Gysels 2007**<sup>10</sup> | • Greater involvement of the patients in their care  
• Lower expenditure on health and social service  
(Variability noted between studies) | • Unstructured PHR content can allow richer dialogue (from a pilot prospective study in palliative care) |
| **Sartain 2015**<sup>16</sup> | • Users feeling more empowered  
• Avoiding repeating similar information to healthcare professionals | • Share information across the healthcare system  
• Share information with friends and relatives  
• View and create management plans  
• Use the PHR prior to consultations |
| **Mukoro 2012**<sup>29</sup> | • Better control and understanding of the medical condition  
• Better communication with the clinician  
• Reassured about treatment | • Access to letters, medicines and test results history |
| **Jilka 2015**<sup>7</sup> | • Better patient involvement and communication, and patient empowerment  
• Promotion of a sense of illness ownership  
• Patient-driven communication  
• Personalised support  
• Mutual trust between the patient and the professional | • No specific functions mentioned |
| **Innovate UK 2015**<sup>30</sup>  
*eRedbook* | • Able to share the record as needed  
• Ease of use  
• Electronic version preferred, compare with the paper record | • Sharing child’s record (especially their developmental firsts and growth)  
• Growth chart  
• Automatic plot-generation tools  
• Access to health promotion information |
Supported communication with health and social care services

In a review of ten qualitative studies, seven studies identified that patients valued their PHR and found it to be a good source of personal information, test and scan results and appointment details.\textsuperscript{16} Having a PHR as a tool to share information across the healthcare system was perceived to be beneficial for patients in five of the studies. Patients felt that it avoided the need to repeat similar information to different professionals. Some patients also found the PHR was useful for sharing information with friends and relatives.

When asked for their views on a personal child health record, parents generally accepted a shift away from paper to a digital tool. They found it easy to use and they liked being able to share the record as needed.\textsuperscript{30} Parents expressed a preference for an electronic rather than a paper-based record (60\% vs 40\%). Parents also suggested that the eRedbook helped to control their child’s calorie intake and was a very informative and interactive source of knowledge.\textsuperscript{27}

Potential users of a PHR who participated in focus group discussions reported that they assume the primary function of a PHR is to share their information with healthcare professionals, most frequently their GP.\textsuperscript{28} In addition to sharing information, they reported wanting to send information to their GP and to ask for advice or query whether they need an appointment.

An Australian study reported that patients with chronic disability view a PHR as a way to help them to communicate with unfamiliar healthcare providers, which is something with which they reported lacking confidence. Participants reported that the PHR would also help them by improved ‘storing’ and ‘sharing’ of health information, which was important to them.\textsuperscript{11}

In a UK focus group study, participants talked about how it can be difficult to remember all the names and dates of the conditions they have had or all the vaccinations that they are up to date with, and so a record that automatically pulls this information from their medical records would be extremely valuable.\textsuperscript{28} Participants who had experience of trying to coordinate healthcare across multiple agencies talked about how it can be very frustrating, as well as costly, that different healthcare systems do not share information. They talked about how having a PHR would mean that they become the ‘information conduit’ between different agencies. In this way, the information boundaries between the NHS, the local authority, private companies and professionals would all disappear. Participants also mentioned the PHR being readily accessible to paramedics ‘in case of emergency’, as well as sharing certain aspects of their PHR with their friends.

One Australian PHR was designed so that, if a patient is incapacitated in an emergency situation, the health professional can identify that it is an emergency and over-ride the access controls.\textsuperscript{31} Clinicians do not need to ask patients about loading each and every document, and it is up to the patients to ask for information not to be uploaded.

There is evidence that patients are selective about who they contact through their PHR. One study showed that patients contact doctors and nutrition nurses more than dietitians or administrators.\textsuperscript{32}
Gaining control and empowerment
Evidence shows that a PHR can support patients to feel that they have more control over their own health and that they therefore identify and respond to problems sooner.

In a systematic review of the impact of PHRs that included eight studies, five reported that patients felt more empowered and able to ask questions or to challenge assumption about results of tests and management plans. Patients therefore felt more active in their own care and that they could legitimately use the PHR as a therapeutic tool for recording their thoughts and feelings. Again, in five studies, patients felt more in control and more prepared for consultations through using a PHR. The most common reasons that patients wanted to look at their medical records were to see what their physician said about them (74%); to be more involved in their healthcare (74%); and to understand their condition better (72%).

Patients reported that PHRs were making them act on information, which increased their sense of empowerment, increased their motivation and promoted positive behaviour change.

Significant positive effects on patient empowerment were reported in four studies, and positive physical activity changes were reported in two studies in a systematic review of RCTs on web-based and interactive interventions for chronic diseases. The interventions were often used in different combinations and adapted to specific patient populations; hence, the individual contribution of the effects of the intervention was not feasible. Based on the evidence, the authors identified seven elements of web-based interventions that could benefit cancer patients, including the provision of a cancer survivorship care plan. A study on a renal PHR indicated that 88% of participants felt more in control of their medical care, 86% agreed or strongly agreed that they gained a better understanding of their illness, while 79% communicated better with their doctor and felt reassured about treatment.

Women reported having greater ownership and feeling more in control of their pregnancy when using a PHR. They felt that carrying paper notes gave them more confidence and they felt more responsible, involved and in charge of their health. However, one study reported that one-third of women who used an antenatal record card (as distinct from a computerised PHR) felt that it had little impact on their care. A generally high level of satisfaction was reported by women when they carried their paper PHR. The positive perceptions that were reported were varied, and included a general acceptance of: increased reliability, faster transmission of information, reduced medical errors, access anywhere, less duplication, less use of paper and improved legibility. One paper reported a positive finding of over two-thirds return rate of the PHR at presentation in a busy antenatal assessment unit. The benefits and satisfaction with PHRs have included easy access to test results and better communication with healthcare professionals.

Realising person-centredness
Very few studies on personal needs in a social care setting were identified. In one non-clinical study for social care, personal outcome measures were developed from focus groups where people with
disabilities and their families defined the ‘outcomes that were most important to them’. Although this study did not include a specific PHR, it helps to understand personal goals that people want to achieve through social care, which can help to design future PHRs. These measures were seen as being ‘based on the unique characteristics, needs and desires of each individual’. The outcome measures include safety, support networks, relationships, participation in the community and choices in different areas of life. Another UK study of social care service users provided further insight into factors that impacted on the participants’ quality of life and opportunities for support.

The use of focus groups prior to design helped developers to customise the PHR according to patients’ wishes. Patient needs can be addressed this way and several other patient reported outcomes measures (PROMs) were added based on the focus groups. User-centred design of the system is therefore vital and should address the needs of the patients.

8.3.2 Factors that impact adoption and use of PHRs

Factors that impact on implementation, uptake and use of PHRs were discussed in most of the systematic reviews as well as in the individual studies that were included. From the literature, certain themes about patient and healthcare professional concerns were identified. The literature also addressed how to mitigate the barriers.

Health status

People with serious chronic conditions, individuals with disabilities, parents with small children, people with a strong interest in maintaining healthy lifestyles, and older people or their caregivers are more likely to adopt PHRs. A higher rate of PHR use among patients with certain conditions, eg diabetes is also reported.

Stage in the user journey

One systematic review reported on a study related to cancer care, which found that introducing a patient to a PHR at or around diagnosis was acceptable. Several further studies that were reviewed suggested that patients are more likely to get involved in their care if PHRs are introduced early in their patient journey.

Age and gender

Evidence of the relationship between age and gender and a decision to adopt and use a PHR is inconclusive.

For example, it has been identified that female adult patients are more likely than males to use PHRs. Furthermore, is reported that female, young, white and affluent patients are more engaged with their PHRs. acceptance of PHRs is higher in younger, computer literate and more enthusiastic patients.

However, a UK-based study found that younger people aged below 35 appeared to be less likely to use a PHR than those aged 35 years or more and that usage did not differ by gender, diagnosis or length of time using services. In addition, a study on a UK-based renal PHR found that age and
treatment group were significant in determining citizens’ initial participation to the PHR system. However, middle-aged patients were more likely to complete a first logon than younger (<34) and older (>75) registrants. In addition, patients who had received a transplant were more likely to log on than patients who were on haemodialysis. A small number of very young registrants were the most likely of all to complete a first logon, although this was assumed to have been done by their parents.

**Socio-economic status**

Patients from addresses that are associated with greatest deprivation were more likely to not complete a first logon (odds ratio 1.24, with 95% confidence interval 1.08–1.42) compared with registrants of middle-rank deprivation. Early lapse in PHR use was associated with age over 75 and greater deprivation and was less likely in transplant recipients; and late lapsing was associated with age over 75 and treatment by hospital haemodialysis. Greater deprivation was associated with a substantially reduced probability of continuing to use a PHR at 6 months but subsequent rates of attrition were similar in all deprivation groups.

Another UK survey on a maternal PHR indicated that the ability to produce the record was significantly lower in disadvantaged electoral wards (89%) compared with advantaged wards (95%) and ethnic minority wards (94%). Younger mothers and those with fewer academic qualifications and lower socio-economic status were less likely to produce a paper PHR, as were mothers with larger families (86% of mothers with four or more children); women with longstanding illness (91%) or a history of depression (91%); and lone parents (83%). Multivariable regression analyses showed that less effective use of the PHRs was associated with factors that reflect social disadvantage, including residence in disadvantaged communities, young maternal age, larger family size, low maternal educational attainment and being a lone parent.

**Data security concerns**

Participants discussed how some information is more sensitive and that they would want to keep this in a separate section that is not accessible to medical professionals unless the participant specifically granted permission. Examples include sexual health and mental health. As well as having different sections, or pages, with different access rights, participants also suggested having different areas where health professionals could leave comments or advice for them. For example, this could help them to remember any changes to their medication.

An Australia-based study that examined PHR system design through stakeholder consultation included comments on how users can control access to their PHRs by health professionals. Users determine the level of access and decide whether a professional can access ‘restricted’ documents are not. The users create a record access code and give this to healthcare professionals. Clinicians can routinely access the shared part of the record; however if the user has given the clinician access to the restricted areas via the records access code, they can specifically look for this part of the record.
Lack of awareness and understanding of a PHR

Barriers to use have been reported if the intended purpose of a PHR is not understood by the users or if the PHR is not embedded within the healthcare system.\textsuperscript{16}

Health professionals were concerned that if notes were viewable, they could potentially be offensive to patients or could cause adverse reactions, and this could impact negatively on the doctor–patient relationship.\textsuperscript{12} Clinicians also reported concerns about liability related to patients who may not be able to interpret clinical content, and resulting anxiety, confusion and perhaps inappropriate or harmful behaviour was also seen as a concern of PHR use.\textsuperscript{13}

A patient’s use of their PHR is influenced by their coping style. Some patients may choose explicitly not to take control of the record, eg choosing to not check prescriptions and interpret test results. Understanding patients’ coping styles can help to design an appropriate level of technology empowerment, and providing information to explain the rationale behind the PHR use can help patients to take control. In addition, providing information on what not to access (eg blood results) and when not to access (eg prior to a consultation) can decrease anxiety about interpreting the information in the PHR.\textsuperscript{38}

Healthcare professionals did not feel confident about the new models of patient care that might give patients more control as well as responsibility.\textsuperscript{13} Elsewhere it was reported that patients felt that the PHR placed unwanted responsibility on them or their carer.\textsuperscript{16}

It was considered that a reason for low use of the HealthSpace PHR was that the record was poorly aligned with patient expectations and self-management practices.\textsuperscript{39} Clinicians did not always explain how the patients were meant to use the system, as the purposes of PHRs were not always well understood by clinicians.\textsuperscript{14}

Healthcare professionals being unfamiliarity with the concept of the PHR was linked with their omission to involve the PHR in the usual conduct of consultations and to their leaving it to the patient to take responsibility to present the PHR to them.\textsuperscript{10}

IT proficiency and access to technology

Different user needs must be considered when designing PHRs.\textsuperscript{38} Patients not feeling competent with using the technology can be a barrier, as they can be frightened that mistakes could have consequences for their health.\textsuperscript{38}

Six studies from the 143 that were included in the de Lusignan (2014) review reported that some patients were disadvantaged by having a lack of access to the internet, while others reported no such barrier.\textsuperscript{12} A lack of digital access was a concern in the My Diabetes My Way PHR, with 41.5% describing technical barriers such as non-availability of or access to a computer or the internet.\textsuperscript{40} Some patients had concerns about the sensitivity and security of information within the PHR. One concern related to accessing the PHR and subsequently forgetting to delete the browsing history.\textsuperscript{35} Some patients needed basic training for computer use, such as navigation and use of a mouse.
Clinician engagement with PHRs

In one systematic review, healthcare professionals found PHRs somewhat beneficial. However there was low involvement and a lack of interest among healthcare professionals. Worries included having more paperwork, and upsetting patients with more information. Liability-related concerns were addressed in two articles: one suggested notifying providers if patients had not opened an email, while the other proposed designing the system to detect messages that signal medical urgency.

Another study found that support workers and allied health professionals have a keen interest in PHRs: they perceived the idea to be ‘wonderful’ and ‘a huge benefit’ to people with severe communication impairments. However, despite seeing themselves as pivotal in prompting GPs to use their clients’ PHRs, they had no personal experience of using PHRs themselves. For example, they were unclear about who would give consent to opt in or out of a PHR when a patient lacked capacity, and about who should give consent for uploading new documents.

Physicians are generally receptive to patients having access to most lab results and other healthcare record information, but with restricted access to physicians’ notes. In some cases they seemed to view PHRs as a source of medical information when the patient record is unavailable. Therefore there appears to be a need to educate physicians about how PHRs can also support patient empowerment, disease prevention and control, and health self-management.

Healthcare professionals can be better engaged in PHRs by (a) providing communication and practical training to equip them to handle technical, interpersonal and workflow aspects; (b) using workflow engineering to mirror the current workflow, to reduce the burden of workflow revisions; and (c) involving professionals in the planning process. Initial uptake from the clinicians was slower in one study, as they were struggling to find clear examples of how the PHR could be adopted in real-use cases.

It was noted that clinicians reported satisfaction with using the PHR, stating that it improved communication with women in their care. One study did consider that communicating with midwives was at times problematic when using the PHR. There was also a reported lack of interest in using electronic PHRs by midwives, who reportedly found the interface problematic and were confused about what a patient PHR was. Midwives also expressed disinterest and considered electronic PHRs to be not integral or relevant to their role.

Patients in one focus group study had concerns about how likely it is that healthcare professionals would act on the information in their PHR. Some participants thought that their GP would think it was strange that they were keeping a PHR. Some participants were sceptical about whether or not their GP or other healthcare professional would believe the records they kept, or be able to understand the information. Most people suggested that their GP should tell them about the PHR, although they highlighted that it would be important that people do not go to their GP practice if they have any technical difficulties with the PHR. Younger people discussed how they could be told
about it in school, and others suggested that community health educators or community group leaders play a part in educating citizens about PHRs.

### 8.3.3 PHR patterns of use: interaction between the PHR and the patient journey

Patients were more motivated to use the PHR after a visit to their hospital or GP (56%), when they had abnormal results (45%) (compared with 20% when they had normal results), when they had had a recent test (88%), or when they were worried about the result (62%).

Early introduction of the PHR (eg soon after diagnosis) may be beneficial so that patients can adopt it as part of their care.

### 8.3.4 Support required for adoption and ongoing use of a PHR

#### Ongoing support

One study developed a web-based patient-centred PHR in a housing authority for low-income families, older people and the disabled. Patients were assisted weekly by graduate nursing assistants. Patients’ use of the system was low, but users were satisfied with the system in general. They paid more attention to their health conditions and care, and they shared records with primary care providers, specialists and nurse practitioners.

#### Computer literacy skills

In one study, patients who were less computer literate were peer supported by patients who had excellent computer literacy, and those who did not have access to technology were lent devices such as tablets or smartphones. After these interventions, patients did not have any difficulty completing the required information in the PHR.

#### Additional needs

For people with learning impairments, a range of supports may be needed to (a) organise and prepare information for upload to the PHR in a systematic way and (b) integrate hard and soft copy documents (on the home computer) with documents in the PHR. Participants in focus groups wanted to be able to pull information from other sources rather than having to enter it afresh each time anything changed. Examples include information being tethered to their NHS records, such as details of appointments and information on medication, or information being collected by mobile phone apps. They did not want to have to enter information manually where it could be avoided and they did not want to have to spend a lot of time updating their record. Participants wanted to use a range of devices to access their record, including tablets, laptops and mobile phones.

### 8.3.5 Core requirements for design

#### Interoperability

Results from a systematic review suggested that PHRs should be able to receive and transmit data to and from other sources. For this, the systems must be able to identify, authenticate and verify the owners of data and corresponding records. The establishment of robust authentication mechanisms was a focus of several articles; however five articles noted that improving security typically lowers
the flexibility and friendliness of use. System interoperability is critical to giving patients access to health records in hospital, physician and laboratory systems, but this relies on the adoption of interoperability standards such as Health Level Seven International (HL7) that support record sharing between systems. In addition to personal data, a PHR could store other data on, for instance, social status, family history, or living and working environment. It could also include information on lifestyle (diet, exercise, smoking, weight loss and working habits).

When PHRs are interoperable with other systems or devices, they become a powerful tool; when PHRs function as standalone accounts, they have limited value. Portability across mobile devices that enables a PHR to send alerts, reminders, or notifications to patients even when they are not using the PHR could trigger necessary actions that are associated with disease or medication management. Interoperability of PHRs with electronic health systems could allow for easier information exchange between patients and providers, and interoperability with monitoring and tracking devices could significantly improve critical healthcare by allowing patients or healthcare providers to foresee and prevent serious health incidents. PHRs could allow patients to set up notifications; for example SMS notification of emergency access, notifications of access by a healthcare provider, or notification of loading a shared health summary.

**PHR content**

An ‘unstructured PHR’ was shown to allow rich dialogue and to complement care. A smaller informal record was preferred by patients; however did not prefer the structured page layout. A systematic review of maternity care PHRs suggested that the PHR can be designed with a clear structure and with single login that integrates information between the community clinic, the patient, the laboratory and the obstetric unit.

PHRs should consider:

a) Data transparency: What data (such as clinical notes, test results and problems lists) should be included in the PHR? When should these data be made available? How should the data be conveyed?

b) Authorisation/privacy control: Who should have access to the PHR and who should be able to determine such access rights, eg when minors or carers are involved?

c) Data integrity (the accuracy and completeness of data): How can data be altered or complemented? Should such revisions be visible in the record?

**Patient involvement in design**

Patient involvement can help PHR design: a focus group session in one study identified that patients with mental ill health preferred a simple, minimal interface because they may have problems with memory and cognition. After receiving training on how to use the PHR which they were involved in designing, patients had no difficulty using the PHR.
### Details of studies reviewed in the literature review

#### Study ID Hawley 2014²⁶

<table>
<thead>
<tr>
<th>Country</th>
<th>Year</th>
<th>Study population</th>
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<tbody>
<tr>
<td>Varied</td>
<td>2014</td>
<td>Maternity care</td>
</tr>
</tbody>
</table>

#### Study design

A total of 43 articles were reviewed: United Kingdom (n=17); Australia (n=16); USA (n=2); Zimbabwe (n=1); Switzerland (n=2); Denmark (n=1); Malta (n=1); Finland (n=2); Canada (n=1).

There were 37 original papers. Nine papers used comparison data and 28 presented descriptive findings. Three papers were reviews, two were responses to original papers and one was a Cochrane review (a systematic review of randomized controlled trials of health-care interventions, which is published in The Cochrane Library).

#### System details

An electronic health record was defined as a system that operates between the hospital, the community setting and the patient. The record was accessible by the hospital clinician, the patient (or woman) and the community clinician.

A PHR was defined as a paper record that was portable and handheld. The record can be known ‘notes’, a ‘chart’ or a ‘card’. A shared-care record can be known as a ‘home-based record’ in developing countries.

#### Patient motivation and needs

The PHR is documented to be a key component of best-practice antenatal care, providing a single document to formalise a framework of communication of important clinical and process information between healthcare providers and the patient. Even in varied and remote settings, the PHR is documented to be useful in improving outcomes and promoting active involvement in care.

#### Benefits and important functions

Women reported having greater ownership and feeling more in control of their pregnancy when using a PHR. They felt that having access to their notes gave them more confidence and they felt more responsible, involved and in charge of their health.

However, one study reported that one-third of women who used an antenatal record card felt that it had little impact on their care. A generally high level of satisfaction was reported by women when they carried their paper PHR.

The positive perceptions that were reported were varied and included a general acceptance of: increased reliability, faster transmission of information, reduced
medical errors, access anywhere, less duplication, less use of paper and improved legibility.

One paper reported a positive finding of over two-thirds return rate of the PHR at presentation in a busy antenatal assessment unit. However, another paper reported findings that doctors were not able to retrieve information easily from the PHR and did not have enough room to document problems or write individual comments.

Functionalities that were incorporated into specific PHRs that were found to be favourable by staff included: links to educational resources, the obstetric calculator, incorporation of women-friendly language and a necessity to keep sensitive information confidential.

| Impact on the patient journey | Papers reported that women thought that talking to midwives and doctors was easier and that communication was improved when they carried their own full PHR. Two papers reported that women felt less anxious when they used a full PHR. Most papers reported that women looked after their notes, that they would prefer to carry their own paper notes and that they would do so in the next pregnancy. Carrying the full PHR was also noted to improve opportunities to receive reminders and educational information and also motivated the women to learn more about pregnancy.

Despite concerns about decreased access by clinicians to paper notes and that women would lose their PHR, few women did not bring their PHR to appointments. Papers also documented that women found it advantageous that their husband, family and/or friends could view their record. One study reported that about half the women presented with their PHRs, despite issues with women being mobile and travelling long distances to receive maternity care. |

| Role of professionals | Clinicians were noted to report satisfaction with using the PHR, stating that it improved communication with women in their care. One paper did consider that, at times, communicating with midwives was problematic when using the PHR.

There was a reported lack of interest in using the electronic PHRs by midwives, who reportedly found the interface problematic and were confused about what a patient electronic health record was. Midwives expressed disinterest and considered the electronic PHRs to be not integral or relevant to their role.

Hospital clinicians considered that data management (recording and retrieving data) from a PHR was time-consuming, particularly for tasks such as accessing histories and generating reports. |
GPs accessed the record about half of the time: about one-fifth accessed the record occasionally and over a quarter never asked about the record.

Core requirements for design

The maternity arena is cited as a setting in which to introduce a patient electronic health record to integrate information between the community clinic, the woman, the laboratory and the obstetric unit. Using requirements from antenatal guidelines, the electronic health record can be designed with a clear structure that requires a single login. The electronic health record can be designed using the data fields that are identified from the PHR, but it has been noted that it should also include antenatal visit and obstetric encounter forms, to link specialist services to the GP.

Barriers

Negative issues reported about PHR use included: the record was hard to read and time-consuming to use; that there were too many prompts for health professionals; that its use resulted in an increased workload; and that the PHR created more administrative load.

Factors relating to access were negatively described in terms of: issues of dealing with privacy of information; restriction or difficulty accessing the PHR; and difficulty ensuring that any data entry or editing could be linked to a person.

One paper described GPs as being reluctant to contribute information freely to other providers. They felt that their practice health records were already comprehensive.

**Study ID Walton 2006**

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<thead>
<tr>
<th>Country</th>
<th>Year</th>
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<tbody>
<tr>
<td>UK</td>
<td>2000–2002</td>
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| Study population | Mothers of 18,503 children born between 2000 and 2002, living in the UK, at 9 months of age |
| Study design     | Cross-sectional survey within a cohort study |
| System details   | The personal child health record (PCHR) is a record of a child’s growth, development and uptake of preventive health services. It is designed to enhance communication between parents and health professionals. |
| Benefits and important functions | Overall, 16,917 mothers (93%) produced the PCHR and 15,883 (weighted percentage 88%) consulted it to check their child’s last weight. Of the PCHRs consulted, 97% had the weight documented. Thus, 15,138 mothers (85%) showed effective use of the record. |
| Priority groups / digital | The ability to produce the record was significantly lower in disadvantaged electoral wards (89%), compared with advantaged wards (95%) and ethnic |
Capabilities

minority wards (94%). Younger mothers and those with fewer academic qualifications and lower socio-economic status were less likely to produce the PCHR, as were mothers with larger families (86% of mothers with four or more children); women with longstanding illness (91%) or a history of depression (91%); and lone parents (83%). A similar range of factors were associated with the proportion of PCHRs that contained documentation of the child’s last weight.

Multivariable regression analyses showed that less effective use of the PCHR was associated with factors reflecting social disadvantage, including residence in disadvantaged communities, young maternal age, larger family size, low maternal educational attainment and being a lone parent. Effective use of the PCHR was also lower in mothers who reported that their child had been admitted to hospital.

Study ID Islington Integrated Digital Care Record and Person Held Record 2015

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<thead>
<tr>
<th>Country</th>
<th>UK</th>
<th>Year</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Islington Council residents</td>
<td></td>
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<tr>
<td>Study design</td>
<td>Descriptive – commissioning document</td>
<td></td>
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<tr>
<td>System details</td>
<td>Having a person-held health and social care record for the citizens of Islington across commissioners and health and social care providers, so that the individual holds and manages their care and gives consent to providers of care to view their record based on an agreed dataset. Providers thereby work together to provide high-quality care. The interoperability and information exchange between organisations would allow the flow of data to be sent between two or more organisations for the benefit of coordinating service provision across care pathways, improving patient care and data analysis. In terms of financial implications, the contract value for the Integrated Digital Care Record (IDCR) and Person Held Record (PHR) is £8.50 million (excluding VAT) over 5 years. Other legal implications are detailed in the paper.</td>
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<tr>
<td>Benefits and important functions</td>
<td>• Put the patient at the heart of care, empower them to manage their own care and to be part of decision making. • Empower clinicians with real-time, accurate information and improve patient outcomes.</td>
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</table>
- Make the shared patient data available to authorised clinicians and carers where and when it is needed.
- Support assessment and other data collection forms so that users from different care settings can add data.
- Support workflow so that clinicians and carers can perform tasks and then inform, refer or hand over to others.
- Include an automated alerting facility using text messages, emails and in-system messaging so that clinicians and carers can be notified of key events – for example, a patient under their care being admitted to hospital.
- Create enhanced real-time information to inform planning and commissioning.

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Risks</th>
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<tbody>
<tr>
<td></td>
<td>1 A high percentage of patients choose to opt out, thereby reducing the achievement of potential system benefits.</td>
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<td></td>
<td>2 If a proprietary solution is identified as the preferred option later in the project, partners may require a larger number of patients than are present in the Islington area.</td>
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<tr>
<td></td>
<td>3 There is a risk of reputational damage if the PHR does not perform in the intended manner or if technical problems prevent the PHR from working.</td>
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<td></td>
<td>4 Future organisational changes within the NHS could mean that existing organisations such as Islington Clinical Commissioning Group (CCG) change.</td>
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<tr>
<td></td>
<td>5 As the number of patients/citizens that connect and share data grows, there is greater risk of data insecurity.</td>
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<td></td>
<td>6 There is a risk of the system being too open as patients share data more widely than has been traditional in a clinical context.</td>
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<td></td>
<td>7 Vulnerable patients may feel under pressure to share data while having little control themselves: eg those who experience domestic violence.</td>
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| Mitigations | 1 Develop and execute a robust communications and engagement plan. |
|             | 2 If a proprietary solution is chosen, it may be necessary to look for opportunities to partner with neighbouring boroughs to meet minimum patient thresholds. |
|             | 3 Ensure that the contract with a partner(s) is constructed so that the partner bears the risk that the solution is built to specification and the technological risks. |
|             | 4 Legacy organisations continue to own the system but any |
new organisation will be able to utilise the functionality that is provided.

5 A robust Consent and Information Governance Model will be put in place, along with strong controls over accreditation for systems that connect with the PHR.

6 Communications will make patients aware of the implications of sharing their records, but it will ultimately be their decision.

7 Patient safety will be ensured by working with clinicians and patient groups to agree standards to protect vulnerable individuals.

### Study ID Apps 2013

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<tr>
<th>Country</th>
<th>Varied</th>
<th>Year</th>
<th>2013</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Varied</td>
<td></td>
<td></td>
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<tr>
<td>Study design</td>
<td>The study did not include a PHR; however it reviewed measures that can be used when designing a PHR in social care. The study included a literature review: principally from work on social care in the UK, supplemented by work from North America and from the fields of health and wellbeing research. This study addressed incorporation of personal outcome measures into social care assessments, care package planning and review. Personal outcomes are the goals that people want to achieve through the social care services and the support that they receive. Personal outcomes are often categorised as ‘soft’ outcomes and placed in contrast to ‘hard’, process-based measures of service performance and throughput. They are also often distinguished from outcomes that are based on policy or clinical outcomes.</td>
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<tr>
<td>Patient motivation and needs</td>
<td>In one study, personal outcome measures were developed from focus groups where people with disabilities and their families defined the ‘outcomes that were most important to them’. These measures were seen as being ‘based on the unique characteristics, needs and desires of each individual’. The outcome measures include safety, support networks, relationships, participation in the community and choices in different areas of life. A UK study of social care service users used ‘three wishes’, where personal outcomes questions were completed by respondents. Researchers made home</td>
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visits to 31 participants aged 60–98 regarding assisted living technologies to support independence at home. An initial interview took place, and then the participant was given various items of equipment to use for 1 week and a ‘Home and Life Scrapbook’ which included a section on wishes (things they wanted to change or improve). After 1 week, the researcher returned and reviewed the content of the scrapbook during an interview with the participant. The wish list question was open-ended but, in order to focus priority, it was limited to three items. Three sections started with the phrase ‘I would like …’. The three wishes activity aimed to explore what participants wanted as well as what they needed. The authors provide examples of responses and then cite one specific response, eg ‘able to breathe better’, before providing broader examples, eg ‘visiting places’ (remaining active), ‘be able to stay in my own flat’ (ageing in place) and ‘able to help orphans’ (reciprocity). The study reports that the responses provided further insight into factors that impact on the participant’s quality of life and opportunities for support.

The Oxford Circles and Wishes project (run by the Older People’s Programme with Age Concern Oxfordshire) asked people in day care centres, lunch clubs and social clubs what they wished for and what they thought it would take to make those wishes come true. In a series of discussion groups, they asked 80 older people, many of whom have disabilities and long-term conditions such as dementia, depression and Parkinson’s disease, what their wishes were. They found that very few people had no wish, and of these, two said that this was because their lives were already very active and full. The majority of people were able to think of two or three wishes immediately.

### Study ID Farrelly 2013

<table>
<thead>
<tr>
<th>Country</th>
<th>UK – All four RCTs were carried out in the UK</th>
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<tbody>
<tr>
<td>Year</td>
<td>2013</td>
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<tr>
<td>Study population</td>
<td>The study included patients with severe mental illness such as psychotic disorders and severe mood disorders such as bipolar disorder and depression with psychotic features. In studies where there was a mixture of diagnostic groups, only the studies where the majority of participants (that is, more than 50%) had psychotic diagnosis were included. This did not include studies where the sole diagnosis was bipolar disorder or depression. Studies of people whose primary diagnosis was one of deliberate self-harm were also not the focus of this review.</td>
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</table>
The total number of participants included in the four studies was \( n=607 \). The average number of participants was \( n=152 \) (range 90–201).

**Study design**
- Systematic review of RCTs
- Four RCTs were included in the review.

**System details**
- ‘User-held records’ may be defined as information, held by the individual with the illness, which contains all or some personal information relating to the course and care of his or her illness. User-held records may include notes made by professionals at appointments and kept by the patient, advance directives and crisis cards (personal information held for use in the event of a crisis or relapse).

  Two of the studies tested a form of advance statement; that is, personal information and treatment preferences that are held for use in the event of a crisis or relapse. In these two studies, the user developed the user-held record with the help of a researcher or the clinical team who are involved in delivering routine care. The content of these interventions included the users’ views on relapse indicators, wishes for future treatment and contact details. They may also have included an indication of treatments that they did not want, eg a refusal of medication. The other two studies tested a form of medical record that included aspects such as contact details, clinical notes, future appointments and medication.

**Patient motivation and needs**
- The one study that reported this outcome found little effect of the user-held information on psychopathology using the Brief Psychiatric Rating Scale (BPRS).
- Three other studies using different scales for mental state found no significant effect.

**Impact on the patient journey**
- The three studies that examined satisfaction found no effect.

Psychiatric hospital admission data were available for four trials involving 597 participants, and three studies involving 507 participants provided information on compulsory admissions to hospital. No significant effect of the intervention was found in any of these studies individually. The pooled treatment effect showed no significant impact of the intervention and was of very low magnitude.

Summary data on the length of admissions were provided by three studies, none of which found a significant impact of the intervention.

Two trials also provided information on length of compulsory admission (that is, days under a section of the Mental Health Act). A significant effect of the intervention was stated to have been found in one study but not the other; the
results generally suggested that people who received user-held personal information spent less time in hospital under compulsory admission.

No effect was found on episodes of home treatment, outpatient attendance and non-mental health referrals.

**Study ID Saparova 2012**

<table>
<thead>
<tr>
<th>Country</th>
<th>Varied</th>
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</thead>
<tbody>
<tr>
<td>Year</td>
<td>2012</td>
</tr>
<tr>
<td>Study population</td>
<td>Varied</td>
</tr>
<tr>
<td>Study design</td>
<td>Literature review: 22 were included in the qualitative analysis</td>
</tr>
<tr>
<td></td>
<td>The study included four randomised controlled, clinical and cluster trials and 19 qualitative articles, five of which were purely descriptive.</td>
</tr>
<tr>
<td></td>
<td>Most studies were conducted in the United States. Three studies represented collaboration of researchers from various countries, including Greece, Germany, Turkey, Austria, Spain, France, Italy and Sweden, and one study conducted in each of the following countries: Netherlands, China, Germany and Canada.</td>
</tr>
<tr>
<td>System details</td>
<td>Most PHRs were designated to be used by adults and only two by children and teenagers. Some PHRs were designed to assist during the management of certain health conditions, while others were not associated with support or guidance for any particular health condition.</td>
</tr>
<tr>
<td>Patient motivation and needs</td>
<td>Qualitative studies reported positive patient feedback about the ease of use and usefulness of PHRs. Randomised controlled trial studies, on the other hand, provided evidence that PHRs did not have a significant impact on patients’ health behaviours or did not result in increases in patients’ self-efficacy.</td>
</tr>
<tr>
<td></td>
<td>Through focus groups and questionnaires, patients expressed their preferences for access to personalised health information and the need for timely feedback about their health conditions accompanied by guidance on what to do. Patients reported that PHRs were making them act on the information they received, which increased their sense of empowerment and their motivation, and promoted positive behaviour change.</td>
</tr>
<tr>
<td></td>
<td>User testing of PHRs revealed the need for usability improvements regarding some of the PHRs’ features and functionality.</td>
</tr>
<tr>
<td></td>
<td>Motivation and persuasion was achieved through tailored health-related</td>
</tr>
</tbody>
</table>
information and personalised recommendations, guidance and decision support that was delivered within or with the assistance of PHRs. The effects of such influence, however, was not consistent throughout the reviewed studies.

### Impact on the patient journey

Only a few qualitative studies reported that PHRs lacked efficiency. One study found that, despite the fact that a PHR provided patients with the sense of empowerment by offering them access to health self-management tools, the actual number of patient visits to the clinic or the number of phone calls received by the clinic did not change.

### Core requirements for design

In almost all of the reviewed studies, PHRs were interoperable with electronic health records / electronic medical record. Other examples of interoperability included integration with mobile phones, patient portals and sensor and monitoring devices. The functionality allowed most PHRs to send reminders or alerts to patients or their physicians to bring health-related situations to their attention. Seven PHRs sent reminders about medication intake and drug interactions alerts based on the readings from monitoring devices; reminders about due screenings and vaccinations; or messages via personal emails or text messages to cell phones informing patients about the need to log in to their PHR and access important time-sensitive information. Eight studies discussed reminders and alerts for due screenings and vaccinations and personal recommendations sent to patients within the PHRs. Seven PHRs also sent alerts to patients’ providers, calling for their involvement in patient care.

When PHRs are interoperable with other systems or devices, they become a powerful tool; when PHRs function as standalone accounts, they have limited value. Interoperability with mobile devices that enable a PHR to send alerts, reminders, or notifications to patients even when they are not using the PHR could trigger necessary actions that are associated with disease or medication management. Interoperability of PHRs with electronic health systems could allow for easier information exchange between patients and providers, and interoperability with monitoring and tracking devices could significantly improve critical healthcare by allowing patients or healthcare providers to foresee and prevent serious health incidents.

<table>
<thead>
<tr>
<th>Study ID Nnabuko 2015 eRedbook[^27]</th>
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<tbody>
<tr>
<td><strong>Country</strong></td>
</tr>
<tr>
<td><strong>Year</strong></td>
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<tr>
<td><strong>Study population</strong></td>
</tr>
</tbody>
</table>

[^27]: Royal College of Physicians 2017
Participants consisted of people aged 20 years and above. Marital status was not a determining factor for the inclusion of participants in the survey.

In total, 15 users participated in the usability testing to ensure that up to 80% of the usability problems were identified.

The ratio of female to male participants was 3:2.

Only one participant had used eRedbook: three other participants had PHRs.

<table>
<thead>
<tr>
<th>Study design</th>
<th>Evaluation study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three main usability metrics were measured: effectiveness, efficiency and user satisfaction.</td>
<td></td>
</tr>
<tr>
<td>Usability tasks and questionnaires were used to evaluate usability.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>System details</th>
<th>The system is a personal child health record (PCHR) that contains general health information of a child’s birth, growth and development.</th>
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</thead>
<tbody>
<tr>
<td>eRedbook is an electronic version of the paper-based Red book and it was developed in 2012 by SiteKit Applications Ltd, in partnership with Harlow Printing – who currently prints the paper-based version. It is built on the Microsoft HealthVault platform which is one of the most secure software servers in the world. The Microsoft HealthVault platform serves as the data repository for eRedbook.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Benefits and important functions</th>
<th>Overall, 92% of the total number of tasks were accurately completed, which is highly effective.</th>
</tr>
</thead>
<tbody>
<tr>
<td>When asked which feature(s) of the prototype they liked the most, eight users said the menu-planning game, two users said the forum, one user said the care team meeting and five said the use of graphics and animation in the design of the prototype. The reasons given by users for liking the menu-planning game included:</td>
<td></td>
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<tr>
<td>• it helps to control the child’s calories intake</td>
<td></td>
</tr>
<tr>
<td>• its game-like and attractive look</td>
<td></td>
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<tr>
<td>• it is very informative but in an engaging and useful way</td>
<td></td>
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<tr>
<td>• it was a fun activity</td>
<td></td>
</tr>
<tr>
<td>• it reflects what the eating habit of the child should be</td>
<td></td>
</tr>
<tr>
<td>• it is interactive.</td>
<td></td>
</tr>
<tr>
<td>Users liked the forum because it grants them the opportunity to share their</td>
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</tbody>
</table>
experiences with other users and health professionals, as ‘doctors may not know it all’. The user who liked the care team meeting said that assigning tasks to care team members gives the user the impression of having a great support system in caring for their child.

Users liked the use of graphics and animation because:
- they made the prototype fun to use
- they made the prototype user-friendly
- they made it easier to identify what had to be done.

<table>
<thead>
<tr>
<th>Study ID Pearce 2014</th>
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<tbody>
<tr>
<td>Country</td>
<td>Australia</td>
</tr>
<tr>
<td>Year</td>
<td>2014</td>
</tr>
<tr>
<td>Study population</td>
<td>Not available</td>
</tr>
<tr>
<td>Study design</td>
<td>Design of the system was through stakeholder consultation and the development of detailed requirements, followed by clinical design assurance.</td>
</tr>
<tr>
<td>System details</td>
<td>Personally controlled electronic health record</td>
</tr>
<tr>
<td>Patient motivation and needs</td>
<td>The most obvious method of control is though patient control of access to their record, which occurs at many levels. The first level is that the system as a whole is an ‘opt-in’ model. Patients can also elect to create a record access code (RAC), which must be given to health professionals before the record can be opened, as an extra layer of security. Records or part of records/documents can be hidden, which means that they are only available on a specific search, and not on routine clinical access.</td>
</tr>
</tbody>
</table>
| Benefits and important functions | Patients had the access to:  
- personal health summary: a document designed for patients to record allergies and medications they are taking  
- personal health note: a free-text area for patients to record any information they wish about their health for their own purposes  
- advance care directive (ACD) location: in the first release, this section only contains information about the presence and location of an ACD.  
- emergency contact details.  
Important contents included:  
- shared health summary: created by the patient’s regular medical practitioner, this is a record of the patient’s current medical conditions, medications, allergies and immunisations at a point in time, and it is then
- discharge summary: copies of the documents generated by hospitals as part of usual practice
- event summary: created by providers at the time of a significant event
- referral letter: copies of referrals
- specialist letter: copies of letters that result from a specialist consultation.

### Role of professionals

If the patient is incapacitated in an emergency situation, the health professional can assert an emergency and over-ride the access controls.

Clinicians do not need to ask patients about uploading every document (which might include individual prescription items, for instance). Instead, it is up to the patient to ask for information not to be shared. In reality, it is expected that clinicians will use common sense and ask about potentially sensitive information (such as sexually transmitted diseases), much as they would in existing communications.

One of the challenges for the program is that patients derive the most benefit, yet most of the workflow costs and change is borne by clinicians. While GPs keep information about allergies etc in their own systems, ensuring that the data are complete, regularly collated, curated and rendered fit for sharing is not part of their current remit.

The program represents a change in workflow and leverages pre-existing effort and (under Australian law) the clinician’s intellectual property. Patients may be seeing many specialists or other GPs for specific problems. GP requests for specific funding for personally controlled electronic health record (PCEHR) activities have not been met, and instead GPs must use existing reimbursement items.

Part of the solution to this is to change the whole system, so that GPs have access to information (such as discharge summaries or specialist letters) that they could not previously obtain. This indirect benefit of participating in the system is meant to counteract the direct ‘disbenefit’ of workflow changes.

### Core requirements for design

Patients can also set notifications, either by SMS or email, for certain activities. They can, for instance, set up SMS notification of emergency access, notifications of first access by a healthcare provider, or notification of loading a shared health summary.

### Barriers

Significantly, these personal health notes are not available to providers. Consultation in the design phase revealed significant problems with the medico-
legal risk of patients recording information in this section. There is no expectation that clinicians will access a patient’s electronic record routinely, and the presence of such information, if not accessed, may create a medico-legal risk.

Advance care directives are governed by individual state legislation, and therefore it was not possible in the development time frames to align all the states to create an electronic ACD.

Current plans are that pathology and radiology results will not be released to the PCEHR until they are reviewed by the ordering clinician. This process is problematic, as it does not apply to existing clinical documents that may contain radiology or pathology information.

### Study ID ‘Joined Up Leeds PHR’

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<th>Country</th>
<th>UK</th>
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<tbody>
<tr>
<td>Year</td>
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**Study population**

Focus group 1: six participants with one or more long-term health condition

Focus group 2: eight participants who all have long-term health conditions and some are carers for relatives

Focus group 3: seven young people aged 14–18 years, with no health conditions

Focus group 4: seven young adults aged 18–24 years, with no health conditions

Focus group 5: seven adults age 60–85 years, who had taken part in the Tele-X project, which explored the use of technology to help socially isolated older people to better manage their health conditions

Focus group 6: seven amateur triathletes who all use devices to monitor some aspect of their health

Focus group 7: seven Leeds Open Data Institute members, five of whom were from the private sector and two of whom were from public sector organisations

Focus group 8: six representatives from the voluntary sector

**Study design**

The study looked at eight different focus groups, with each group focusing on a particular set of experiences and characteristics that was agreed to be included in the research.

Each focus group lasted around 90 minutes and, with the permission of participants, was audio recorded. Participants received a £25 incentive.
<table>
<thead>
<tr>
<th><strong>System details</strong></th>
<th>A PHR was defined as an electronic record that individuals can use to help manage and share their health information.</th>
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</thead>
</table>
| **Patient motivation and needs** | One participant described how useful he finds keeping his own electronic record, as it enables him to easily access the dates and outcomes of consultations. He talked about how the PHR should be structured to easily allow him to extract relevant information and to display or print it for him or others to read.  
Participants also discussed how the things that are relevant to their health and wellbeing change over time, so they would like to be able to change different aspects of their PHR accordingly. This included the data fields in the PHR and the apps that it interfaces. |
| **Benefits and important functions** | Participants’ discussions indicated that they can assume that the primary function of a PHR is to share their information with healthcare professionals, most frequently their GP. As such, they believed that a big benefit is that they can send information to their GP and ask for advice or query whether they need an appointment.  
Participants discussed how a PHR would make them feel that they have more control over their own health and wellbeing. This would arise from being able to see and interact with their records, actively tracking their health measures, checking for test results, or requesting advice from healthcare professionals.  
Participants discussed how they might use a PHR to identify and respond to problems sooner. By monitoring certain aspects of their health, they would notice when problems arise or their condition is deteriorating before it causes health difficulties. They might take action to reduce their risk of developing a condition, or to better control their existing condition. |
| **Impact on the patient journey** | Participants talked about how it can be difficult to remember all the names and dates of the conditions they have had or all the vaccinations they are up to date with, and so a record that automatically pulls this from their medical records would be extremely valuable.  
Participants who had experience of trying to coordinate healthcare across multiple agencies talked about how it can be very frustrating, as well as costly, that different healthcare systems do not share information. They talked about how having a PHR would mean that they become the information conduit between different agencies. In this way, the information boundaries between the NHS, the local authority, private companies and professionals would all disappear. They talked about how this would make caring for themselves or |

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others much easier.

Some participants suggested having a section of their PHR that they could use in a way similar to social media, in which they could join certain online communities and share information and comments with others.

Participants frequently talked about this section being readily accessible to paramedics ‘in case of emergency’ to help them to decide the most appropriate course of action. Several participants talked about how they currently carry this sort of information in paper form in their wallets or bags, or how they wear a wristband to alert people to a health condition. Some participants discussed how they might want to share information on their lifestyle with their friends; for example to give them help to get fit or to change their diet, although they would not want to share their health information with everyone. They talked about using an app to enable them to share certain aspects of their PHR with their friends.

Role of professionals

Participants had several concerns about how likely it is that healthcare professionals would act on the information in their PHR. Some participants thought that their GP would think it was strange that they were keeping a PHR. Some participants were sceptical about whether or not their GP or other healthcare professional would believe the records they kept, or be able to understand the information.

Participants discussed how important it would be for the PHR to be explained appropriately if people are to engage with it. Most people suggested that their GP should tell them about the PHR, although they highlighted that it would be important that people do not go to their GP practice if they have any technical difficulties with the PHR. Younger people discussed how they could be told about it in school, and others suggested that community health educators or community group leaders could play a part.

Core requirements for design

Participants wanted to be able to pull information from other sources rather than having to enter it afresh each time anything changed. Examples include information tethered to their NHS records such as details of appointments and information on medication, or information collected by apps such as Strava. They did not want to have to enter information manually where it could be avoided, and they did not want to have to spend a lot of time updating their record.

Participants discussed an app that allows them to enter information into their PHR by scanning barcodes; for example scanning barcodes from over-the-counter medicines would add these details to their list of medications. Some participants
had used shopping apps that use barcode scans and they talked about how this would make it much more likely that they would keep a comprehensive record of the full range of medications that they take. Some participants highlighted how this could, in the future, extend to the food that they buy and they could scan the barcodes of food products to keep a record of their diet.

Participants wanted to use a range of devices to access their record, including tablets, laptops and mobile phones.

Some participants would prefer to print out details of medication, others prefer to send a message containing this information, and others suggested that it would be useful to show the professionals their phone or device screen with this information on it.

Participants discussed how some information is more sensitive and they would want to keep this in a separate section that is not accessible to medical professionals unless they specifically granted permission; examples include sexual health and mental health. As well as having different sections, or pages, with different access rights, participants also suggested having different areas where health professionals could leave comments or advice for them. This would help them remember any changes to their medication.

**Study ID Archer 2011**

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<thead>
<tr>
<th>Country</th>
<th>Varied</th>
<th>Year</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study population</td>
<td>Varied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study design</td>
<td>Scoping review</td>
<td>In total, 130 papers were included in the review.</td>
<td></td>
</tr>
<tr>
<td>System details</td>
<td>Varied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient motivation and needs</td>
<td>Patients prefer email communication for some interactions. On study developed a web-based patient-centred PHR in a housing authority for low-income families, older people and the disabled. Patients were assisted weekly by graduate nursing assistants. Patient use of the system was low, but users were satisfied with the system in general, they paid more attention to their health conditions and care, and they shared records with primary care providers, specialists and nurse practitioners. They agreed that the system had improved the overall quality of their healthcare.</td>
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</table>
### Benefits and important functions

The benefits of (and users’ satisfaction with) PHRs have included easy access to test results and better communication with healthcare professionals.

Information entered by patients may not be as complete, accurate and organised as data exchanged between healthcare professionals, hence content must be easy to understand.

Physicians’ experience has shown that patient problem lists, clinical notes, medication and allergy data, and laboratory and diagnostic test results can be shared with patients.

Functionalities of the PHR include sending and receiving electronic messages to and from doctors’ offices; completing prescription renewal forms, appointments, and referral authorisations; viewing lists of current medications and allergies; and accessing health and practice information. Decision support can also assist patients in managing chronic illnesses, based on monitoring data.

The nature of the patient’s illness affects their preference for functionalities. For example, a ranked priority list of patients with diabetes included: a personal log to record and compare blood glucose levels (86%); a daily blood glucose log calculator to estimate diabetes control for the past 3 months (86%); links to educational websites (71%); an electronic newsletter for answers to questions, diabetes-friendly recipes and information on community events (67%); online scheduling for routine appointments (67%); and electronic reminders for appointments (67%).

After 6 months, 25% of patients reported changes in their health situation (exercise, diet and habits related to stress). Patients may also benefit from sharing information on their conditions with others who have similar problems via online patient communities, e-forums, private messaging and comments.

### Priority groups / digital capabilities

People with serious chronic conditions, individuals with disabilities, parents with small children, people with a strong interest in maintaining healthy lifestyles and older people or their caregivers are more likely to adopt PHRs. Therefore, although a low overall PHR sustainable adoption rate can be expected, steps need to be taken by developers to improve the performance of PHRs and their long-term benefits for the people who are most likely to use them. This includes ensuring that potential user groups who have specific health self-management needs are directly involved in requirement specification, design and testing, to ensure that the PHRs match the cognitive abilities of their intended users and thereby support health self-management and disease prevention.
| Impact on the patient journey | Attempt should be made (particularly in the case of bad news) to adjust office workflows so physicians can discuss results with patients before they appear in the online records.

Allowing patients to enter or view their own health data in their healthcare record can convey much more to the patient than stand-alone PHRs.

In one study, patients could access education and automated advice programs and add their own information to hospital systems. In this case, patients primarily reviewed laboratory results: patients and physicians reported enhanced communications and patient understanding. |
| Role of professionals | Clinicians preferred telephone rather than email communication for routine interactions. Most studies suggest at least modest benefits, ranging from enhanced doctor–patient communication to patient access to medical records.

Physicians are less likely than patients to anticipate benefits, and more likely to anticipate problems from patient PHR use.

Physicians also have concerns about physicians’ use of patient-entered information and whether PHR adoption will create unreimbursed work.

Physicians are generally receptive to patient access to most lab results and other healthcare record information, but with restricted access to physician notes. In some cases, they seemed to view PHRs as a source of medical information when the patient’s record is unavailable. There therefore appears to be a need to educate physicians about how PHRs can also support patient empowerment, disease prevention and control, and health self-management. |
| Core requirements for design | Content must be important, understandable and credible to patients and their caregivers, and appropriate for web access by patient-authorised individuals.

A personally controlled PHR, integrated with a primary care record, can manage communications for prescriptions and appointments at reasonable cost. System interoperability is critical to giving patients access to health records in hospital, physician and laboratory systems, but this relies on the adoption of interoperability standards, such as HL7, that support record sharing between systems.

In addition to personal data, a PHR could store other data on, for instance, social status, family history, or living and working environment. It could also include information on healthy lifestyles (eg diet, exercise, smoking, weight loss and working habits). |
Two-thirds of adult patients are concerned about the privacy and security of their health information, but most of those using PHRs are not worried about privacy implications. The chronically and acutely ill and those who frequently use healthcare services tend to be less concerned about privacy.

**Study ID Hemsley 2015**

<table>
<thead>
<tr>
<th>Country</th>
<th>Australia</th>
<th>Year</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study population</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>People who have severe communication impairments associated with a range of chronic disabling health conditions including: cerebral palsy, aphasia following stroke, intellectual disability, and traumatic brain injury</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Study design</td>
<td>A case study, a survey and focus groups</td>
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<td></td>
</tr>
<tr>
<td>One case study of a patient with severe cerebral palsy</td>
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<tr>
<td>Twelve adults with diverse severe communication impairments (after stroke, cerebral palsy or brain injury) about using PCEHR, including nine by face-to-face interviews and three via an online survey</td>
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<td></td>
</tr>
<tr>
<td>Two focus groups with care workers in supported accommodation (n=9) and allied health clinicians (n=5) supporting adults with severe communication impairments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>System details</td>
<td>A PHR was defined as an electronic record for a patient that contains a summary of their health information from all their participating healthcare providers. It provided a timely means to rectify the problems associated with the poor exchange of healthcare information for people with severe communication impairments. Introduced in Australia in 2012, the main purpose of the record was to improve the quality, safety and efficiency of patient care.</td>
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<tr>
<td>(a) patients and their healthcare providers are engaged in updating, uploading, sharing and reading information in the record; (b) with regular use, the record builds up a picture of ‘health events’ for an individual; and (c) the information in the PHR is referenced at critical points such as admission to hospital, discharge from hospital, and change of health or disability service providers.</td>
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<tr>
<td>Impact on the patient journey</td>
<td>All participants lacked confidence when communicating with unfamiliar healthcare providers and thought that the PHR would help them by improving the ‘storing’ and ‘sharing’ of health information that was important to them.</td>
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<tr>
<td>One patient said: ‘It is so tiring to continually explain my history and progress. Every meeting with a new health professional requires a lot of work for them to understand.’</td>
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</table>
Role of professionals

Discussions reflected that direct support workers and allied health professionals have a keen interest in the PHR, perceiving it to be ‘wonderful’ and ‘a huge benefit’ to people with severe communication impairments. However, despite seeing themselves as pivotal in prompting GPs to use their clients’ PHRs, the allied health professionals had no personal experience of using PHR themselves. For example, they were unclear about who would give consent to opt in or out of PHR when a patient lacked capacity, and about who gave consent for uploading new documents.

Core requirements for design

One example was of a patient with severe cerebral palsy whose health information was stored loosely at home as hard copy documents in an expandable file, and in soft copy on her personal computer in the ‘documents’ folder or on ‘email’. She required full assistance from a carer to access the health documents in the expandable file (ie retrieving it from under her desk, opening it, searching through it and finding the information). In contrast, she accessed the computer and the internet independently using assistive technologies, and she could retrieve information that health professionals had sent to her by email.

For people with learning impairments, a range of supports may be needed to (a) organise and prepare information for upload to the PHR in a systematic way and (b) integrate hard and soft copy documents (on the home computer) with documents in the PHR.

Study ID Otte-Trojel 2016

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<tr>
<th>Country</th>
<th>Varied</th>
<th>Year</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study population</td>
<td>Varied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study design</td>
<td>Systematic review</td>
<td></td>
<td></td>
</tr>
<tr>
<td>System details</td>
<td>A patient portal was defined as a secure website through which patients can access personal health information and typically make use of several</td>
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</table>
communication, self-management and administrative functionalities. This included both electronic health record-tethered portals and ‘universal PHRs’, as long as the PHRs were clinically integrated.

| Patient motivation and needs | The following were identified as solutions to patient’s needs:  
• patient-centred design  
• training and education  
• promotional initiatives. |
| Benefits and important functions | Not a focus of the review |
| Priority groups / digital capabilities | Generally, use of portals was associated with female, young, white, affluent and having a chronic disease. |
| Impact on the patient journey | Designing portals to meet the needs defined by patients’ characteristics, preferences and capacities, as opposed to the most easily operationalised features of the technology, is believed to result in portals that have high patient-perceived usefulness and usability. This can be achieved through patient interviews, surveys and focus groups or usability testing.  
It is possible to concentrate on those who lack access and skills by training these patients to use the portals or by providing access through, for example, onsite kiosks.  
Initiatives (either through encouragement by healthcare professionals, materials or registration reminders) can be helpful for attracting patients’ attention and increasing awareness. |
| Role of professionals | It was suggested that healthcare professionals should be better engaged with patient portals. Activities suggested to support professionals to engage with patient portals are:  
1 provide communication and practical training to equip them to handle technical, interpersonal and workflow aspects; and introduce information about electronic health records and PHRs into the medical and nursing school curricula  
2 use workflow engineering to mirror current workflow, to reduce burdensome workflow revisions  
3 involve professionals in the planning process, to fully understanding their work environment and tasks; one article explained that completed care plans were not transmitted to a relevant healthcare professional until 2 weeks prior to the scheduled visit. |
Liability-related concerns were addressed in two articles. One suggested notifying providers if patients had not opened an email, while the other proposed designing the system to detect messages that signal medical urgency.

<table>
<thead>
<tr>
<th>Core requirements for design</th>
<th>In terms of interoperability, four articles suggested that portals should be able to receive and transmit data to and from several electronic health records, as well as web data. For this, the systems must be able to identify, authenticate and verify the owners of the data and the corresponding records. Several articles focused on establishing robust authentication mechanisms. While two of the articles suggested the importance of protecting against security breaches, five articles noted that increasing security measures typically lowers the flexibility and friendliness of use of the PHR. Appropriate data protection was discussed in 16 articles. This included consideration of:</th>
</tr>
</thead>
</table>
|                             | 1. Data transparency: What data (such as clinical notes, test results and problems lists) should be included in the PHR, when should these data be made available, and in what way should they be conveyed?  
2. Authorisation/privacy control: Who should have access to records and who should be able to determine such access rights, eg when minors/carers are involved?  
3. Data integrity – the accuracy and completeness of data: How can data be altered or complemented and should such revisions would be visible in the record? |
| Barriers | Twenty-two articles described healthcare professionals’ concerns, including:  
1. fears about an increase in the workload and disruption of workflow (this was especially true for the secure email service)  
2. views that healthcare professionals did not possess the technical skills and capacities to use PHRs |
3 feelings of a lack of confidence about the new models of patient care that might give patients more control as well as responsibility
4 liability in case of breached privacy or harmful patient behaviour if they fail to respond in a timely manner to enquiries and base clinical decision on patient-entered data that might be inaccurate
5 liability related to patients who may not be able to interpret clinical content and the resulting anxiety, confusion and perhaps inappropriate or harmful behaviour.

In addition, two articles mentioned that healthcare professional were hesitant to give up autonomy, which would be a consequence of giving patients control over activities that are traditionally arranged by the providers, such as booking appointments.

Patients’ use of portals was reported as generally low in most of the studies.

Some of the explanations given in the studies included:

1 patient concerns about confidentiality of their personal health data
2 patients were unaware that they had access to a portal or did not know the purpose of the portal,
3 patients found the PHR to not be user friendly
4 a lack of digital access and/or low health-literacy among patients.

A lack of documented cost savings from using patient portals proved to be a problem for developing a sufficiently sound business model for patient portals.

### Study ID Gysels 2007

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<thead>
<tr>
<th>Country</th>
<th>Varied</th>
<th>Year</th>
<th>Databases were searched until 2004</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Varied</td>
<td></td>
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<tr>
<td>Study design</td>
<td>Systematic review</td>
<td></td>
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<td></td>
<td>In total, 13 studies were included in the review: seven RCTs and six non-experimental studies. The RCTs included: one each from the Netherlands and Canada and five from the UK. There were three observational studies and two qualitative studies from the UK, and one survey evaluation from Sweden.</td>
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<tr>
<td>System details</td>
<td>PHRs in this study were identified as: logbooks, patient travelling records, personal records, a client record and a shared care record or care diary. PHRs included documents that complemented existing medical and nursing records.</td>
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<tr>
<td><strong>Patient motivation and needs</strong></td>
<td>PHRs were initiated by patients and persons who were involved in patients’ care pathway. Trials in cancer care have major limitations, as there were significant difficulties in recruitment and maintenance of patients with palliative care needs. It was acceptable to introduce the PHR at or around diagnosis, and several studies suggested that patients are more likely to get involved in their care if the PHRs were introduced early.</td>
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<tr>
<td><strong>Benefits and important functions</strong></td>
<td>The authors concluded that evidence on PHR use in cancer care showed no positive outcomes in RCTs that were seen in pilot studies or studies of qualitative nature. There was variability between the studies: while one sample of radiotherapy patients found no effect on satisfaction with communication, participation and quality of care, another trial found a significant impact on communication and greater involvement from the patients. Another study found no difference in satisfaction or communication, but patients did feel actively involved in their own care. One trial found that the intervention group had less expenditure on health and social service use, although it was not statistically significant. The authors have discussed whether the RCT is the most appropriate design for the evaluation of PHR interventions, as the wider context of health professionals’ and patients’ attitudes, beliefs, preferences and satisfaction are often ignored in the trials. Professionals also tended to use the PHRs to communicate with other healthcare professionals rather than with the patient.</td>
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<tr>
<td><strong>Priority groups / digital capabilities</strong></td>
<td>There was a difference in opinions among the patients in terms of the acceptance and use of PHRs: there were no details on which type of population were more likely to use the PHRs.</td>
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<tr>
<td><strong>Impact on the patient journey</strong></td>
<td>There was also unfamiliarity with the concept of the PHR, as it did not feature in the usual conduct of a consultations and it was left to the patient to take responsibility to present the PHR to the healthcare professional.</td>
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<tr>
<td><strong>Role of professionals</strong></td>
<td>In three studies, PHRs were monitored – either at a clinic visit or by a specific coordinator for the PHR. Patients’ views on the PHR were largely positive and healthcare professionals found it somewhat beneficial. However, there was low involvement and a lack of interest among healthcare professionals, whose worries included that there</td>
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</table>
would be more paperwork, duplication of medical records and that patients would be upset by having access to more information.

Core requirements for design

An unstructured PHR was shown to allow rich dialogue and to complement care. A smaller sized informal record was preferred; however the structured page layout was not preferred.

Early introduction of the PHR, ie soon after diagnosis, may be beneficial so that patients can adopt it as part of their care.

Barriers

Outcomes of intervention included that studies showed limited benefits of PHRs in terms of satisfaction and participation in care as well as quality of life. No positive impact was found on aspects of communication that are associated with patients having greater involvement in their own management. In addition, no impact was found in terms of patients’ information seeking, retention and understanding.

Study ID Schneider 2016 ‘Patient Know Best’

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<tr>
<th>Country</th>
<th>UK</th>
<th>Year</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Patients had either intestinal failure or inflammatory bowel disease. The initial group included individuals who were aged between 1 and 25 years managed at home by the family / a carer. As this group required multiple team input on a regular basis, there was frequent communication between the hospital team via telephone as well as the PHR. A latter group were under 18 years of age, and this was a larger group of patients who had low uptake of the PHRs (hence their consultants were not using the PHRs). There were 14 families in the first group and two patient families in the second group.</td>
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<tr>
<td>Study design</td>
<td>Semi-structured qualitative study with families of children and clinicians</td>
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<td>There were a total of 23 hours of observation and 9 hours of interviews, each lasting an average of 23 minutes. In addition, there were nine hospital visits.</td>
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<tr>
<td>System details</td>
<td>The PHR allows patients/carer and clinicians to enter, view and edit health-related information. In addition, it allows electronic messaging, video conferencing and file management.</td>
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<tr>
<td>Benefits and important functions</td>
<td>The ‘controller’ (one patient family) used the PHR much more than others, and the authors considered that this group could have important characteristics that can be used for designing and deploying PHRs. Initially the family had low perceived competence about whether they could enter the data themselves and</td>
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</table>
they worried about ensuring the correct use of the data. Although the patient’s family had a high amount of input into the data, they did not necessarily have more patient empowerment. The ‘collaborating’ group (six families), also had a high level of competence and autonomy but they showed a lower level of distress. The way that the collaborators used the PHR helped both patients and clinicians, and the current design of the PHR suited this group of patients. The ‘cooperators’ (five families) were equally interested in the health data and clinic letters, but mainly to manage their condition more effectively and they were not interested in other features of the PHR such as symptom tracking and journaling. The ‘avoiders’ group (four families) included families who were neither engaging in the PHR nor with their disease in general. They never used PHRs citing reasons such as having a high workload and experiencing technical problems that they did not seek help with, and having less trust in the healthcare system.

<table>
<thead>
<tr>
<th>Impact on the patient journey</th>
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<tbody>
<tr>
<td>The family strategy for coping with the patient’s illness influenced their PHR use. Users have different needs, which need to be considered when designing PHRs. Patients not feeling competent with the technology can be a barrier, as they can be frightened that mistakes could have consequences on their health. There needs to be both taking and relinquishing of control of PHR use. Providing information to comprehend the rationale behind the PHR use can help patients to take control. In addition, the information could help patient not to receive information, eg blood results, to decrease their anxiety about interpreting them.</td>
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**Study ID Sartain 2015**

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<th>Country</th>
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<td>2014</td>
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**Study design**

A total of 10 studies that reported the experiences of 455 patients were included in the analysis. The diseases that were covered included cancer care (five studies), mental health (two studies) and one study each for antenatal care, chronic disease and learning disability. Eight studies were from the UK and two were from Australia.

The types of studies included – semi-structured interviews, either face to face or on the telephone, and focus group sessions.

**Benefits and important functions**

In seven studies, patients ‘valued’ the PHR and found it to be a good source of personal information, as well as a good course of results of tests and scans and details of appointments. Having a PHR as a tool to share information across the healthcare system was perceived to be beneficial and facilitating for patients in
Patients also felt that the PHR avoided having to repeat similar information to different professionals. Some patients also found the PHR was useful for sharing information with friends and relatives.

**Impact on the patient journey**

Five studies reported that patients feel more empowered and able to ask questions or challenge assumptions about the test results and management plans. Patients hence felt more active in their care and could legitimately use the PHR as a therapeutic tool for recording their thoughts and feelings. In five studies, patients felt more in control and more prepared for a consultation through the use of a PHR.

**Barriers**

Four studies reported a negative impact of the PHR. This included patients feeling that the PHR placed unwanted responsibility on them or their carer. Some patients felt that the PHR was ineffective (reported in eight papers). Issues included there being no local awareness of the PHR by clinical staff and less involvement by staff in completing/reviewing it. In addition, patients also reported forgetting to use the PHR on a regular basis. Some of the concerns were due to the differing needs of patients and individual practices.

Barriers to use have been reported if the intended purpose of the PHR is not understood by the users or if the PHR is not embedded within the healthcare system. The systematic review concluded that the reporting of patients’ experience with PHRs is not comprehensive and that more robust qualitative studies are needed.

### Study ID Innovate UK, Year Zero Survey April 2015 ‘eRedbook’

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<tr>
<th>Country</th>
<th>UK</th>
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<tbody>
<tr>
<td>Year</td>
<td>2015</td>
</tr>
<tr>
<td>Study population</td>
<td>Parents and healthcare professionals</td>
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<tr>
<td>Study design</td>
<td>Not available</td>
</tr>
<tr>
<td>Benefits and important functions</td>
<td>Parents’ views included a general acceptance that there is a need to shift away from paper to a record that is easy to use and that can be shared. However, the cost of phone credit was seen as a barrier. Most users logged in only when they visited the clinic (35%) or once a month (29%). About 19% of parents had never used the PHR. Their preference was for an electronic version over a paper-based record (60% vs 40%).</td>
</tr>
<tr>
<td>Role of professionals</td>
<td>Professional were concerned about additional workload caused by duplication of work.</td>
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</table>
### Study ID Robotham 2015 ‘myhealthlocker’

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<tr>
<th>Country</th>
<th>UK</th>
<th>Year</th>
<th>2005</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Participants were recruited from community outpatient services (for people with psychosis) and from inpatient ‘triage’ units across south London. Care coordinators within community services referred people into the programme. The overall sample included 58 people: 32 participants used the electronic PHR.</td>
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</table>
| Study design | Mixed methods longitudinal study:  
- self-report questionnaires  
- auditing participants’ usage of the PHR  
- participants’ completion of PROMs  
- interviews with a sample of patients who had used myhealthlocker. |
| System details | A website was developed within South London and Maudsley NHS Foundation Trust (SLaM). This covers a large, ethnically diverse population. The myhealthlocker electronic PHR allows patients to monitor health-related outcomes and to complete PROMs. These data are sent automatically to the clinical record, where they can be read both by patients and their clinician. |
| Patient motivation and needs | According to participants’ responses to the feasibility survey (n=32), all but one participant said that they found the site useful, and 27 thought that they would continue to use it in the future. The majority (n=22) reported that they were confident in using computers prior to using myhealthlocker. The majority (n=24) also said that the login process was ‘simple’ (only four found it ‘complicated’). |
| Benefits and important functions | There was improvement when comparing participants’ last completed PROMs (mean=45, standard deviation (SD)=14) against their first completed PROMs (mean=40, SD=9). These differences were significant using paired t-test (t=−2.6, df=26, 2-sided sig=.016). |
| Priority groups / digital capabilities | Younger people (aged below 35) appeared to be less likely to use myhealthlocker than those aged 35. Usage did not differ by gender (Fisher’s exact test=.017, df=1, sig=1), by diagnosis (Fisher’s exact test=.096, df=1, sig=1), length of time using services (one year or less versus longer service history (n=44; Fisher Exact test=1.1, df=1, sig=.36). |
| Role of professionals | Patients were referred to myhealthlocker by clinicians, either after exiting inpatient wards or through community services. Patients were invited to attend a facilitated ‘drop-in’ session at a local community venue, led by an occupational |
therapist. The purpose of these sessions was to enable patients to access the internet, to teach them basic computer skills and to introduce them to the features of the electronic PHR. Patients who attended a drop-in but who had no other way of accessing the internet were lent mobile devices.

Barriers

Participants reported having few problems with the layout of the site (mean=2.4, SD=1.5), the text size (mean=1.8, SD=1.5), navigating the site (mean=2.7, SD=1.9) or understanding the content (mean=1.8, SD=1.5). Each of the features listed above had been measured on a five-point Likert scale, where a lower score represents a more positive response. Additional comments referred to limitations in how the results of the PROMs were presented, eg ‘the graph a bit difficult to interpret’. One patient commented that the site should be linked to primary care: ‘good to be able to access GP and health records in future’.

Study ID Phelps 2014 ‘Renal Patient View’

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<tr>
<th>Country</th>
<th>UK</th>
<th>Year</th>
<th>2014</th>
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<tbody>
<tr>
<td>Study population</td>
<td>A total of 11,352 patients registered from 37 UK adult centres. Overall, 77% patients were aged between 35 and 74 years, and 60% were male.</td>
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<tr>
<td>Study design</td>
<td>Case report</td>
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<tr>
<td>System details</td>
<td>Renal Patient View enables patients to view blood test results, clinician letters and information resources on a web browser. There is no financial incentive for patient to use the system.</td>
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</table>
| Benefits and important functions | Analysis of patient activity was restricted to the 8,249 registrants who completed a first logon more than 3 months prior to the census:  
- 822/8,249 (9.96%) made no logon beyond the first month  
- 6,023/8,249 (73.01%) made continued use up to the census date  
- 1,404/8,249 (16.98%) were judged to have lapsed  
- median 14 (mean 42.7) logons over 0–42 months  
- lapping users had a median of 4 logons  
- persistent users had a median of 26 logons. A key feature of Renal Patient View is the timely provision of blood test results. |
| Priority groups / digital capabilities | Age and treatment group were significant in determining a patient’s initial participation in the PHR system. Middle-aged patients were more likely to complete a first logon than younger (<34 years) and older (>75 years) registrants. In addition, patients who had received a transplant were more likely to log on |
than patients who were on haemodialysis. A small number of very young registrants were the most likely of all to complete a first logon, and this was assumed to have been done by their parents.

Patients from addresses that are associated with the greatest deprivation were more likely to not complete a first logon (odds ratio (OR) 1.24, 95% confidence interval (CI) 1.08–1.42) compared with registrants of middle-rank deprivation.

Patients from addresses that are associated with low levels of deprivation were less likely to not complete a first logon (OR 0.79, 95% CI 0.65–0.97) compared with registrants from addresses associated with middle-ranked deprivation.

Early lapse was associated with registrants being over 75 years old and greater deprivation, and was less likely in transplant recipients.

Late lapsing was associated with registrants being over 75 years old and being treated by hospital haemodialysis.

Greater deprivation was associated with substantially reduced probability of registrants continuing with PHR use at 6 months. But subsequent rates of attrition were similar in all deprivation groups.

Greater early attrition in older people and those on haemodialysis was followed by a continuing higher rate of attrition than in young registrants and those who had received transplants.

Most logon events occurred on weekdays and between 8am and 10pm. There were fewest logons on Sundays.

<table>
<thead>
<tr>
<th>Role of professionals</th>
<th>Initial promotion was via patient consultations and local advertising. The PHR was developed by clinicians and has been iteratively improved over the years to meet patients’ needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core requirements for design</td>
<td>Initial patient support increases persistent patient use. At two centres, the interval from registration to logon was less than 1 day, as they had elected an administrator to help patients complete their first logon immediately after registering. Interestingly, this practice also influenced subsequent logon behaviour.</td>
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</table>
### Study ID Ambrose 2014 ‘Patients Know Best’

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<thead>
<tr>
<th>Country</th>
<th>UK</th>
<th>Year</th>
<th>2014</th>
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<tbody>
<tr>
<td><strong>Study population</strong></td>
<td>Overall, there were 119 patients (50 male and 69 female).&lt;br&gt;The median age was 49 years (range 17–85 years, mean 48 years)&lt;br&gt;In total, 31/57 patients (54.4%) were over 50 years of age.&lt;br&gt;The study included 128 outside clinicians (nutrition nurses, dietitians, transplant coordinators) and 29 carers.</td>
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<tr>
<td><strong>Study design</strong></td>
<td>Survey</td>
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<td>The study recorded 5,015 unique electronic conversations, mostly via telephone – these included two patients who were abroad.&lt;br&gt;The study assessed patient satisfaction with the health record.&lt;br&gt;The response rate from patients was 49.7%, and 54.4% of respondents were over 50 years of age.</td>
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<tr>
<td><strong>System details</strong></td>
<td>Patients Know Best is an electronic PHR that gives patients access to interact with clinicians.&lt;br&gt;This study looked at the use of this system by patients who were receiving home parenteral nutrition.</td>
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<tr>
<td><strong>Benefits and important functions</strong></td>
<td>Overall, 51/58 (87.9%) patients felt at least ‘somewhat confident’ or that it was ‘somewhat helpful’ to work online with clinicians through the PHR. Of these, 62.7% felt that this was very/extremely helpful.&lt;br&gt;Of these respondents, 32 (62.7%) said it was ‘very/extremely helpful’. Overall, 51.7% of the patients used the PHR a few times a month; 6.9% used it a few times a week; and the remainder used it less frequently.&lt;br&gt;The following were found to be most useful by patients:&lt;br&gt;• contacting the healthcare team online for discussions&lt;br&gt;• monitoring test results.</td>
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<tr>
<td><strong>Role of professionals</strong></td>
<td>Patients used the PHR to contact doctors and nutrition nurses more than dietitians or administrators.</td>
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</table>
### Study ID Cunningham 2014 ‘My Diabetes My Way’[^40]

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<tr>
<th>Country</th>
<th>UK</th>
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<tbody>
<tr>
<td>Year</td>
<td>2014</td>
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<table>
<thead>
<tr>
<th>Study population</th>
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<tr>
<td>People with diabetes were sent a registration form and letter. Two weeks later, non-respondents were contacted by phone. Overall, 4,716 patients had completed the enrolment process (out of the 6,528 individuals who registered to access the data), and 1,898 patients had logged in at least once. In addition, a primary care pilot was carried out in NHS Highland GP Surgery (135 patients).</td>
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<table>
<thead>
<tr>
<th>Study design</th>
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<tr>
<td>Case report Three years</td>
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<thead>
<tr>
<th>System details</th>
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<tbody>
<tr>
<td>My Diabetes My Way (MDMW) is the NHS Scotland interactive website for people with diabetes and their carers. It contains a variety of validated multimedia resources that aim to improve self-management. These include traditional information leaflets, interactive educational tools and videos that describe diabetes-related complications and testimonials from people with diabetes talking about their experiences. This electronic PHR is available to every individual with diabetes in Scotland who is aged 16 or older.</td>
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<thead>
<tr>
<th>Benefits and important functions</th>
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<tbody>
<tr>
<td>The most-used pages on the website included: diet, foot care, causes of diabetes, insulin pumps and healthier lifestyle. During the 3-year period, the most-viewed item was the lab results (18.2 per patient). The most accessed graph was for HbA1c levels.</td>
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<table>
<thead>
<tr>
<th>Core requirements for design</th>
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<tbody>
<tr>
<td>Activities to increase recruitment to the PHR involved a campaign that was launched in collaboration with the Scottish government and Diabetes UK. Posters were displayed in all community pharmacies for a 6-week period. Social media, including Facebook and Twitter, were used to encourage discussion among users. These discussions were moderated.</td>
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<tr>
<th>Barriers</th>
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<tr>
<td>Barriers to non-usage (primary care pilot study): Overall, 58.5% of users were not simply interested or felt they already had the information they needed.</td>
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</table>

[^40]: Personal health record user insights: final report
In total, 41.5% described technical barriers including non-availability or having no access to a computer or the internet.

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<tr>
<th>Study ID Price 2015⁹</th>
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<tr>
<td><strong>Country</strong></td>
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<td><strong>Year</strong></td>
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<tr>
<td><strong>Study population</strong></td>
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<td><strong>Study design</strong></td>
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<tr>
<td><strong>System details</strong></td>
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<tr>
<td><strong>Patient motivation and needs</strong></td>
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<tr>
<td><strong>Benefits and important functions</strong></td>
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<tr>
<td><strong>Priority groups / digital capabilities</strong></td>
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<tr>
<td><strong>Impact on the patient journey</strong></td>
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Only one study reported harms to use. Healthcare professionals reported that patients were under the wrong assumption that they were continuously being monitored by the professionals and therefore they did not report any change in their health conditions.

### Study ID de Lusignan 2014

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<th>Country</th>
<th>UK</th>
<th>Year</th>
<th>2014</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Primary care setting patients</td>
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<tr>
<td>Study design</td>
<td>Systematic review, including 143 studies (17 studies were experimental in design). Ten databases were searched.</td>
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<tr>
<td>System details</td>
<td>Varied</td>
<td></td>
<td></td>
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<tr>
<td>Patient motivation and needs</td>
<td>Patient online access has a low uptake, and the effect on face-to-face utilisation of healthcare was equivocal.</td>
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<tr>
<td>Benefits and important functions</td>
<td>Four studies reported an increase in patient adherence and attendance to clinic visits.</td>
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<td>A better patient experience and satisfaction was reported in 16 studies.</td>
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<tr>
<td></td>
<td>Better communication with healthcare professionals was reported in 13 studies.</td>
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<td>While online access allows patients to reflect on their records and to prepare for the next consultation, there was no evidence of improved health outcomes.</td>
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<td>However, evidence from eight studies indicated that there may be an improvement in patient safety, primarily through identifying errors in medication lists and adverse drug reactions.</td>
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<tr>
<td></td>
<td>Seven studies reported that patient access to online services facilitated uptake of preventative care services and four studies reported small improvements in adherence with medication and clinical attendance.</td>
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<tr>
<td>Priority groups / digital capabilities</td>
<td>Female adult patients were more likely to use the PHRs.</td>
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<td></td>
<td>Patient contact emails were compact and brief.</td>
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<td></td>
<td>There was better patient satisfaction if healthcare professionals responded quicker to patient concerns.</td>
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</tbody>
</table>
Although a few studies reported privacy concerns, patients in some studies were even happy to appoint a proxy to access their records. Older patients were happy to accept assistance with using the PHR.

<table>
<thead>
<tr>
<th>Role of professionals</th>
<th>There should be an appropriate framework of governance and related guidance before the systems are in place. Only six studies reported that healthcare professionals wanted training and only two studies reported that they felt they lacked the skills to use the system.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers</td>
<td>Eight studies reported patients identifying errors in medication list and drug reactions. A significant number of discrepancies with some potential for severe harm were identified. Four studies reported patients with poor health and vulnerability having difficulty using the system. In two studies, patients preferred direct contact. Several studies reported disadvantages with access to online technology for certain groups, such as those in poorer health and vulnerable groups. Patients were not willing to pay for the use of PHRs (evidence only in US studies). Healthcare professionals were concerned that patients would have unnecessary stress and anxiety if results were not moderated. Six studies report that some patients were disadvantaged by a lack of access to the internet, while others reported no such barrier. In one study about the potential to access and identify medication errors, there was a significant difference between the number of discrepancies in medication with the potential for severe harm in the intervention group, compared with controls (0.03 intervention vs 0.08 control per patient, adjusted risk ratio (RR) 0.31, 95% CI 0.10 to 0.92, p=0.04). There was no evidence of harm to patients from the provision of patient online access, although there were concerns among health professionals that access to unexplained reports may cause anxiety or stress for patients. Healthcare professionals needed support staff to filter messages.</td>
</tr>
</tbody>
</table>

Six studies reported privacy concerns from healthcare professionals. Health professionals were concerned that viewing notes could potentially be offensive to patients or could cause an adverse reaction that could impact negatively on the doctor–patient relationship.

### Study ID Ennis 2014 ‘myhealthlocker’

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<tr>
<th>Country</th>
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<tbody>
<tr>
<td><strong>Year</strong></td>
<td>2014</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Study population</strong></th>
<th>Mental health service users (a total of 121 users in south London)</th>
</tr>
</thead>
<tbody>
<tr>
<td>At the time of analysis, 23 people had used the services: 13 people in the sample (56.5%) were male. The sample represented a fairly diverse range of ages: one person in the sample (4.3%) was aged 25–34; 11 people (47.8%) were aged 35–44; five people (21.7%) were aged 45–54 and six people (26.1%) were aged 55–64.</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Study design</strong></th>
<th>Focus groups and preliminary survey</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>System details</strong></th>
<th>The PHR was designed with and for those with severe and enduring mental health problems.</th>
</tr>
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</table>

<table>
<thead>
<tr>
<th><strong>Patient motivation and needs</strong></th>
<th>The use of focus groups prior to design helped developers to customise the PHR according to patients’ wishes.</th>
</tr>
</thead>
</table>

Several other PROMs were added, based on the focus groups. Patients who were excellent in computer literacy were used to train other patients. Devices such as tablets or smartphones were lent to those who did not have access to the technology. From then on, patients did not have any difficulty completing the PROMs. All but one patient said that they found the site useful, and 73% (17 out of 23) thought they would continue to use it in the future. Service users thought that the layout of the site was clear (mean=4.0, n=19); and they had few problems with the font size (mean=4.2, n=20), with navigating the site (mean=3.7, n=20), or with understanding the content (mean=4.2, n=20).

<table>
<thead>
<tr>
<th><strong>Core requirements for design</strong></th>
<th>The focus group identified that patients who had mental ill-health needed a simple, minimal interface.</th>
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</thead>
</table>

After initial training, the patients had no difficulty completing the PROMs.
<table>
<thead>
<tr>
<th>Barriers</th>
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</thead>
<tbody>
<tr>
<td>Some patients had concerns about the sensitivity and security of information within the PHR. One concern related to accessing the PHR and subsequently forgetting to delete the browsing history. Security concerns were particularly salient for paranoid service users.</td>
</tr>
<tr>
<td>Some patients needed basic training for computer use, eg navigation and use of a mouse.</td>
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<tr>
<td>Black and ethnic minority patients needed more help to use the PHR.</td>
</tr>
<tr>
<td>Some patients had usability problems, including font size, navigation and understanding the content of the PHR.</td>
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</table>

**Study ID Mukoro 2012 ‘Renal Patient View’**

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<tr>
<th>Country</th>
<th>UK</th>
<th>Year</th>
<th>2012</th>
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<tbody>
<tr>
<td><strong>Study population</strong></td>
<td>In total, 257 (50%) validated responses were received from the 507 users. Overall, 70% of survey respondents were aged 26 to 65 years, with the majority (39%) being in the 51 to 65 years age group. They were mostly male (60%) and white British (87%). In total, 88% had home access, and 71% of uses were by patient responders (89%).</td>
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<tr>
<td><strong>Study design</strong></td>
<td>Evaluation study – web analytics, surveys and interviews</td>
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<tr>
<td></td>
<td>Both quantitative and qualitative data were collected and analysed.</td>
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<tr>
<td><strong>System details</strong></td>
<td>Renal Patient View enables patients to view blood test results, clinician letters and information resources on a web browser.</td>
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<tr>
<td><strong>Patient motivation and needs</strong></td>
<td>Patients were most likely to use Renal Patient View for a recent test (88%) or if they were worried about a test result (62%); after a visit to their hospital or GP (56%); when their BP is abnormal (45%) (normal (20%)); and 49% will not use the system unless they are reminded.</td>
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<tr>
<td><strong>Benefits and important functions</strong></td>
<td>Overall, 88% of users felt more in control of their medical care, and 86% agreed or strongly agreed that they got a better understanding of their illness.</td>
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<td></td>
<td>In total, 79% felt that they communicated better with their doctor and were reassured about treatment.</td>
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<td></td>
<td>The visual display of the test results history over time was most useful. More than half (55%) had never experienced difficulties with the system. The most useful sections were: results (94%), medicines (47%) and letters (43%). The forum section was of little or no value (51%).</td>
<td></td>
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</tbody>
</table>
Patients who were interested in their illness were more likely to use the PHR. It is important to manage patients’ expectations regarding who sees the readings that they enter onto the PHR.

Patients were better prepared for consultations and for instigating communication with healthcare staff when they received timely information and updates on their PHRs.

A real-time update of test results is vital – patients reported peace of mind and that this reduced unnecessary anxiety.

Initially, 28% of patients were concerned about security, with only 15% being concerned after using the PHR.

Access to the site is controlled by the patient, who may choose to give permission to their family, healthcare professionals and others to view their data.

Only a self-selected group of interested patients used the system.

There needs to be more consideration to who gets access to patient information, eg one patient wanted their healthcare professionals at the renal unit to have access to their information.

Only few patients were aware of all the functions of the PHRs, eg not all patients were aware that they could enter their own data.

The forum was moderated; however patients and professionals were not aware of this.

<table>
<thead>
<tr>
<th>Priority groups / digital capabilities</th>
<th>Patients who were interested in their illness were more likely to use the PHR. It is important to manage patients’ expectations regarding who sees the readings that they enter onto the PHR. Patients were better prepared for consultations and for instigating communication with healthcare staff when they received timely information and updates on their PHRs. A real-time update of test results is vital – patients reported peace of mind and that this reduced unnecessary anxiety. Initially, 28% of patients were concerned about security, with only 15% being concerned after using the PHR.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core requirements for design</td>
<td>Access to the site is controlled by the patient, who may choose to give permission to their family, healthcare professionals and others to view their data.</td>
</tr>
<tr>
<td>Barriers</td>
<td>Only a self-selected group of interested patients used the system. There needs to be more consideration to who gets access to patient information, eg one patient wanted their healthcare professionals at the renal unit to have access to their information. Only few patients were aware of all the functions of the PHRs, eg not all patients were aware that they could enter their own data. The forum was moderated; however patients and professionals were not aware of this.</td>
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</tbody>
</table>

**Study ID Leeds Hypertension PHR 2015**

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<tr>
<th>Country</th>
<th>UK</th>
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<tbody>
<tr>
<td>Year</td>
<td>2015</td>
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</table>

<table>
<thead>
<tr>
<th>Study population</th>
<th>One patient with risk of high hypertension was identified from one GP practice, to develop a use case scenario.</th>
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<tbody>
<tr>
<td>Study design</td>
<td>EMIS web portal</td>
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<tr>
<td>System details</td>
<td>A PHR platform for patients to access and store their health data on the app and to feed the data to a PHR that can be shared with the local GP</td>
</tr>
<tr>
<td>Benefits and important</td>
<td>The patient felt that the benefits of using the system were: being able to filter health data, viewing the data at all times and the ease of use.</td>
</tr>
</tbody>
</table>
| functions | They also noted increasing confidence in the quality of the blood pressure readings, better control of their health and easing of anxiety due to gaining a better understanding of the disease.  
The ability to import the data into the EMIS web portal was considered to be valuable.  
The ability to view the results prior to a consultation meant that time could be focused on other discussions. |
| Impact on the patient journey | Initial implementation involved setting up the patient access account, downloading the app for the patients and demonstrating how to take a BP reading, and to input and view results on the system.  
It was also ensured that the patient was fully aware of what was expected of them and that they had ongoing support.  
There was a weekly contact programme with the patient, to ensure that the equipment was functioning and that patient was still engaging in the project. |
| Role of professionals | Initial uptake from the clinicians was slower – they were struggling to find clear examples of how the PHR could be adopted in real-use cases. |

### Study ID Jilka 2015

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<th>Country</th>
<th>Varied</th>
<th>Year</th>
<th>2015</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Varied</td>
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<tr>
<td>Study design</td>
<td>A systematic search was conducted using Web of Science, to identify review articles on the impact of patient-accessible electronic health records (PAEHRs). The search was limited to English-language reviews that were published between January 2002 and November 2014. A total of 73 citations were retrieved from a series of Boolean search terms including ‘review’ with ‘patient access to records’</td>
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<tr>
<td>System details</td>
<td>Varied</td>
<td></td>
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<tr>
<td>Benefits and important functions</td>
<td>This ‘review of reviews’ covers a broad range of outcome measures, including patient safety, patient satisfaction, privacy and security, self-efficacy, and health outcome. Health outcomes and behaviour include diet, alcohol intake, medication changes, and smoking or exercise habits and are different to ‘clinical</td>
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outcomes’, which refer to outcomes that can be empirically tested such as haemoglobin A1c levels.

One review shows a typical pattern of PHR impact, whereby they found a mix of results relating to specific clinical measures (such as blood pressure and various diabetes measures) with 50% (2/4) of studies reporting a positive change in clinical measure. The review that found the greatest positive change shows 75% (6/8) of studies in their review reporting a positive change as a result of PHR access.36

Self-efficacy outcome measures included a patient’s beliefs about how they feel, including patient involvement, communication and patient empowerment as a result of PHR access. Overall, this review of reviews showed 67% (31/46) of studies reported positive changes as a result of PHR use across all self-efficacy domains, including patient involvement (67%, 10/15), patient empowerment (78%, 18/23) and patient communication (38%, 3/8).

In one review, using PHRs for writing all inpatient orders significantly lowered patient charges and hospital costs.44 Three studies included in the review demonstrated how PHRs in the USA could provide a positive return on investment, with evidence of major financial benefit.

Findings on the impact of PAEHRs on clinician workload are mixed, with nurses more likely than physicians to gain time efficiencies. One review paper examined found that half of the studies included (13/26) showed that PHRs have a positive impact on changes to workload or workflow (ie a decrease in workload).12

Another review focused on the effects of PHR access on healthcare professionals’ documentation time.44 It found that in a PHR project, decreased documentation time is not likely to be realised, especially for physicians. From a total of 23 studies included in this latter review, 11 studies examined the impact of PHRs on time efficiencies of nurses, of which six studies found that nurses are more likely than physicians to gain time efficiencies by using a computer system to document patient information.

### Impact on the patient journey

| The most common reasons that patients wanted to look at their medical records were to see what their physician said about them (74%), to be more involved in their healthcare (74%) and to better understand their condition (72%). |

### Barriers

| Two studies found that bedside PHR increased documentation time, and one study reported different results depending on the specific content of the information being documented. |
With respect to physicians, ten studies on the impact of PHR on time efficiencies of physicians. It was found that using a PHR system increased physician documentation time by 17%. Of these ten studies, 60% (6/10) reported significant results regarding an unfavourable impact on initial visit time, and 10% (1/10) lacked sufficient information to identify whether the results were significant. In the remaining three studies, there were no significant differences between computer-based and paper-based documentation time. One study reported that physicians found no change in their workload or no adverse consequences as a result of PHRs, and all the physicians supported the use of PHRs.

The poor uptake of electronic health records may be driven by healthcare professionals who are wary of patients having access to medical records, fearing that it may cause patient anxiety. Eight studies where physicians feared that having PHR access without a physician being available to interpret the information might cause patients to worry. Although these risks are low, doctors have concerns about shared medical records and they see less potential for benefit than patients. These concerns included doctors finding a computer system ‘stressful’, having spent twice as much time using the computer than they had previously spent using their hand-written notes.

**Study ID Greenhalgh 2010 ‘HealthSpace’**

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<tr>
<th>Country</th>
<th>UK</th>
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<tbody>
<tr>
<td>Year</td>
<td>2010</td>
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**Study population**
The study included 56 patients and carers, of whom 21 opened a basic HealthSpace account, 20 had diabetes but were not initially using HealthSpace, and 15 used advanced HealthSpace accounts.

**System details**
The basic HealthSpace technology (available throughout England) and the advanced version (available in a few localities where this option had been introduced) were considered.

HealthSpace, an internet accessible personal electronic health record, was introduced in the English NHS in 2007. Using a basic HealthSpace account, people can enter values (such as their blood pressure readings) and record healthcare appointments on a calendar. Through an advanced account, they can gain secure access to their summary care record (a nationally stored summary of their medical details drawn from the GP record), book outpatient appointments and exchange email-style electronic messages with their clinician using a secure link called Communicator.
Between 2007 and October 2010, 172,950 people opened a basic HealthSpace account. Of those invited, 2,913 (0.13%) opened an advanced account, compared with 5–10% of the population anticipated in the original business case.

Few people who registered for a basic HealthSpace account were willing to be interviewed. The 21 people in this sub study who tried using HealthSpace found it to be of limited value. No one entered any health data onto it and no one intended to continue to use it in its present form, although some anticipated that a future upgraded version might be more worthwhile. Overall, patients perceived HealthSpace as neither useful nor easy to use and that its functionality aligned poorly with their expectations and self-management practices.

Participants’ main concern was the fundamental design of the HealthSpace technology and the mismatch between the design and their expectations. Despite background literature and explanations by researchers that made clear to potential users that they would need to enter their health data themselves, all 21 people interviewed were disappointed and some were angry that they found an ‘empty’ record. Seven of the 21 people expected to see their entire GP-held medical record and two expected to see hospital records as well.

**Study ID Kuijpers 2012**

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<th>Country</th>
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<th>Year</th>
<th>2012</th>
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| Study population | The review included 18 unique studies of chronic diseases.  
The overall percentage of dropout was between 0.0% and 52.3%, with a median of 17.5% (intervention group 19.7% and control group 14.0%).  
Studies where participants were adults and suffered from at least one of the following chronic diseases: cancer, diabetes, heart failure, cardiovascular disease, or COPD. |

| Study design | Systematic review  
RCTs published between 1990 and 2012  
Web-based and interactive interventions for chronic diseases  
All studies from 2000 or later, with most after 2005  
A total of 12 US-based studies, two Canadian and two Norwegian, and one each from Australia and Korea  
Two studies were of high quality, 13 studies were of moderate quality and three |
studies were of low quality, as per the authors’ classification based on a 13-point rating system. Only seven studies described a method of randomisation.

Benefits and important functions

Significant positive effects on patient empowerment were reported in four studies and positive effects on physical activity were reported in two studies. The interventions were often used in different combinations and adapted to specific patient populations; hence, it was not possible to identify the contribution of individual interventions. Based on the evidence, the authors identified seven elements of web-based interventions that could benefit cancer patients, including the provision of a cancer survivorship care plan.

Study ID Osborn 2010

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<th>Country</th>
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<th>Year</th>
<th>2010</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Type 1 and type 2 diabetes patients (17 studies focused only on diabetic patients were included: one study focused only on type 1 diabetes mellitus (DM), eight focused only on type 2 DM and eight studies included both groups of patients.</td>
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<tr>
<td>Study design</td>
<td>Systematic review</td>
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<tr>
<td>Overall, 26 studies included 2,436 patients, including 271 patients for usability studies.</td>
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<td>Study times were between 3 months to 12 months in duration.</td>
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<tr>
<td>The systematic review included a total of 26 publications: RCTs (8), quasi-experimental studies (4), pre-post evaluations, portal system design and function, and qualitative studies of usability.</td>
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<tr>
<td>System details</td>
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<tr>
<td>Benefits and important functions</td>
<td>One RCT (12-month duration) included 104 patients in the USA with chronic disease who showed significant improvement in cognitive status (+0.8% in the control group vs -1.0% in the intervention group) and functional level (19.4 vs. 20.0) in the intervention group that received a home electronic portal compared with usual home healthcare. However patient satisfaction and self-related health were not significant. The total number of urgent visits was significantly reduced (+5 vs – 83); however there was no difference in the total number of nurse visits during the study period.</td>
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<tr>
<td>A second RCT in the USA including both type 1 and type 2 DM patients (n=104) showed a significant reduction in HbA1c levels between the control group and the intervention group that received web-based care management (-1.2 vs -1.6%).</td>
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in 12 months’ time. In addition, there was a significant difference in HbA1c reduction between high users of the electronic portal and low users (-1.2 vs -1.6%). There was also a significant better reduction in systolic blood pressure (-7 vs -10), and there was a significant better reduction in the triglyceride levels and an increase in high-density lipoprotein (HDL) levels in the intervention group.

Use of a type 2 diabetes portal in an RCT was higher when the information was personalised to individual patient (319 days vs 772 days). HbA1c levels did not show any significant reduction when patients were followed up for 3 months’ duration. They also reported no significant change in blood pressure and exercise. The portal also had poor usability due to technical complications.

**Study ID Goldzweig 2013**

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<th>Country</th>
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<tbody>
<tr>
<td>Year</td>
<td>2013</td>
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</table>

**Study population**

Chronic health conditions including diabetes, heart failure, hypertension, depression; and preventive services.

**Study design**

Systematic review

Publications in PubMed and Web of Sciences between 1990 to 2013

In total, 14 RCTs, 21 observational and hypothesis testing studies, 5 quantitative and descriptive studies and 6 qualitative studies were included.

**System details**

Varied

**Benefits and important functions**

In one RCT evaluating diabetes care, patients who received a web-based and nurse care management had significantly lower HbA1c compared with the control group. There was no difference in outpatient visits or primary care / specialty visits or inpatient days.

Another US-based study showed no difference in HbA1c, blood pressure or low-density lipoprotein (LDL) levels between the groups after 12 months of access to an electronic PHR, while a different RCT showed lower HbA1c at 6 months but not at 12 months’ time.

One study on heart failure demonstrated no significant difference in the ‘self – efficacy’ part of the Kansas City Cardiomyopathy Questionnaire. The intervention group showed more adherences to medical advice but no difference in adherence to medications

**Priority groups / digital capabilities**

Acceptance of portals was higher in younger, computer literate and more enthusiastic patients. Patient satisfaction was generally high among the portal users.
One study found that there was a significantly high number of emergency department visits in the intervention group (20 vs 8 visits), with no difference in hospitalisations.

### Study ID Robotham 2015

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<th>Country</th>
<th>UK</th>
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<tr>
<td>Year</td>
<td>2014</td>
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This study describes the process of training clinicians to explain EHR-linked research register to service users, and to recruit them onto the register. Most of the participants were either care coordinators or clinical psychologists.

In total, 100 patients were identified, aged between 18 to 47 years (mean age 26 years).

The majority of participants were from black and minority ethnic groups.

The majority of staff were white, female participants.

A total of 100 consultations were used for analysis.

The study used a mixed method design to illustrate the methods used by clinicians to explain the health record linkage.

Consultations between clinician and patients were analysed against a checklist of items and scored 0 if clinicians did not use a checklist item in their explanation and 1 if they did.

<table>
<thead>
<tr>
<th>System details</th>
<th>Linking a health record to a research register</th>
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</table>

Only 66% of consultations mentioned the health records and most of them (94%) had a reference to research. Whilst most consultations contained reference to the fact that researchers might contact patients in future to invite service users into research studies (94 %), clinicians less often mentioned the fact that this contact would be based upon researchers accessing their EHR (62 %). In total, 44% of patients recalled that researchers would contact them in future, but only 12% recalled that this would be based upon information in their EHR.

Only 28% of the consultations included reference to confidentiality.

Significant factors that affected the patient joining the register included:

- explaining to the patients that inclusion was voluntary
- notifying patients that they can change their mind and that they can stipulate the sign-up process
| Barriers | Clinicians did not always explain how the patients were to use the system.  
Health records are not always well understood by clinicians. |
|----------|----------------------------------------------------------------------------------------------------------------|

**Study ID Brady 2012 ‘myhealth@QEHB’**

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<tr>
<th>Country</th>
<th>UK</th>
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<tbody>
<tr>
<td>Year</td>
<td>2012</td>
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| Study population | Twelve liver medicine patients in 2012  
Note that the system was reported to be used by over 8,200 patients in 2014–15. |
|------------------|----------------------------------------------------------------------------------------------------------------------------------|

<table>
<thead>
<tr>
<th>Study design</th>
<th>Case report</th>
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</table>

| System details | A web-based system offered by the University Hospitals Birmingham NHS Foundation Trust with access to the Queen Elizabeth Hospital Birmingham (QEHB) clinical record and online support for patients.  
The web-based system provides patients with chronic health conditions with access to key parts of their clinical records including test results. Patients can also input data into the system and share the data with the clinician. |
|----------------|----------------------------------------------------------------------------------------------------------------------------------|

| Role of professionals | The system was developed by the local hospital IT and informatics staff, with input from clinicians and patients.  
Clinical leadership and executive sponsorship is vital. |
|-----------------------|----------------------------------------------------------------------------------------------------------------------------------|

| Barriers | Better shared patient care was reported, eg ‘my clinician has asked me to enter BP readings at home & upload my GP prescriptions … so we can find the best medication plan [for my condition]’.  
For many clinicians, the cultural change was more of a barrier than the use of the technology itself. |
|----------|----------------------------------------------------------------------------------------------------------------------------------|
8.4 Detailed recommendations

The detailed recommendations in this section should be read with Section 4.9 and the user journeys narratives, which can be found on the RCP HIU’s webpages.

1. Design implementation plans that meet the needs of those who are less motivated to adopt a PHR.
2. At PHR adoption, demonstrate in an accessible way the data security procedures that are in place.
3. Consider introducing an additional layer of security to access health records that are deemed by the user to be sensitive. Types of records that are labelled as sensitive will differ from person to person, but will often be information related to sexual and mental health.
4. Prior to adoption of the PHR, identify where users are at risk of being coerced into sharing login details to their PHR, and put safeguards in place.
5. Consider incorporating a function that sends the user an alert when their record is accessed; for example, a text message or email alert.
6. Ensure that users are in control of what information is uploaded to their PHR and who has access to that information.
7. Prior to adoption, ensure that clinicians are confident that users understand what information they will have access to via their PHR, and that users have considered what they will do if they find something on the PHR that upsets them.
8. Provide access to up-to-date and historic records, where the historic records are related to a current condition.
9. Give users guidance on where to get reliable support and information regarding their condition and test results, and the best time to access it.
10. Give users clear and easily accessible guidance on how to read and interpret data; for example, whether a test result shows an abnormal result and what that means for the user. Ensure that clinicians write or clean data so that it can be understood by users.
11. Ensure that information on how to read and interpret test results and other health records is easily and quickly accessible from the section of the PHR that shows the data.
12. Advise users not to access test results when support is not available; for example, at the weekend if the clinic is open Monday to Friday.
13. Ensure that users are aware of how and when health and social care professionals are monitoring their data (and which data, if any). Inform users of the conditions under which they can expect input from professionals. This is particularly important if a user is completing an assessment tool or undertaking tests.
14. Organise the content, including documents, in a way that is easy for the user to navigate and explain the document filing system.
15. Offer the opportunity for occasional face-to-face, Skype or telephone appointments to users whose regular appointments have been replaced by a PHR function, to ensure that they are using the PHR as it was intended and that they understand how it fits into their care package.
16 Provide training and technology to ensure that users have the resources they need to use a PHR.
17 Ensure that there is a way to engage in quick and effective communication with professionals.
18 Provide functionality to allow records to be shared across services, where the user gives permission.
19 Provide functions that ease the administrative burden on service users, such as appointment calendars and contact lists.
20 Prior to users’ adoption of the PHR, manage their expectations by being clear about what the PHR can do and its limitations. This includes being explicit about what health records will be accessible via the PHR and what records will not.
21 Do not launch functions that are not yet developed to the stage where they meet users’ basic expectations and needs. If a function is not ready to launch, do not ‘show’ the function button on the PHR.
22 Communicate with users when any changes are made to the parameters of the content or structure of health records in the PHR or its functions. Recognise that not all users will log in regularly and that some may need to receive more than a message on the PHR, such as an email.
23 Test the design and functions with a cohort that is representative of the intended users.
24 Encourage continuous feedback from users on how they use the PHR and whether they would know how to contact professionals or a support team if they have questions about their health or PHR. Provide a response where feedback has been given.
25 Ensure that users have access to information that is relevant to their condition and how they experience their condition.
26 Provide prominent messages on the PHR about how users can contact services.
27 Ensure that those who use the PHR are aware of how to access additional functions if their needs change.
28 Provide a help function within the PHR and a frequently asked questions section.
8.5 References


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44 **Brady 2012:** Brady L. myhealth@QEHB. BCS ASSIST Autumn Conference, Manchester. October 2012.
