Royal College of Physicians

Personal health record (PHR) landscape review
Final report

May 2016

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Executive summary

NHS England provided the Royal College of Physicians (RCP) Health Informatics Unit (HIU) with grant funding to undertake a landscape review of current personal electronic health and care record (PHR) activity in the UK. The purpose of the review is to inform NHS England's strategy in this area, which is driven by the _NHS Five Year Forward View,_[1] the National Information Board's (NIB) report _Personalised health and care 2020: a framework for action_[2] and the NIB work stream 1.2 roadmap.[3] These set out a vision for greater adoption of digital technologies, including PHRs, to empower patients and promote self-management.

For the purposes of this review, a PHR was defined in the project specification as:

> _... a digital tool that helps people to maintain their health and manage their care. It may do this by enabling them to capture their own health and care data, to communicate with health and care services, and/or to have access to their care record._

The review scope was set to include UK electronic PHRs only, including both those in health and social care settings. There was a focus on developments and progress since 2012, when previous reviews had been undertaken.

The methods used are set out below.

- An online questionnaire used to obtain an overview of PHR activity, together with supplier, implementer and user (citizens/patients and health and or care professionals)* views on success factors, barriers and benefits.

- In-depth case studies of six well-established PHR projects.

- A literature review, focused on UK research, but supplemented by US studies.

- Discussions with the NHS in Wales, Scotland and Northern Ireland to understand the status of their work on PHRs and their plans.

The main findings are set out below.

1   There is little information available on the number of people using PHRs, what they use them for, and how frequently they are used. From the information available, it is not clear how many of those who are offered a PHR go on to register, nor the proportion who continue to use them on a regular basis.

2   From the evidence, demographic factors (eg age, gender, deprivation and ethnicity) do not appear to have a significant impact on PHR adoption or ongoing use.

3   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.

4   To date, PHRs tend to have been implemented by individual organisations (eg a hospital, GP practice) rather than by a care community. Hence there is little experience yet of the information governance, semantic interoperability etc issues that are likely to be raised when bringing together information from multiple sources into a single coherent record.

5   Access by patients/citizens to care provider electronic patient records is mainly 'view only'. While the use of personal health apps and monitoring devices is growing fast, there have been few organisations that have transferred information from them into care providers' electronic records, where they can be shared with health/care professionals. Hence it is unclear as yet how health/care professionals would value or use these patient-generated data, nor how their working practices would need to adapt.

*Note: 'health and or care professionals' are referred to throughout as 'health/care professionals'.

6   Health/care professionals tend to continue to use their own care provider electronic records. Surprisingly, we were unable to locate a significant implementation of shared records to support shared care anywhere in the UK, ie where patients/citizens and health/care professionals contribute to the same record within a shared patient pathway.

7   PHRs are currently mainly used to view blood test results on a timely basis, to communicate with care professionals (via secure email-like services) and to obtain information on a patient's condition and treatments. There is also substantial use of appointment booking, requesting repeat prescriptions and viewing patient history, through online access to GP systems (known as 'Patient Online').

8   The literature review found evidence of unmet needs. Patient expectations were not being met by PHRs; in particular limited content of the record was being made available to patients and there was an inability to bring together records from different care settings into one place.

9   The survey and case studies indicate that time taken from planning through procurement to initial implementation can be around 3 years. Roll-out to patients/citizens is generally a gradual, phased process, taking several years, with ongoing iterative development of the PHR services taking place in parallel. Case studies reported that roll-out and iterative development have not yet been completed and are likely to be ongoing for the foreseeable future.

10   Commonly identified success factors in the adoption of PHRs were: health/care professionals encouraging patients, good communications through multiple channels and support for users at the start (eg demonstrating use of PHR). The importance of involvement of patients and professionals throughout design, development and testing was also a common theme.

11   A barrier to use that was identified in the literature was concern about confidentiality and security, raised both by patients and health/care professionals. However, patient concerns appeared to diminish once they used the PHR. PHRs can also help to increase patient control, by providing tools to increase their empowerment and involvement in their care.

12   Case studies reported that health/care professionals' concerns about additional workload caused by PHRs had not in fact materialised in practice. Potential time savings through PHRs were identified, but only in a small study with two enthusiastic practices, so this needs to be validated on a larger scale with more typical clinicians. In addition, both the uptake by citizens and the uses to which PHRs are put are currently limited; hence the impact of larger-scale PHRs with more interaction with health/care professionals is unknown.

13   The implementation of PHRs has tended to focus on enhancing information sharing and communication between patients and their health or social care providers. There is little evidence of PHRs being used to change the methods of delivering care. The failure to fully utilise PHRs for health service improvement projects may mean that potential improvements in cost-efficiency and effectiveness are not being realised.

14   Many of the case study sites had invested in PHRs on the basis that they are 'a good thing', but with little evidence of quantified benefits. The literature review findings indicate that patients are generally positive about PHRs. However, evidence in the UK is based on small studies that obtained views on how patients feel about PHRs, rather than on well-designed quantitative studies that objectively assessed their impact on health processes or outcomes. The UK studies so far also largely engaged with a self-selected group of PHR users (both patients/clients and professionals), rather than a study of a more general population, including people who initially prefer not to use them.

15 Short-term funding sources appear to have been used for investment in PHRs, with a relatively high level of investment for a small number of patients. The lack of a viable business case could slow further developments and make existing PHRs unsustainable.

16 Recommendations for further research that could be commissioned by the National Institute for Health Research (NIHR) or other agencies are outlined below.

a   Understand what patients require from PHRs – what information do they want to see and what do they want to use PHRs for, and why (ie gain or benefit)? This understanding needs to include people who do not currently use PHRs and the requirements of different groups (eg adults, older people, children, people who are 'hard to reach', those with sensory and other disabilities and those with mental health issues, etc). Any study needs to examine requirements in a person-centred way across care setting boundaries, rather than from the perspective of specific care providers.

b   Explore and pilot projects that utilise the features available within a PHR to deliver health or social care in novel, innovative ways. This requires a greater understanding of user and provider attitudes to new models of care delivery, for example remote monitoring, virtual consultations or follow-up, and enhanced self-care supported by elements of the PHR.

c   Quantify the benefits, costs and risks from PHRs, including their impact on clinical/care service processes and on health outcomes for patients. This includes quantifying the costs and benefits to organisations of implementing PHRs, including impact on health/care professionals.

d   Identify information governance issues, including withholding sensitive information, consent, authentication, protecting vulnerable individuals, third party data etc. The aim of this research would be to identify acceptable, workable and efficient approaches.

Introduction

Background

The [NHS Five Year Forward View](#),[1] the NIB's report [Personalised health and care 2020: a framework for action](#)[2] and the [NIB work stream 1.2 roadmap](#)[3] 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 NHS England ambition is that patient access to their records should be extended to include all care settings and the ability for patients to write into their own record by 2018.

While there has been small-scale use of electronic PHRs in some care settings and by some clinical commissioning groups (CCGs), citizen take-up has been relatively slow. The most recent summaries and case studies of PHRs were published by the [Patient Information Forum](#)[4] and [2020health](#)[5] in 2012.

NHS England has provided the RCP's Health Informatics Unit (HIU) with grant funding to undertake a landscape review of current personal electronic health and care record activity in the UK.

For the purposes of this review, a PHR was defined in the project specification as:

> ... a digital tool that helps people to maintain their health and manage their care. It may do this by enabling them to capture their own health and care data, to communicate with health and care services, and/or to have access to their care record.

It may be that a different definition will be proposed as a result of the findings of this landscape review.

The landscape review will examine developments in PHRs since the Patient Information Forum and 2020health PHR publications of 2012.

Purpose

The aim of the landscape review is to collate information about the current status of PHR activity and best practice across the NHS, evidence of PHR benefits and learning about how to address barriers to adoption; and to identify equivalent activities, benefits and barriers in social care. This will then inform NHS policy and the roll-out of these important new technologies.

This report provides the findings of an online PHR survey that was live from 24 August 2015 until 29 September 2015, findings from six case studies[6–11] and a literature review that was carried out between June and September 2015.

Scope

The scope of the landscape review, as set out in the project specification, was sufficiently covered during the project. The scope included:

- UK PHRs only, with a particular focus on England
- PHRs that provide more functionality than just GP record access, appointment booking and online prescriptions
- electronic PHRs only
- recent PHR developments, with a particular focus on developments since 2012
- both health and social care PHR developments
- user requirements (but not researching them, as this is the focus of another NHS England project)
- the relationship between patients and their PHR requirements and clinicians (but not clinician requirements from integrated digital care records, as this is part of a separate NHS England work programme).

The scope excludes:

- non-UK PHRs
- paper-based PHRs
- issues regarding technical barriers to data flow between clinical systems and PHRs.

It is important to note that PHRs described in this report may have changed since the landscape review was carried out and readers should keep this in mind when considering the findings.

Methodology

A stakeholder mapping exercise was conducted to identify the following stakeholders:

- PHR users (members of the public or their carers who currently use or have previously used a UK electronic PHR)
- health or care professional users (people who currently use or have previously used a UK electronic PHR in a professional capacity)
- PHR implementers (health and care staff who have implemented or are planning to implement electronic PHRs in their organisations)
- PHR suppliers (suppliers who have developed or are developing electronic PHRs for use in the UK).

There were three methods used to produce the content of this report:

- an online survey
- a literature review
- detailed case studies.

In addition, discussions were held with the NHS in Wales, Scotland and Northern Ireland to understand their PHR activity and plans.

The online survey was developed by the project team and details were circulated to all identified stakeholders, including a request for them to cascade the survey invitation to appropriate contacts. The survey was live from 24 August 2015 until 29 September 2015.

Literature on PHRs was searched for on computerised databases – PUBMED, CINAHL and MEDLINE (via NHS Athens). Searches were carried out using medical subject headings (MeSH) terminology in the above databases. In addition to the electronic databases, in some instances specific UK-based PHR projects were identified using search engines to identify published literature. References from the initial literature search were reviewed for identification of further sources of literature. Systematic reviews, randomised controlled trials (RCTs), case control / cohort / cross-sectional studies as well as other descriptive studies were included in the literature review. Although the systematic reviews were classified as high level of evidence and mentioned accordingly in the review, case studies and reports were included to cover a wide range of studies and questions.

Six case study projects were selected by the project team so that they:

- provided updates on PHR projects covered in the 2012 reports
- were relatively mature, so that there were lessons to share
- spanned health and social care settings and both secondary and primary care
- were geographically dispersed within the UK.

The case studies were:

- St Mark's Hospital implementation of Patients Know Best®[6]
- myhealthlocker at South London and Maudsley NHS Foundation Trust (SLaM)[7]
- multimedia advocacy in Nottinghamshire[8]
- myhealth@QEHB (Queen Elizabeth Hospital Birmingham – QEHB)[9]
- Patient access to GP records[10]
- PatientView (formerly known as Renal PatientView)[11]

The case studies entailed interviews with a range of stakeholders involved in the projects (including patients, clinicians, social care professionals, information and communication technology (ICT) professionals, administrators, chief clinical information officers (CCIOs), chief information officers (CIOs) and suppliers). The discussions were supplemented by documents provided by the projects and other public information sources (including information on websites, YouTube, academic literature etc).

It is important to note that the case study projects are examples of leading PHR implementations and are thus not likely to be representative of PHR activity across the UK. The case studies are intended to provide lessons learned from early adopters that will hopefully be useful for others who are considering developing or implementing PHRs.

Findings from the survey, case studies and literature review

This section provides findings from the survey. Where relevant, findings from case studies and the literature review are also summarised to support or contrast with the survey findings.

There were 128 responses to the online survey, of which 98 were able to be used in the analysis. See Fig 1 for the types of survey respondents.

Fig 1: Types of survey respondents
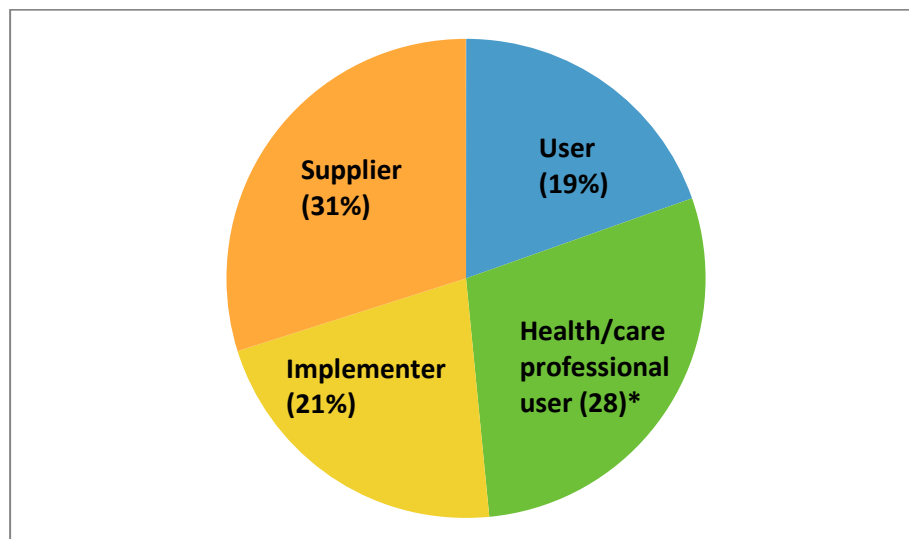
*Although 58 health/care professionals completed the survey, a review of their responses concluded that 30 had provided information on the clinical information systems they used rather than PHRs and thus their responses were not included in this analysis.

Some survey respondents were providing information on PHRs that were not yet in operational use. Their responses have been retained and included in this report where appropriate.

PHR components, individual users and organisational users

Survey respondents provided information on 39 PHR products (see Appendix 1). Respondents described their PHRs in different ways, with PHRs having different purposes and services (see Table 1). There was no single PHR that covered all potential services. Of the PHRs described by survey respondents, ten systems had a healthcare organisation focus, six were patient- or citizen-group specific, four had a social care focus and seven supported integrated care. In total, 12 PHRs were personal health apps or devices.

Table 1: Reported PHR components

Category	Definition	Examples
Patient/citizen-group specific	Focus on specific patient or citizen group or groups, including specific conditions	• eRedbook • Coordinate My Care • PatientView • SiKL (sickle cell disease PHR)
Organisation specific	Based on a particular organisation's record, eg GP practice, local authority or trust	• Patient Online • myhealth@QEHB • myhealthlocker
Pan-organisation integration tools and platforms	Platforms and services to draw together information from multiple electronic patient records (EPRs) and other sources	• Graphnet CareCentric • Microsoft HealthVault

| Personal health record apps | Apps that enable patients/citizens to record information on their health and link to their medical/care records | • uMotif
• My Medical |
| Sensors and monitoring devices feeding into PHR | Devices that can supply information to a PHR | • Activ8rlives
• My Pain Manager |

The PHR projects identified for the landscape review case studies were either patient/citizen-group specific (eg PatientView,[11] multimedia advocacy in Nottinghamshire[8]) or organisation specific (eg SLaM,[7] myhealth@QEHB,[9] Patient Access[10]).

Another related service was identified during the review – generic (cf health or social care specific) personal data stores (PDS), also known as personal data spaces, clouds or vaults. A UK example is Mydex (https://mydex.org/understand-pds/). These allow customers to store securely all kinds of personal data and to control access to it. They can have applications in many areas, eg holding identification information, health records, government data (eg driver and vehicle licensing agency (DVLA) data, tax records), council tax etc, so that data can be shared where needed to save having to re-enter it. There is also potential for PDS to contribute to 'big data' where people volunteer to share personal information that they provide. As PDS are relatively new, it is not yet clear how they will take off, but it is interesting to note that some health-specific personal data stores (such as Patients Know Best®) were initially based on these generic data stores (in that case, Mydex). The main challenges to adoption identified in a study on generic personal data stores carried out at the Cambridge Judge Business School[23] were legal (consent and control agreements), interoperability and the need to reach a critical mass in the context of a double-sided market: both individuals and organisations.

In total, 14 suppliers responded to the survey question on the number of registered users, with 2 others added subsequently from case studies (Table 2). Some of the responses may be reporting numbers in use outside the UK or user numbers of their electronic health record rather than a PHR, so these figures and the approximate median number of users per PHR system of 10,000, need to be treated with caution.

The number of registered PHR users per system is often small and there is little information available to measure regular usage (eg the average number of uses per month). No responses were provided on clinician usage rates of PHRs, probably because they are not the primary user. The usage pattern is shown in Table 2.

Table 2: PHR individual users

PHR	Approximate number of registered users	Approximate average number of uses per month
Aseptika monitoring devices	80,000	
Bodymap Apps	>3,000	
ClinicYou	>11,700	>500
Coordinate My Care	23,900	750
EMIS	1.5 million (Patient Online) 11,000 (PHR)	
eRedbook	1,340	
Fusion Fx Patient Portal	145,000	66,000
MyDiabetesMyWay	10,000	1,600
myhealthlocker	1,000	200
My Health Record	600	
Myhealth@QEHB	10,771 (from across the UK, aged 17 to 90)	

PHR	Approximate number of registered users	Approximate average number of uses per month
Nourish	600	
PatientView	45,645	10,000
Puffell/TimeCheck	5,000	
SmartCare person held file	10–50	
uMotif	1,000	
multimedia advocacy in Nottinghamshire	>100 families	

N of supplier respondents: 17
Approximate median number of users: 10,000

The case studies mainly supported the survey findings that only a relatively small proportion of patients register to use PHRs and only a small proportion of registered users access PHRs on a regular basis. For example, although approximately 1,000 people are signed up for myhealthlocker, there are only around 200 uses of the PHR per month. It will be important to understand why this is the case and what could encourage individuals to make more use of PHRs and their features.

It was noted from the case studies that the nature of the users' condition, the intensity of monitoring required as well as the availability of a suitable parameter to measure may affect the level of use, eg renal patients with kidney disease may want to check their potassium levels frequently. People without long-term conditions are less likely to use their PHR as regularly, as they have less frequent contact with health and care services and do not have the same need to monitor their condition through test results. However, with 17 million people with long-term conditions in the UK, this could add up to a significant demand for PHRs that provide easy access to key disease monitoring variables.

In the survey, suppliers were asked about the number of organisational customers for their PHR (see Table 3). Some suppliers sell their products directly to patients, rather than to organisations, so did not respond. Some suppliers may have reported the number of organisations using their electronic health record or integration platform while others may have offered optimistic figures, so the numbers should again be treated with caution.

Table 3: PHR organisational users

PHR	Trusts	Commissioners	GP practices	Local authorities	Social care providers	Health boards
eRedbook		1				
Graphnet	40		1,100			
HealthVault	6		2	1	1	
Liquidlogic Autonomy Portal					10+	
Medipad	1					
MyRightCare	4	2	50	2	1	
OLM – MyLife				25+	1	
Patients Know Best®	61	4	32		2	
Puffell /TimeCheck		8		5		
Self Care Framework		1				7
uMotif	10					

N of supplier respondents: 11

Access to electronic health/care records via PHRs

In the survey, 18 suppliers told us that their PHRs could link to electronic health records (EHRs). In total, 11 suppliers told us that their products did not link to EHRs. Of these, from other responses, some were theoretical possibilities rather than operational. There were 15 supplier responses to a question asking about what information could be accessed via the PHR. Table 4 shows the types of information that are generally held in electronic health/care records and how users can interact with this information (see Appendix 2 for a breakdown by supplier). Most of the types of information that are generally found in electronic health/care records are viewable to users. This is most common with medication and care/support plan information, but less common with family history, screening records, consultations, patient history and investigation results. The ability to add new information is available in just over half of the PHRs and is most common with patient history. It is less common with consultations, screening records, assessments/examinations and investigation results – all of which would traditionally be recorded by the care professional. The ability to annotate information (ie to add comments) is less common, with just over one-third of systems providing this capability. It is common with care/support planning.

Table 4: Access to electronic records via PHRs

Types of information that are accessible via PHRs	Ways to interact with the information			
	View	Ability to add new information	Ability to annotate	Not available
Medications/prescriptions	100%	57%	43%	0%
Vaccinations	80%	60%	40%	6%
Allergies	86%	50%	46%	0%
Summary of medical conditions	80%	50%	40%	0%
Investigations (eg pathology tests, X-ray reports)	73%	40%	40%	6%
Patient history	73%	66%	46%	0%
Family history	50%	50%	33%	13%
Letters and other documents (eg hospital discharges)	80%	46%	33%	0%
Care/support plans	93%	50%	50%	0%
Assessments/examinations	80%	40%	33%	13%
Referrals/appointments	86%	50%	40%	6%
Screenings	66%	33%	40%	13%
Consultations	73%	40%	40%	13%

N of supplier respondents: 15

Findings from the case studies demonstrated that PHRs are not fully integrated with organisations' electronic health/care records. Most of the case study systems provided access to some data in the electronic health/care records. The main information that is being made available is investigation test

results, letters, medication and a summary of patient history, with appointments also being made available in two of the case studies.

The ability for patients to contribute to the organisation's electronic health/care record was present in three of the case studies. In each, uploading the information into the electronic health/care record was controlled by the clinician. Myhealth@QEHB uploaded patient-provided information as documents, so it can be viewed but not, for example, included in trend analysis with hospital data.[9] We also spoke to EMIS about their PHR development with Apple Healthkit. This allows a specific dataset of patient-entered information to be coded and uploaded into the GP system but displays separately, so that it can be easily distinguished as patient-provided data.

None of the case studies allowed annotation of official electronic health/care record information. Where patients identified record inaccuracies, all organisations had processes in place for patients to contact them to request amendments.

PHR services

This section analyses the services provided currently by PHRs. In the survey, we divided these into the following four categories:

- communicating with your care team through the PHR
- seeing your medication records and tools, to review them and remind you to take medication
- services to help you to plan and manage your own care
- information and support services.

Communicating with your care team through the PHR

Table 5 shows the communication services provided by PHRs (see Appendix 3 for a breakdown by supplier). The survey demonstrated that, currently, communication with care team members via the PHR is the most commonly provided service (approximately two-thirds of respondents). Online consultations are only provided by one-third of respondents, but an additional third are developing this functionality. Booking appointments is provided by just under half of respondents.

The Patient Online programme found that users frequently booked their GP appointments online. Of the 196 people who responded to a Patient Online survey, 78% had used this feature and 76% found it easy to do so. Roughly half of respondents said that booking appointments online helped them to remember when their appointment was and 57% said that online appointment booking provided them with more choices of times/dates. However, only 34% of respondents said that they could get appointments sooner by using the online booking feature.

Table 5: PHR communication services

Communication with care providers	Operational	Offered but not yet implemented	Under development	Not available
Online consultations via the PHR	25%	13%	33%	29%
Communicating with care team members via the PHR	63%	8%	13%	17%
Booking appointments via the PHR	33%	8%	25%	33%

N of supplier respondents: 24

The PHR landscape review survey also asked about the tools provided for users to communicate with their care team (see Table 6). The majority (80%) provide email-type messaging. Discussion forums are available in 32% of PHRs. Real-time communications (video (20%), audio (12%) and instant messaging (28%)) are less frequently available.

Table 6: PHR communication methods

Communication methods provided by the PHR	Percentage
Secure email-type messaging	80%
Discussion forum	32%
Secure instant messaging	28%
Video (eg video calls)	20%
Audio (eg voice calls)	12%
None	8%

N of supplier respondents: 25

The case studies generally supported the findings from the survey regarding communication services.

In total, five of the six case studies provided tools for communicating with the care team. Booking appointments was provided only by Patient Access. None of the case studies yet provide online consultations, although they are planned by QEHB, who have done detailed work on the processes and technical services involved in testing/setting up etc secure video connections with patients. SLaM explained that, although remote consultations had been trialled with some patients, there was limited uptake because patients preferred face-to-face meetings with their clinicians.[7] There is little experience or evidence of what types of patient interaction may be suitable for online or virtual consultations.

Case study systems provided secure email-type messaging, rather than instant messaging. The wiki website tool in Nottinghamshire used by people with special educational needs and disabilities (SEND) allowed service users to use a variety of multimedia (including video clips, audio files, sound clips and images) to communicate with people involved in their care.[8] This allowed young people to tell their story their way, so that they were more clearly understood.

Discussion forums were provided by some of the case studies, but with mixed experiences, and issues were raised relating to forum moderation. A service user using the myhealthlocker tool explained that the PHR allowed him to communicate with others, which prevented him from feeling isolated. Myhealth@QEHB enabled patients to identify others who were willing to share their profile and to ask them to join their networks, but those networks were run outside of myhealth@QEHB by patients (such as Facebook) and the voluntary sector etc.[9]

PatientView had decided to remove the discussion forum feature after patients were inadvertently identifying themselves and instances of sharing poor advice were identified.

Seeing your medication records and tools to review them and remind you to take medication

Table 7 shows the medication services offered by PHRs (see Appendix 4 for breakdown by supplier). The survey shows that while access to medication information held in an EPR via the PHR is provided by 14 out of the 15 supplier respondents, most PHRs do not provide additional medication services. Just under half of respondents enable patients to obtain more information on their medication via the PHR. Few PHRs provide tools to enable patients to review and identify errors in their medications records or to remind them to take their medicines.

Not surprisingly, the number of PHRs that allow ordering of repeat prescriptions is low, as this is likely to be limited to GP systems. In fact, the Patient Online survey found that 156/196 (88%) of respondents used this online feature and that 83% found the process straightforward.

Table 7: PHR medication services

Medication services	Operational	Offered but not yet implemented	Under development	Not available
Ordering repeat prescriptions through the PHR	21%	4%	13%	63%
Medicines reconciliation (eg checking the accuracy of medication records, reporting side effects etc)	14%	5%	14%	68%
Medicine adherence (eg reminders to take medication)	29%	4%	17%	50%
Getting more information about medication (eg what it is used for, interactions etc)	43%	9%	13%	35%

N of supplier respondents: 24

Some case study PHRs provided information about their prescribed medications. For example, myhealthlocker provided information about what prescribed medications were used for, the potential side effects and instructions for how to take the medicine (eg 1 x 50 mg tablet daily).

We are aware of pilot projects that are using PHRs to support remote medication monitoring; for example, patients on immunosuppressant drugs can have blood tests at a clinic, with results shared and discussed remotely via their PHR. Clinicians at SLaM told us about a tool for users to report how they were feeling.[7] They found it useful to receive information about how patients were feeling on their medication without having to wait for the next medication review meeting.

The PatientView case study[11] included findings from a medicines reconciliation pilot, which identified potential patient safety, patient experience and cost-efficiency benefits. However, the approach was labour intensive and more work is needed to identify how this could be done routinely.

Services to help you to plan and manage your own care

Table 8 shows self-care and shared care services offered by PHRs (see Appendix 5 for breakdown by supplier). Of the 22 survey respondents to this question, around two-thirds of PHRs can record information to enable patients to monitor and track their own health, and slightly fewer can record information to be used in a crisis, to support care planning, to be linked to monitoring devices and to enable patients to record health outcomes. Around a half can be used for setting personal goals, agendas, prompts, to-do lists and reminders. Only 22% of PHRs enabled users to rate service providers.

Table 8: PHR self-care and shared care services

Self-care and shared care	Operational	Offered but not yet implemented	Under development	Not available
Linking to monitoring devices (eg blood pressure, weight etc)	48%	13%	13%	26%
Recording information to help patients/service users monitor/track their health/condition	67%	4%	13%	17%
Setting personal goals	55%	9%	9%	27%
Setting agendas and prompts	52%	5%	14%	29%

Self-care and shared care	Operational	Offered but not yet implemented	Under development	Not available
To-do lists and reminders	41%	9%	23%	27%
Recording information to be used in an emergency/crisis	52%	13%	13%	22%
Care and support planning	57%	9%	13%	22%
Rating services of care providers	21%	8%	13%	58%
Recording health outcomes	58%	4%	8%	29%

N of supplier respondents: 24

A theme from some of the case studies was that PHRs can enable patients to be more actively engaged in the care planning process. For example, the wiki website tool in Nottinghamshire allowed young people with SEND and their families to upload videos of the young person, to be shared at care planning meetings.[8] The myhealthlocker PHR allowed patients to access their care plans, which was the most frequently used feature of the PHR.

PHRs facilitate shared care by enabling patients to share their health and care information with other people involved in their care. Some of the case study PHRs had a feature where users could invite others to access the PHR (eg wiki website tool in Nottinghamshire,[8] Patients Know Best®[6]) but others required users to share their login details with those people who they wanted to give access to. The latter is problematic and potentially unsafe, as it may be unclear who is entering data into the PHR when several people are accessing the record under the same login details.

Some of the case study PHRs enable patients to record their own information about their mood, health condition etc, and to monitor it over time. For example, PatientView enables patients to plot trends in their test results over time. None of the case study PHRs currently enable patients to upload information from monitoring devices. We also talked to EMIS about their PHR development with Apple Healthkit and they told us about a pilot with a patient at a Leeds practice who used a blood pressure monitoring device to upload readings to Apple Healthkit, where they could be shared with the practice. This service was liked by the patient and the clinicians using it in the practice, but it raised requirements for new ways of working that need further research, including responsibilities for setting up and managing devices and their connection to the PHR, and incorporating patient-provided information into the practice workflow. None of the case studies provided services for rating provider services.

PHR information and support services

Table 9 demonstrates that information about 'illness/conditions', 'treatment and care options' and 'local services' are available in many PHRs (see Appendix 6 for a breakdown by supplier). However, fewer than half of the respondents have the functionality to help users 'get support' via the PHR (for example, tools to help people quit smoking or take more exercise).

Table 9: PHR information and support functionality

Information and support	Operational	Offered but not yet implemented	Under development	Not available
Finding out about your illness/condition	75%	8%	4%	13%
Information on treatment or care options	61%	9%	4%	26%
Getting support (eg quitting smoking)	48%	4%	13%	35%
Finding out about local services	63%	0%	4%	33%

N of supplier respondents: 24

Most of the case study PHRs enable users to access information resources. In addition to generic information (eg websites, support groups, documents etc), some provide more tailored information. For example, PatientView provides users with links to explanatory information about diagnoses, test results etc using the coded data to link to the appropriate information resource. For example, the normal result range for a particular test can be viewed by hovering over the result with the cursor. Myhealthlocker provides users with a list of local healthy living and wellbeing groups. Myhealth@QEHB provides users with educational tools, such as links to online tutorials for how to use insulin pens correctly.[9] This is part of the development of a more pathway-based approach, providing services for diabetes patients throughout their pathway, from initial diagnosis, through monitoring, follow-up and review.

We sought advice from HIMSS Europe about whether they had a maturity model for PHRs. Their response was that they do not have a specific maturity model that measures PHR adoption trends. However, they do have an ambulatory electronic medical record adoption model (EMRAM) (also called the primary care EMRAM, which is completely separate from the hospital EMRAM). This includes a requirement for patient engagement through a patient portal. In the patient portal, the capabilities that a primary care practice gives the patient include:

- access to clinical summaries (eg an after-visit summary)
- access to diagnostic results (eg laboratory and imaging)
- ability to book an appointment
- ability to request repeat medication
- ability to securely communicate with their primary care provider
- ability to make payments for care provided
- access to information about diagnoses or conditions documented in the patient's electronic patient record
- any other capabilities.

They also reported that HIMSS Europe is beginning to receive more interest in primary care EMRAM assessments from outside the USA, where it is currently used.

The above model does not take account of the need to access records across care settings; nor does it include some of the interactions that patients may have with the PHR. By analysing the PHR services and access to health and care records, categories of PHR (that loosely form a hierarchy of PHR maturity) have been identified (see Table 10).

Table 10: Categories of PHRs

PHR aspects	Features
Connection	- Standalone (eg wiki website tool in Nottinghamshire)[8] - Connected to single organisation (eg myhealthlocker, myhealth@QEHB) - Connected – pan-organisation (eg PatientView, Patients Know Best®)
Interaction with EPRs	- View only (official record) - View only, but with user display/language - Add comments/annotate - Update/upload own data into combined record

PHR aspects	Features
Support for users	• Online explanatory notes linked to specific data items • Links to relevant websites/information sources • Offers advice based on own data (decision support) • Online support from other users or organisations (discussion forum)
Scope	• Patient/citizen-group specific, including specific condition(s) • Organisation or care setting specific • Universal health and social care

Time taken to implement PHRs

Of the 20 implementers who responded to the survey, nine provided details of the amount of time it took to implement their PHR product. On average, it took a total of 34 months to complete implementation from start to finish, comprising (on average):

- 9 months for planning
- 6 months for procurement
- 11 months for development and configuration
- 8 months for implementation including piloting.

On average, of the 20 implementers who responded, their PHR product had been in live operation for around 3 years.

The case studies found similar results to the online survey. The roll-out across patients or citizens is generally a gradual, phased process that takes several years. There is also a need for ongoing iterative development of the PHR services. For example, myhealthlocker is currently being updated and will shortly be released with additional functionality and an improved interface.

Factors associated with successful implementation

Survey findings

Table 11 shows the results of a thematic analysis of the qualitative responses from suppliers and implementers about what appeared to work well in the implementation of their PHR project.

Table 11: Reported good practice in PHR implementation

Theme	Sample quotations
Early engagement with stakeholders	'Get all stakeholders involved as early as possible – involve patients in all governing groups' 'Patient involvement from the outset' 'Buy in from all health and care organisations' 'Engagement with the voluntary sector, engaging with managed clinical networks'
Health/care professional engagement	'A key success factor to the programme will be to ensure that the hearts and minds of affected staff are won over throughout the project life (and beyond)' 'Targeting secondary care clinical teams'
Removal of previous record systems	'Removing paper record routine availability'

Theme	Sample quotations
Focus on and demonstrate positive outcomes	'Showing the patient outcomes to GP'
	'Emphasising benefits to patients'
Sufficient pilot testing	'Start with proof of concept / pilot prior to wide rollout'
Supporting users in the early stages	'Face-to-face staff training with users'
	'Local events aimed at service users and health professionals to show them different apps available'
Champions to promote the PHR	'Identifying clinical champions and early adopters who embrace change in order to skill up others'
	'Using self-help third-party groups (charities) to spread the word'
A good marketing/communications strategy	'Intensive marketing/relationship building'
Appropriate information governance practice	'Make sure we have Information Governance and other paperwork in place'

N of respondents: 29

Case study findings

Many of the case studies described similar factors to those reported in the survey for good practice in implementation of their PHRs. A common theme was the importance of health/care professionals in encouraging patients to start using the PHR; hence professional leadership from the start is key.

Another common theme was the strong belief that PHRs were 'the right thing to do', but that there is a lack of evidence of benefits underpinning decisions to embark on PHR projects. In some case studies, there was an assumption that PHRs would be of benefit to users and the service but there was little formal assessment of the users, nor what they would use the PHR for and no evaluation following PHR implementation. Few of the PHR case studies had a business case prior to implementation and there was often no quantifiable return on investment or service improvement plan. Furthermore, some of the PHRs were used by particular specialties and by keen clinicians but had not been extended more generally across the service.

Literature review findings

Engaging clinicians in PHR development and iteratively improving it over years to meet patients' needs was found to work well.[29] In the systems that were connected to the care providers' EHR (17/23), 76% showed a benefit in the use of the PHR. However in standalone PHRs, benefits were seen only in 50% of the studies (3/6).[30]

Having an appropriate framework of governance and guideline development before the systems are in place is important.[15] Enabling new unplanned activities when patients access their records encourages use, eg reminding patients about their consultation and printing letters in case of emergency, raising discrepancies and self-monitoring.[32] Control of access to a PHR by patients, who may choose to give permission for family, health/care professionals and others to view their data, is also seen as important.[26]

Studies reported certain strategies that helped with adoption of the PHR and its use at various stages. The most widely reported strategy was directly linked to the benefits offered by the PHR (discussed in the benefits section), including ability to monitor their health, feeling empowered etc.

Initial patient support to use the PHR increases persistent patient use. Having a nominated administrator helps patients to complete their first login immediately after registering and this was found to influence subsequent login behaviour. The desire of patients to share their records with

clinicians also encouraged their use. Over half of the patients in one study that included renal patients reported that they wanted to share their records with other health/care providers.[29]

A systematic review of 17 studies found that:[15]

- female adult patients were more likely to use the PHRs
- there was better patient satisfaction if healthcare professionals responded quicker to patient concerns
- 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 to use the PHR.

Identifying patients with certain diseases, such as diabetes, was found to be likely to increase uptake.[30] The use of focus groups prior to design of the PHR helped developers to customise the PHR according to patients' wishes.[16] Several other patient reported outcomes measures (PROMs) were added based on the focus groups in this study. Certain other strategies that worked well included:

- use of patients who were excellent in computer literacy to train other patients[16]
- lending devices such as tablets or smartphones to those who did not have access to the technology[16]
- promoting the initiative prior to launch, both via the doctors and media coverage[32]
- managing patients' expectations regarding who sees the readings that they enter onto the PHR[26]
- patients getting timely information and updates on their PHRs, which enabled them to be better prepared for consultations and to instigate communication with healthcare staff[26]
- real-time update of test results is vital – patients report peace of mind, reduced unnecessary anxiety[26]
- encouraging use can reduce concerns about privacy, eg 28% patients were concerned about security initially but only 15% were concerned after using it.[26] Also 38.5% of patients indicated that record access had improved their trust in the health centre and their confidence in sharing information or decisions with their doctor, while 61.5% indicated that it had not affected these factors.[28]

In a study carried out in one practice in the UK (Patient Access to Electronic Records System), aspects that were reported as helping with the implementation of a PHR included:[19]

- nurses in vaccination clinic reminded mothers to get access
- doctors asked patients at each point of contact
- local care record development board consisting of clinicians, managers and patients were involved in the project – this encouraged further practices to use the system
- a Caldicott Guardian was used to hold a series of meetings with the public and the local press to explain the importance of the information sharing process
- a local library set up a 6-week IT course to teach patients about basic internet use
- activities to increase recruitment involved a campaign launched in collaboration with the government.

In the MyDiabetesMyWay study in Scotland, posters were displayed in all community pharmacies for a 6-week period, and social media including Facebook and Twitter were used to encourage moderated discussion among the users.[14]

PHR implementation challenges and ways to overcome them

Table 12 shows the results of a thematic analysis of the qualitative responses from suppliers and implementers about the challenges faced in implementing PHRs and the identified possible mitigations.

Table 12: Reported PHR implementation challenges and mitigations

Challenges	Sample quotations	Mitigations	Sample quotations
Integration with existing systems	'Integration with UK GP system suppliers' 'The time taken to re-arrange the hospital services to allow implementation of the system'	Work with supplier and local IT teams	'Ensuring that the technical environment is made available at the right time and meets agreed specifications and is clinically safe and secure'
Clinical engagement/culture change	'Lack of acceptance from medical profession; culture of self-care' 'Clinician aversion to or fear of technology' 'Some clinician reluctance, but this is quickly changing'	Champions to encourage others	'Identifying clinical champions and early adopters who embrace change in order to skill up others' 'Peer opinions, patient influencers'
Information governance barriers	'The Information Governance culture has been slow to change in order to gain local Information Governance approval' 'Data security and information governance. Rules make it hard to hold any information that is of real use long term due to the public facing nature of the system'	Collaborative working with information governance experts	'Support from Dame Fiona Caldicott has been instrumental in unlocking this barrier and recently Information Governance approval has been expedited'
Low user sign-up	'Raising awareness with patients' 'Raising awareness with patients and encouraging healthcare professionals of all specialties to signpost patients towards it'	Demonstrate benefits	'Emphasising benefits to patients, giving ownership and ability to self-manage own condition'
Resources	'Limited funding has impacted the pace of development and adoption rate' 'Lack of budgets for new things' 'Main challenge is finding sustained funding for our solution'		

N of respondents: 32

Case studies reported similar challenges to those identified in the survey. Information governance challenges were sometimes reported as a barrier even when patients were happy for their information to be shared. For example, some professionals were concerned about people with SEND being filmed for the multimedia advocacy project in Nottinghamshire, even when users and their families had provided consent.[8] The Patient Access case study includes some guidance on information governance issues that address some of the concerns that were expressed in survey responses.[10]

The case studies found that clinician concerns about PHRs leading to increased workload were unfounded. Health/care professionals needed to adapt their ways of working, but PHRs did not lead to increased professional burden. Case study organisations had made clear that communication via the PHR should not be used in emergencies and clarified what patients should expect in terms of responses to communications via this route. Some had also set up and used group emails rather than individual addresses, to enable coverage for leave and to share the workload. Both patients and clinicians reported benefits in having the record of previous communications available to them to refer back to.

Another theme from the case studies was that the current PHR projects required a significant amount of effort and drive for initially a relatively small numbers of users. Given that large-scale implementation and utilisation of PHRs is currently untested, it is difficult to predict the impact on workload and clinical work patterns. Similarly, the costs and potential efficiency and cost savings are so far not fully known.

Some projects were funded through one-off funding sources, which create a challenge for further development of the PHR. One case study explained that they had to meet certain requirements set out by the funding organisation, which impacted on the direction of the PHR implementation. Some of the funding for the myhealthlocker PHR was assigned to the research department, which meant that the PHR had to support research in addition to the primary focus of clinical care.

Literature review findings

Barriers are reported separately below for those that relate to patient adoption and use and those that relate to organisational uptake. The first findings relate to patient adoption and use.

A UK-based study[23] found that a total of 28 of 213 respondents (13%) had registered to use the system but had not accessed their records. The main reasons for not accessing records are outlined below.

- eighty-two per cent included technical difficulties, for example difficulty logging on, network problems and forgotten passwords
- five (18%) reported not using the system because they did not have health problems
- thirty-three per cent of patients (n=56/169) reported difficulties with understanding the content of their medical records: the most commonly reported difficulties related to abbreviations, medical words and terminology, and the meaning and significance of test results
- sixty-three (38%) had found errors – these included medical events or procedures not being recorded and inaccurate information about allergies and health conditions.

Another UK-based study on a diabetes PHR showed that 58.5% were simply not interested or felt they already had the information they needed, while 41.5% described technical barriers including non-availability or access to a computer or the internet.[14] In a systematic review, several studies reported disadvantages with access to online technology for other groups, such as those in poorer health and vulnerable groups.[15] Six studies report that some were disadvantaged by having a lack of access to the internet while others reported having no such barrier. Healthcare professionals were concerned that patients would have unnecessary stress and anxiety if results were not moderated. However, another systematic review found that only 1–8% (n=5391) of patients stated that viewing consultation notes caused confusion or worry, or that they felt offended by note comments.[25]

Results from the HealthSpace project suggested that patients perceived HealthSpace as neither useful nor easy to use, and its functionality aligned poorly with their expectations and self-management

practices. The main concerns were the design of the technology and the mismatch between this and their expectations.

In conclusion, the following were identified as barriers from the literature review:

- limitation of content in relation to patient expectations
- patients unable to understand terminology
- loss of trust due to errors in the PHR
- patients lacking IT knowledge and support
- patients being too ill to use the PHR
- clinicians being unsure about the use of the PHR.

The following findings relate to barriers to organisational uptake of PHRs.

Healthcare professionals needed support staff to filter messages,[15] and six studies reported privacy concerns from healthcare professionals. Health professionals were also concerned that viewing notes could potentially be offensive to patients or could cause an adverse reactions, and that this could impact negatively on the doctor–patient relationship.

A further barrier was a lack of usability for some patients eg initial login process was found to be 'a bit protracted' and restricted access to content as perceived by some patients.[32] Patients and clinicians are not usually fully aware of the functionality and settings, eg the discussion forum was moderated but patients and professionals did not know this.[26] Initial uptake from clinicians was slower – they were struggling with clear examples of how the PHR could be adopted in real use cases.[24]

In a questionnaire survey[28] of 42 people including clinicians, practice managers and patients in the UK, the following reasons for non-usage were given:

- a lack of priority
- lack of internal agreement
- perceived workload
- uncertainly about operating procedures or likely benefits
- lack of patient demand
- security concerns.

Findings from a systematic search of reviews[20] found that the poor uptake of PHRs was driven by healthcare professionals who are wary of patient access to medical records, fearing that it may cause patient anxiety. Doctors have concerns about shared medical records and 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 handwritten notes.

Clinicians had concerns about the additional burden and workload from online access but found their fears were only partly realised.[25] Few intervention group clinicians felt that emails were too lengthy (14.6%, n=43) or were concerned about incomplete information (10%). Clinicians did not always explain how the patients were to use the system. Health records are not always well understood by clinicians, and cultural change for many clinicians was more of a barrier than the use of the technology itself.

Many patients would not be willing to pay for, or only placed a low value on, online services such as online communication with clinicians[25] and those who had communicated with their clinician electronically for at least a year had a lower willingness to pay than those who did not have access (p=0.0028).

Factors related to adoption and use of PHRs

This section covers how people find out about PHRs, what PHRs are used for and when. It also includes user and health/care professional users' views of how adoption could be encouraged. It provides findings from the survey, case studies and literature review.

Survey findings

Of the 18 PHR users who responded to the survey, the majority said that they started using the PHR after being told about it by their health/care professionals. Other respondents said that they found their PHR online or heard about the PHR by other means (eg they heard about it at a conference etc). The majority of users accessed their PHR on a daily (25%) or weekly (25%) basis, indicating that the responses were mainly from enthusiastic users or those needing significant interaction with their health/social care providers. The most common reasons for patients using PHR services were:

- finding out more information about their illness/condition (43%)
- ordering repeat prescriptions through the PHR (38%) (this may be Patient Online rather than PHR)
- getting information on treatment/care options (36%)
- recording information to help them keep track of their health/care (36%).

Table 13 shows the purposes for which PHR user respondents were mostly likely to use their PHR.

Table 13: When PHRs are mostly commonly used

When PHRs are used	Percentage
To order repeat prescriptions	36%
Before appointments	27%
After appointments	27%
When I want to provide feedback	10%
To check test results	9%
To book appointments	7%
When I need advice	0%
When I am feeling unwell	0%
When I need to change my care/support plan	0%

N of user respondents: 11

The survey finding regarding ordering repeat prescriptions via PHRs was not reflected in the case studies. This is probably because only one of the case studies was primary care focused, which would be the main route for ordering repeat prescriptions.

Case study findings

The Patient Access case study[10] included findings of an analysis of when patients access their primary care record and what they used it for – mainly to save time, eg looking at test results online rather than phoning the practice, or to obtain information (eg for insurance purposes) or checking vaccination status prior to a holiday etc. The PatientView case study[11] found that users mostly logged on to their PHR after appointments, to check test results. The study also found that patients logged on prior to appointments, but has not analysed the reasons for this. Few of the other case studies had evaluated when users accessed their PHRs. There seems to be little evidence about what people use PHRs for and this is an area where more research would be helpful.

Literature review findings

Patient use of the PHR varied among the studies.

- In one study patients accessed the PHR between once and twice on average. Use was higher if the patients had long-term conditions and some patients only used it out of curiosity.
- In another UK-based study, all but one patient had been using record access for 10 or more months.[28] Most (84.6%) had viewed their record six or more times since registering, and 30.8% had viewed it more than 10 times. Most (84.6%) had used the system once or more within the preceding fortnight.

The following PHR functions were found to be most useful by patients:

- discussions by contacting the healthcare team online[12]
- monitoring test results[12,26,28,32,34]
- reading letters to and from those involved in their health/care[28,34]
- looking at information concerning past treatments[34]
- checking records prior to a consultation.[28]

With regard to communication with health/care professionals:

- patients used the PHR to contact doctors and nutrition nurses more than dietitians or administrators.[12]

Relating to those who were more likely to use / not use the PHR:

- the most frequent users tended to have a condition, illness or injury that required regular medical treatment[34]
- greater deprivation was associated with substantially reduced probability of continuing to use PHR after 6 months[29]
- younger people (aged below 35 years) appeared to be less likely to use the PHR than those aged 35 and over in the myhealthlocker project;[31] in addition, usage did not differ by gender, diagnosis or length of time using services
- those in poorer health accessed records more than those reporting good health; there was no significant relationships between the number of uses and age or ethnicity.[34]

Certain aspects of the PHR use were more tailored to disease-specific features. In a diabetes PHR project, MyDiabetesMyWay, the most used pages on the website included: diet, foot care, causes of diabetes, insulin pumps and healthier lifestyle.[14] During the 3-year period, the most viewed items were laboratory results (18.2 per patient) and the most accessed graph was for HbA1c levels (4 per patient).

Patients were also most likely to use the PHR when they were worried about result (62%), or after a visit to their hospital or GP (56%).[26] Also, they were more likely to check the PHR when they had just recorded an abnormal result. The evidence from the included studies suggests that the viewing of laboratory results is the most useful part of the PHR. This is consistently reported across the majority of the evidence.

The Patient Online survey found that 18/39 (46%) respondents found looking at their health information online prior to appointments helped them prepare for the appointment.

Survey findings

Table 14 shows the results of a thematic analysis of users' qualitative responses about what actions could encourage others to use a PHR.

Table 14: Encouraging others to use PHRs

Theme	Sample quotation
Fully viewable health/care records	'Full read-access to medical record, with possibility to ask for clarification or to challenge conclusions'
NHS systems integration with PHRs	'My PHR isn't the problem, the problem is the NHS is 10 years behind and can't interact with it, but my PHR has full capability for them to do that if they wanted to' 'Integration with GP EHR'

Ability to add to their record	'Opportunities for me to add relevant data'
Contacting health/care professionals	'More interactivity for contact with health services/professionals'

N of user respondents: 8

Case study findings

The individual patients who were interviewed for the case studies said that it would be useful to have access to their entire record in one place rather than having access to specific parts of the record via multiple tools. One patient said that she kept all her scanned letters from different care providers on her iPad, and had uploaded some to her myhealth@QEHB record.

An additional theme from the case studies was that passionate user and clinician advocates were particularly important in encouraging others to sign up for PHRs.

Literature review findings

In a case report of the PatientView PHR, which is used by over 11,000 people in the UK, initial promotion was undertaken during patient consultations and by local advertising.[29] Age and treatment group were significant in determining the initial use of the PHR system. Middle-aged patients were more likely to log in initially to the PHR than younger (<34 years) and older (>75 years) patients. In addition, patients who had received a transplant were more likely to log on than patients on haemodialysis. A small number of very young patients were the most likely of all to complete a first logon, and this was assumed to be done by their parents. In relation to socioeconomic status, patients from addresses associated with the greatest deprivation were more likely to not log in for the first time, compared with those with middle-ranked deprivation.

Early non-usage was associated with those aged over 75 years, those with greater deprivation and was less likely in those who were transplant recipients. Later non-usage was associated with those aged over 75 years and those who had received treatment by hospital haemodialysis.

Different methods had been used in various projects with the aim to increase PHR use. These include:

- waiting room leaflets or posters (71.4%)[28]
- clinician input during consultations (57.1%)[28]
- structured discussion describing the health record, including a DVD of the structured discussion[19]
- videos on YouTube[19,32]
- posters, articles in newspapers, on radio and TV[19,32]
- referral by clinicians from inpatient wards or community services[31]
- 'drop-in' session in a community venue, led by an occupational therapist.[31]

Some of the sessions during early implementation involved setting up the patient access account, teaching basic computer skills and introducing patients to the features of the PHR.[24,31] Patients were also shown how to take readings from other devices and how to view the results in the PHR.

In addition to the above initial contact, the Leeds hypertension study also carried out a weekly contact programme with the patient engaged in the project, to ensure that the equipment was functioning and the patient still engaged in the project. However, only one patient was recruited as part of a use case study in this project.

In one study carried out in one UK practice, the greatest impact was reported to be clinicians asking patients about PHR use during consultations.[19] However, there is no clear evidence of the impact of each of the above interventions or the advantage of one over the other, and this should be researched in future studies.

Table 15 shows the results of a thematic analysis of the health/care professional users qualitative responses about what improvements they would like to see in their PHR.

Table 15: Health/care professional views on PHR improvements they would like to see

Theme	Sample quotation
Improved functionality	'Wider range of functionality to support the full range of services within an integrated PHR'
Improved integration with existing systems	'Better integration with hospital systems (when they finally catch up and get them)' 'Better integration between packages'
Patient ability to provide feedback on their records	'Improved ability of patients to feed information back in to the electronic patient record'
Patient ownership of their health/care information	'Patient ownership of web-based records should be default, with patient choosing the website provider. Patient should then allow access according to own wishes, by individual, professional group, institutional or situational consents'

N of health/care professional user respondents: 20

The main theme identified from the case studies was that clinicians tended not to access the PHR because they had the information that they needed on their own clinical systems. For example, myhealthlocker version 1 was designed to be completely patient facing because the expectation was that clinicians would not be using the PHR at all. For myhealthlocker version 2, it was deemed to be important to include a clinician view so that they could see the patients on their case load and what use they were making of the PHR. While one of the case study sites mentioned that a separate patient and professional window or portal onto a unified record would be the ultimate goal, none of the case study sites are anywhere near developing this.

Anticipated and reported PHR benefits

Survey findings

Table 16 shows the results of a thematic analysis merging patient/citizen users, health/care professional users', suppliers' and implementers' qualitative responses about the apparent benefits of using PHRs. Many of the benefits identified are qualitative, eg improved patient outcomes, with little underpinning evidence or basis for quantification. Some included quantities, eg cost savings, but again with no clear description about how this evidence was obtained. We have included them in Table 16 below, but recognise that they are difficult to interpret without this detail. Where individual respondents had provided contact details, we asked them for any further information on benefits. This provided some documentation with more qualitative benefits, but not quantifiable ones.

Table 16: Claimed benefits of PHRs

Theme	Sample quotation	Information provided by
Improved patient outcomes	'Improved patient outcomes (HbA1c, cholesterol, BP, etc) amongst users'	PHR implementer
	'Reduction of hospitalisations of COPD patients by 50–80%'	PHR supplier

Theme	Sample quotation	Information provided by
	'Improved quality of clinical decisons'	PHR implementer
Financial savings	'>£1m pa projected'	PHR implementer
	'Clinical time saving (at £100/£150 per visit)'	PHR supplier
Fewer face-to-face appointments	'Reduction in face-to-face appointments'	PHR implementer
	'Less hospital visits'	PHR implementer
Patients/citizens better able to self-manage	'Better self-management'	PHR implementer
	'I can manage my health and make sure all my clinicians are informed & I don't have to keep ringing the practice'	PHR user
Improved patient experience	'Better patient experience and engagement'	PHR implementer
	'The sense of control and trust it gives patients'	Health/care professional PHR user
Improved communication	'Two way communication between medical professional and patient'	PHR supplier
Improved record keeping	'Standards of records keeping much higher, rarely see omissions'	PHR implementer
Smaller overheads	'Reduced overheads associated with manual / paper processes'	PHR supplier
	'Reduced admin and paper trail'	PHR supplier
Time savings	'Time saved through reduction in duplication and missing / incomplete data at the point of care'	PHR supplier
	'Saves GP time and appointments. And so for the patient too'	PHR supplier
Efficiency savings for the health/care service	'Reduced demand on health and social care'	PHR supplier
	'Increase in clinic capacity'	PHR supplier
Improved medication adherence	'Improved medications adherence'	PHR supplier
Improved data quality	'Very much richer information to improve care'	Health/care professional PHR user
	'Improved quantity and quality of information available to	PHR supplier

Theme	Sample quotation	Information provided by
	patients and carers'	
More productive consultations	'Empowers some patients and leads to better consultations'	Health/care professional PHR user
	'Helps self-care and shared decision-making'	PHR supplier
Improved access to information	'I like the fact that I can carry my health info wherever I am 24/7. Makes me feel safe. I can manage my health and make sure all my clinicians are informed & I don't have to keep ringing the practice'	PHR user
Improved auditing	'Aids audit and reporting'	Health/care professional PHR user

N of respondents: 58

Case study findings

Many of the apparent benefits of PHRs reported by survey respondents were also reported in the case studies. However, there was a lack of quantifiable benefits of PHRs and many of the reported benefits were assumptions or anecdotal. Very few evaluations were carried out and, where they had been, they were often on a very small scale. For example, although St Mark's carried out a patient satisfaction survey for the use of Patients Know Best® with patients on home parenteral nutrition, this only had a response rate of 58 users.[6] An evaluation of benefits to patients and practices is included in the Patient Access case study,[10] but the numbers are small and a larger study would be needed to ascertain whether the savings might be achievable on a wider scale.

Potential opportunities were identified to utilise some of the functions of many PHRs to better support patient pathways such as remote monitoring of medication response and safety, which could have a number of benefits including convenience for patients, reduced pressure on services and less waste of drugs. For example, clinicians initiating medications that may cause side effects, that require safety monitoring or may indeed be ineffective, commonly devote multiple consultations to monitoring drug effects. However, using a PHR, patients could complete online assessments, have bloods taken at their convenience and communicate with their care givers to jointly manage their ongoing treatment.

Literature review findings

The majority of outcomes reported in the studies include patient benefits. In summary, most of the studies report:

1. better patient empowerment
2. better understanding of their condition
3. ability to share care with the clinicians
4. better health-related outcomes
5. increased trust in healthcare
6. identifying errors, hence preventing harm
7. better adherence to medication and advice
8. patients felt more in charge of their health and felt like a partner in their healthcare.

In a UK-based study including three GP surgeries based in London and Manchester, 76% felt more involved in their health/care because of record access and 111 respondents (62%) felt that they understood better what had previously been discussed at appointments because of having access to

their records.[34] A total of 67 of 158 patients (42%) reported that record access had made a difference to their medication adherence and had contributed to their better understanding of the medication (83%). Fifty-six of 88 patients, reported that record access had made a difference to following lifestyle advice. Also, 51% felt that looking at records beforehand saved time during appointments.

A systematic review found that most of the benefits were realised from patients with diabetes.[30] There was evidence of no benefit in cancer, multiple sclerosis (MS) and immune thrombocytopenic purpura (ITP) patients. Benefits were found in 16 of the 23 studies. However, these benefits varied according to whether the results were validated or not. Of the six studies that had patient reported benefits, five showed benefits of using a PHR. However, among the validated results, only 50% (5/10 studies) showed benefit in using PHRs.

Another systematic review showed that four studies reported an increase in patient adherence and attendance at clinic visits, better patient experience and satisfaction (in 16 studies), and better communication with healthcare professionals (13 studies). While online access allows patients to reflect on their records and prepare for the next consultation, there was no evidence of improved health outcomes. 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.

A UK-based study on the use of PHR by renal patients indicated that 88% felt more in control of their medical care and 86% agreed that they had a better understanding of their illness.[26] In addition, 79% communicated better with their doctor and were reassured about treatment.

All patients found record access 'somewhat useful' (38.5%) or 'very useful' (61.5%).[17] Most believed it had improved their knowledge of their condition (92.3%), encouraging them to take medication on time (23.1%) and follow lifestyle advice (46.2%). Some of the US-based studies measured 'clinical outcomes' such as HbA1c levels and this has been analysed by Jilka *et al* in a systematic review.[20] One review showed a mix of results relating to specific clinical measures, with 50% (2/4) of studies reporting a positive change. Another review found mostly positive changes, with 75% (6/8) of studies reporting a positive change as a result of PHR access. Overall, 67% (31/46) of positive changes as a result of PHR use across all self-efficacy domains comprised: patient involvement (67%, 10/15), patient empowerment (78%, 18/23) and patient communication (38%, 3/8).

A 2015 systematic review on the use of PHRs in a primary care context showed that patients were more satisfied with automated communication of test results (odds ratio (OR) 2.35) and with online information about their treatment or condition (OR 3.45); compared with those who accessed this information in person or by telephone.[25] Some patients (34%, n=68/200) felt better able to express their concerns in writing; and 36% (n=72/200) felt it easier to communicate about difficult topics. Also, patients given access to their medication list online corrected more than twice as many medication discrepancies with potential for severe harm (0.03 versus 0.08 per patient). Children in a PHR group received 95.5% of immunisations compared with 87.2% in the control group. Online access to consultation notes was also found to increase reported medication adherence as 60–78% (n=5,391) of patients taking medications reported increased adherence. PHR users had significantly fewer visits over the study period, compared with the control group (average of 2.9 versus 4.3 visits).

Another systematic review noted significant positive effects on patient empowerment reported in four studies and positive physical activity reported in two studies.[22] A systematic review of the use of a PHR in diabetes care[27] found significant improvement in cognitive status (+0.8% in control group vs -1.0% in intervention group) and functional level (19.4 vs 20.0), and significantly reduced home visits (+5 vs -83) in a USA-based RCT. An RCT showed a significant reduction in HbA1c Levels between the control group and an intervention group receiving web-based care management (-1.2 vs -1.6%) in HbA1c levels over 12 months. However, another 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. Another USA-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 personal health record (Grant 2008), while a different RCT showed lower HbA1c at 6 months but not at 12 months' time (Tang

2013).[17] One study on heart failure in the same systematic review 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.

The evidence from various systematic reviews is also positive. However most of the studies were carried out in the USA, and the reviews usually include a maximum of one or two UK-based studies of acceptable quality.

Both healthcare professionals and patients reported that PHRs saved them time.[15] Patients associated having online access to their medical records with savings both for themselves and for their healthcare providers. Patients reported saving themselves time (eg less need to take time off work for appointments) and money (eg for petrol or phone calls).[32] The ability to view the results prior to the consultation meant that time could be focused on other discussions.

Overall, 79.9% of clinicians felt that record access could be provided without creating a significant additional burden on the organisation.[28] A total of 86.7% of clinicians perceived no adverse effect on consultation length and 13.3% stated that record access had decreased consultation length. Furthermore, 66.7% believed that it had not affected the frequency of consultations, and 13.3% that it had reduced the frequency.

In one study, using PHRs for writing all inpatient orders significantly lowered patient charges and hospital costs. Three studies demonstrated how PHRs in the USA could provide a positive return on investment providing evidence of major financial benefit.[20] Nurses are more likely than physicians to gain time efficiencies by using a computer system to document patient information.

In one cohort study about the implementation of a video to support the use of a patient's portal, during office visits 12 of 13 (92%) support staff agreed that it was easy to use, and six (46%) agreed that the technology did not take up more time.[25] One paper suggested that telephone call volume can decline, with the intervention group seeing a reduction in the annual number of visits and telephone calls by 28% and a total reduction in the number of calls to the GP of 10%.

A brief case report in the UK on patients with inflammatory bowel disease (IBD) using PHRs reported £130,000 in gross savings;[21] however no published results were found.

Patient online survey findings

Other benefits were identified by a survey carried out by the NHS England Patient Online programme. In total, 24/42 (57%) of respondents found that having access to their health information online helped them to better manage their own health. In addition, Table 17 shows the results of the Patient Online survey about other benefits of using online GP services.

Table 17: Patient Online programme reported benefits

Patient Online programme benefits	Agree	Disagree	Neither agree nor disagree
Using online services is more convenient for me than telephoning or calling into my surgery	88%	5%	7%
Using online services saves me time compared with telephoning or calling into my surgery	89%	5%	6%
Using online services has improved the quality of care that I receive	27%	22%	51%
Since starting to use online services I am more satisfied with the service provided by my GP surgery	44%	17%	39%
Since using online services my knowledge of where to look on the internet for health-related information has improved	30%	34%	36%

Patient Online programme benefits	Agree	Disagree	Neither agree nor disagree
Using online services has improved the communication I have with my GP surgery	44%	28%	28%
Using online services has given me more choices on how I communicate	80%	7%	13%

N of respondents: 197

Anticipated and reported PHR harms or disbenefits

Survey findings

Table 18 shows the results of a thematic analysis of the users, health/care professional users, suppliers and implementers' qualitative responses about the disbenefits / potential harms of using PHRs.

Table 18: Disbenefits of using PHRs

Theme	Sample quotation	Information provided by
Time consuming	'It takes much longer to complete each entry, as it is more comprehensive'	PHR implementer
Inaccurate data	'We have had reports that occasionally the wrong data have been recorded in a hospital record for a patient and then sent to their PHR' 'Wrong filing of info can be harmful'	PHR implementer PHR supplier
Exclusion of hard-to-reach groups	'Failure of public communications to engage hard-to-reach populations'	PHR implementer
Over-use of the technology	'Some patients could over-use our technology, but this is considered a useful indicator by clinicians as it could highlight the need to discuss this with patients'	PHR supplier
Data breaches	'There is no guarantee that 3rd party information will always be protected' 'Data security/access breaches are the prime concern'	PHR supplier PHR supplier

N of respondents: 59

Case study findings

The case studies indicate that concerns about additional burden on health/care professionals are unfounded, but it must be noted that use of PHRs is relatively limited at the moment.

There were no instances of data breaches reported by case study sites. Furthermore, although a survey respondent was concerned about inaccurate data being shared with patients, the case studies found that patients liked being able to identify and request changes where information was not correct. The Patient Online survey found that the majority of users, 37/48 (77%), felt that their online data was up to date and correct.

Although there were concerns about hard to reach groups being excluded, some of the case study sites addressed this directly; for example, in Nottinghamshire multimedia centres of excellence were set up to provide access to the wiki tool for individuals who did not have the required equipment or skills.[8]

One potential disbenefit identified in the case studies was that of the loss of a personal touch, caused by interaction with health/care professionals via PHRs rather than face to face. This may be particularly problematic for isolated groups. Use of PHRs may be dependent on the character of the users and it is important that traditional methods are still available for users who do not want to use this type of service. For example, SLaM found that video consultations were not particularly popular, as many users preferred face-to-face meetings with their health/care professionals.[7]

Literature review findings

The evidence of any harm to patients directly linked to PHR use was not well reported among the studies. Errors in records were found in one PHR and were corrected.[19] No further information was given on these.

In a systematic review of 23 studies (none from the UK), one study reported harms to use.[30] Healthcare professionals reported that patients were under the wrong assumption that they were continuously being monitored by the professionals and therefore did not report any change to their health conditions. Another systematic review reported that eight studies had identified errors in medication lists and drug reactions.[15] A significant number of discrepancies with some potential for severe harm were identified.

Two studies in a systematic review found that a bedside PHR increased documentation time, and one study reported different results depending on the specific content of the information being documented.[20] Ten studies examined the impact of PHR on time-efficiencies of physicians. One study showed increased physician documentation time by 17%; and 60% (6/10) reported significant results in the direction of 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 and paper documentation time.

A recent systematic review[25] concluded that clinicians (n=99) were concerned that access to open notes would lengthen visits, reported a minor rise in consultation rates across three study sites (0–8%) and spent more time addressing patients' questions outside of visits (0–8%). Clinicians also reported changes in how they recorded clinical information, with between 3% and 36% of clinicians (n=99) changing record content to allow for online access, and 0–21% reported taking more time writing notes. In a post-intervention survey, a significant difference was found in time spent writing or dictating notes between practice size, with 4 out of 37 clinicians (10.8%) in smaller practices spending more time writing notes compared with 7 out of 24 clinicians (29.2%) in larger practices. Face-to-face contact also increased in a before-and-after study of online test result viewing and secure messaging with clinicians. There was also a significant increase in rates of after-hours clinic visits (18.7 per 1,000 patients per year), emergency department encounters (11.2 per 1,000 patients per year) and hospitalisations (19.9 per 1,000 patients per year) for patients who used the online system compared with non-users. Studies also found a significant increase in the per member rates of telephone encounters.

Patient Online survey findings

The Patient Online survey identified the following disbenefits of using online GP services:

- problems when the service crashed
- exclusion of hard-to-reach groups (people without computer access/skills)
- difficulty for users in obtaining urgent appointments
- lost prescriptions / errors with prescriptions
- lack of personal touch
- limited number of online appointments/double appointments
- inability to book appointments with nurses.

PHR business models and funding arrangements

From the survey, it appears that 50% of PHR suppliers market their product to both organisations and individuals, 30% to individuals only and 20% to organisations only. In total, 50% of suppliers market their product to both organisations and individuals, 30% to individuals only and 20% to organisations only.

Of the 13 implementers who described funding arrangements for their PHR projects, the following funding sources were identified:

- government funding
- trust funding
- CCG funding
- grant funding
- piecemeal funding
- baseline funded
- local authority funding
- industry partner contributions
- European Union funding.

A thematic analysis of the commercial approaches provided by suppliers identified themes in terms of customer types and methods of payment (see Fig 2).

Fig 2: PHR customers and payment methods
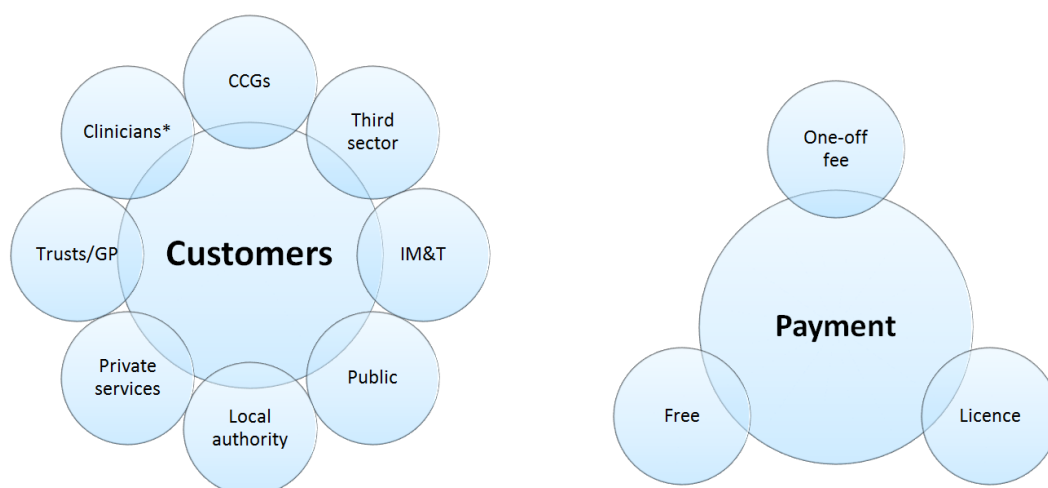
*One PHR supplier has a practice management system with patient access

Supplier and implementer aspirations for the future of PHRs

Some of the implementers and suppliers who responded to the survey provided details of the future plans for their PHR projects. Thematic analysis identified the following themes for future plans:

- expand geographical reach, including international expansion
- identify further sources of funding
- add and amend user functions based on user feedback
- work with charities for research opportunities
- integration with other digital systems
- integration with wearable technologies
- expand into other disease areas
- improve interface and user experience.

PHR activity in Scotland, Wales and Northern Ireland

The scope of the PHR landscape review, as set out in the project specification, was to focus mainly on PHR activity in England. The project team also spoke with colleagues in Scotland, Wales and Northern Ireland to obtain an update on related activity in the other nations of the UK.

Scotland

NHS Scotland is taking a holistic approach to electronic records and developing a vision and strategy for such records. This will be consulted on with all stakeholders in the near future. They plan to provide a national patient portal (to avoid patients having multiple separate entry points) where patients can get access to their official record, add information and access online advice and services. There will be separate clinical portals for clinicians to access the official record. A key route for engaging with patients/citizens with this work is through the third-sector Health and Social Care Alliance, which has a funded post to help with this. NHS Scotland will rely on individual NHS boards for implementation for many of the planned changes. The 'portal' concept is key to accessing information and records and eventually for citizens to combine their user-created data with data from official records, as part of a co-production process. There is a target for patient access to baseline information and services by 2020, but this is likely to be achieved earlier.

The approach on GP records is in contrast to NHS England's Patient Online programme. Only appointment booking and some other services will initially be made available via GP systems. However, access to the record would be via the national patient portal. A business case, specification and technical architecture are currently being developed. NHS Scotland aims to have the platform in place to start implementation by March 2016.

NHS Scotland is also working on an integration platform to enable patient-created data to be moved into NHS-held systems. The aim is to make this platform, which will link to the patient portal, as flexible as possible, to have as wide a range of devices and apps as possible feeding into it. They will talk to industry about what is feasible.

Identified issues are the quality of the patient data and that interoperability standards have not yet been defined. NHS Scotland is also working on a technical app strategy, which will inform the approach/policy to apps and any certification requirements. There are information governance issues that need to be addressed, for example the issues arising once patient data is combined with official records (data controller, consent, provenance etc).

Examples of PHRs in Scotland:

- MyDiabetesMyWay – an interactive diabetes website to help support people with diabetes and their family and friends

- Ginsberg – a PHR app developed by the Scottish government, which tracks mood and links to life events; it is presently standalone, but the aim is for GPs to prescribe it

- Living It Up – a health, wellbeing and self-management information platform with functionality for data capture for people aged >50 years old; it helps users identify social activities and ways to improve their health and wellbeing; and it is funded through the DALLAS programme and the Scottish government, and operated by NHS 24

- SmartCare – a falls and fragility app: not linked to NHS records as yet.

Wales

Improving access to information with digital technologies is at the heart of service plans in Wales. The aim is for patients, carers and health/care professionals to make use of accurate information, safely, wherever and whenever it is needed.

To make it easier for patients and citizens to access the information they need to support their own care, the National Welsh Information Service (NWIS) is developing a new digital platform that will provide a single route to trusted information about health and care in Wales. This new public-facing website will include information about how to access local and national services, provide advice and support to maintain and improve health, and provide information to help citizens and patients choose the most appropriate service, eg GP or pharmacy. It will also signpost to the 'Add to Your Life' app, which is an online health check that gives an overall picture of wellbeing, provides advice and tailored information, and helps patients to plan small steps to improve their health.

Citizens and patients in Wales are already able to book GP appointments and request repeat prescriptions online using the My Health Online service. The Welsh government's plan for primary care up to March 2018, published in February 2015, set out a commitment to provide patients with online access to their health records by 2017, through further development of My Health Online.

Northern Ireland

Northern Ireland has a multiphase project called Health and Social Care (HSC) Online. The aim of the project is to provide a single point of contact for citizens in Northern Ireland to access health and social care information. The project will be delivered via the NI Direct website (www.nidirect.gov.uk). There are two phases to the project.

- Phase 1 will provide richer health and social care information to citizens to support self-management.
- Phase 2 will cover transactional elements such as booking a GP appointment or ordering a repeat prescription.

In addition, there is the NI Electronic Care Record (NIECR) portal that provides a view for clinicians from across health and social care in Northern Ireland onto a collated record for each patient, pulling information from various systems (patient administration systems (PAS), GP clinical systems, laboratory systems, radiology etc). Patient access to records could potentially be delivered via a number of routes, including but not limited to, the NIECR. Discussions are ongoing as to how best to deliver meaningful records access to patients. Some patients with particular conditions already have access to their records, eg renal patients can access their record via PatientView.

Discussion

This project was undertaken in a context of high expectations of availability and benefits of PHRs. Prior to the survey, our initial literature review tempered these expectations. We therefore put specific effort into finding out as much detail as possible about the availability, implementation, use and reported benefits of PHRs.

The responses came from both health and social care PHR suppliers and from suppliers providing platforms and integration tools onto which a PHR could be built. We also had responses from suppliers who provide devices or monitoring apps from which data can be uploaded to a PHR. We have reported these because there were clear potential benefits for the patient to be able to include such data in their PHR for self-management and sharing with their care professionals.

There were fewer than expected responses to the survey and some of the responses were aspirational rather than describing current PHR implementations.

We were unable to find out the total extent of implementation or a definitive number of users of PHRs, as many suppliers did not provide this information. When suppliers provided the number of their organisational customers, the extent of the implementation within that organisation was unclear, eg it may be used by a single specialty or service, rather than trust wide. However, from the information provided it was clear that the number of users per PHR is currently limited, with an optimistic median figure of 10,000.

Responses about PHR services indicate that they are at a relatively low level of maturity.

- Most of the PHRs are currently setting-specific (ie primary, hospital or social care), although some suppliers have aspirations for integrated implementation across more than one setting.

- PHRs mainly provide patients with a view of their records, rather than the ability to update or annotate them, let alone upload their own data.

- Linkage of PHRs to electronic health or care record systems was in some cases aspirational, particularly when compared with implementer responses about current linkage. Also, the links are generally unidirectional (from the electronic health or care record to the PHR, rather than vice versa).

- The main way in which users could communicate with their care teams was via email-type messaging rather than instant methods, such as video and instant messaging etc.

- While PHRs enable patients or citizens to view their medications, they are generally setting-specific, for example only their GP or hospital medication records. Patients are unable to interact electronically with their medication record, eg to point out errors or to remind themselves to take their medicines.

Few implementers described how difficult it had been or how long it took for their system to be implemented once a decision had been made. Some reported how long it took to implement, with the average being nearly 3 years from planning to implementation, including piloting. (Piloting was reported as being important for successful implementation.) Most implementations that are currently live have been in operation for an average of 3 years. PHRs selected for the case studies – which are generally well-established – are still rolling-out to patients and iteratively extending the services that they offer, and they plan to continue to do so for the foreseeable future.

Users generally reported that they found out about the PHR through their care professional, indicating the key role of care professionals as well as patients in adoption of PHRs. Communication and engagement (for example using care professional champions) with clinicians, patients and citizens was one factor reported as being important for successful implementation. Clinician champions were particularly important in changing clinical culture and practices.

The main use of PHRs is currently access to blood test results. In patient online access to GP records, repeat prescriptions and appointment booking are also major uses. PHRs tend to be used before or after appointments, which indicates that preparation for and debriefing on consultations is important. These uses are quite limited and, in the case of blood results, are limited to specific patient groups. There is still little evidence about how PHRs are used, what they are used for and why.

The factors that users considered would increase user uptake of PHRs were largely the provision of additional services, such as more integration of patient information with health and care record systems across care settings, and the ability to communicate via the PHR with their care team. The content of an integrated record and how patients would use such a record needs further research.

Potential benefits for both patients (improved experience and outcomes) and organisations (time, effectiveness and cost savings) were identified in the survey responses, but the majority were aspirational and we were able to obtain little supporting evidence of objectively realised benefits. The literature review identified a number of studies that identified patient benefits, but these were largely qualitative, focusing on how patients felt about the PHRs, rather than any quantitative assessment of their impact on health outcomes (eg lifestyle improvements) derived from bias-free study designs.

Similarly, reports of disbenefits were mainly related to fears and anxieties, for example of increased burden on clinicians or patient confidentiality, with little supporting evidence.

Implementations have been funded from a variety of sources: many having been short term, rather than provision of a PHR as part of a commissioned service. The lack of a business case may deter other organisations from implementing PHRs and may also make existing ones unsustainable.

The literature review, survey and case studies demonstrate that a wide range of PHRs are currently in development and use. Commercially marketed, locally developed and open-source models are all evident. While many PHRs support integration with other systems through published application program interfaces (APIs), none are currently utilising nationally-agreed standards for the structure and content of patient records. The success of future health record interoperability is dependent on this, and developers should be encouraged to adopt these standards (www.rcplondon.ac.uk/projects/outputs/standards-clinical-structure-and-content-patient-records).

Given the above analysis, further research is recommended in the following areas.

1   **Understanding what patients/citizens require from PHRs** – what information do they want to see and what do they want to use PHRs for, and why (ie gain or benefit)? This needs to cover people who do not currently use PHRs and the requirements of specific identified groups (eg adults, older people, children, people who are 'hard to reach', those with sensory and other disabilities, and those with mental health issues). This research needs to look at requirements in a person-centred way across care setting boundaries, rather than from the perspective of specific care providers.

2   **Exploring and piloting** projects that utilise the features available within a PHR to deliver health or social care in novel, innovative ways. This requires a greater understanding of user and provider attitudes to new models of care delivery, for example remote monitoring, virtual consultations or follow-up, and enhanced self-care supported by elements of the PHR.

3   **Quantifying the costs of and benefits from PHRs**, including health outcomes, for patients. There are sufficient places with PHRs to enable such research to take place and much qualitative information on benefits that could be used to identify quantitative measures. The costs and benefits to organisations from implementing PHRs, also need to be assessed, including the impact on health/care professionals and support staff. Such research needs to be carried out using objective measures of impact and the kind of study designs that minimise bias that, ultimately, the National Institute for Health and Care Excellence (NICE) would consider suitable to inform a clinical practice guideline or a technology appraisal.

4   **Information governance issues**, including withholding sensitive information, consent, authentication, protecting vulnerable individuals, third-party data etc. The aim of this research would be to work with all relevant stakeholders (eg PHR users, health and social care professionals, clinical commissioners, Caldicott Guardians, professional associations eg the British Medical Association (BMA), the Local Government Association, the Association of Directors of Adult Social Care and the Information Commissioner) to explore barriers to information flows in PHRs and to identify acceptable, workable and efficient approaches to overcome these.

Drivers

From analysis of the combined evidence, we have identified the following inter-related drivers that need to be in place to encourage more rapid adoption of PHRs:

- availability of a business case for PHRs: identifying and quantifying benefits from investment, which will encourage care providers to invest

- availability of published APIs to the main hospital and primary care electronic patient record systems, to encourage suppliers to develop PHRs providing patient record access

- recognition in the commissioning framework of the use of PHRs as a way of providing care and supporting self-care, to remove barriers or disincentives to using PHRs; for example, to replace outpatient and GP practice consultations

- promotion of PHR-based service improvement, with quantifiable outcome measures: case studies and exemplars of the use of PHRs within service improvements (illustrating benefits and how changes in working practices were effected) could be used to promote the use of PHRs to health/care professionals who are key to encouraging patient adoption

- guidance on information governance issues (as included in the primary care case study) to remove some of the perceived barriers to implementation

- clinicians promoting use of PHRs to their patients: this means clinician engagement, which is dependent on their belief in the benefits for patients and hence on the development of a robust business case

- support for patients during initial use of the PHR, eg demonstration, training and a help desk: there is evidence that this encourages longer-term use

- training for health/care professionals (eg use of IT, cultural change and communication), and support for those who are supporting PHR implementation, for example administrative support, allocated time within job plans etc.

Even with these drivers, it is not clear that rapid and widespread uptake would happen. Current use is focused on the use of PHRs to help manage specific conditions, and many healthy people will not be interested in having a PHR. So, understanding what people would want to use PHRs for, what they want them to do and how they think they will benefit by using them, is key to understanding the likely level and rate of uptake.

This report can only provide a snapshot of PHR activity and adoption at a point in time. Ongoing measurement of adoption rates and review of progress is needed, as this is a rapidly changing environment with, for example, new products appearing on the market during the course of this study. Plans for PHR implementation will also need to adapt and evolve as understanding increases. Review should include measurement of benefits, as the business case for PHRs is not yet established. Intended benefits may not be realised in the short term, so prolonged evaluation may be needed.

Conclusions

There is little information available on the usage of PHRs in the UK, but it appears that the number of both individual users and organisational users is low. The functional maturity, implementation and uses of PHRs are also relatively limited.

Although it seems self-evident that patients and service users should have access to their electronic records, the ways in which they can do that is currently unclear, as are what data they want to see or which functions they are able to carry out using their PHR. This may also be constrained by lack of interoperability.

There is only at best anecdotal information on PHR benefits, with little concrete evidence, and funding tends to be short term. Where a PHR is used, it tends to be for a very specific purpose with a very specific user base; for example, PatientView, which is widely used by renal patients for accessing their test results. This suggests that there has been a lack of market research on what patients want with regard to wider uses and the ways in which care professionals and service managers might find PHRs beneficial.

Many of the potential benefits, including cost and efficiency savings, are speculative or largely unknown. This is primarily because PHRs have not been widely used as tools to facilitate the delivery of care in innovative or novel ways, but also because rigorous research using objective measures of benefit is lacking. The acceptability to patients of such changes in care delivery is also unknown and should be a priority for further research.

As the understanding of patients' and care providers' requirements and preferences becomes clearer, it is important that PHRs are able to evolve to meet those needs. It is vital that patients and health/social care professionals are active participants in the design, implementation and appraisal of PHRs.

With the anticipated greater use, functionality and complexity of PHRs, sufficient attention must be paid to the design and user interface of these systems to ensure ease of use by, and benefits for, all sectors of the community.

Appendix 1: Details of PHRs described in the online survey

Supplier	Product	Description	Supplier provided information	Implementer provided information	N of registered users	Average N of uses per month	N of health/care professional users	N of organisational customers	Can health/care records be accessed via the PHR?
Aseptika Ltd	Activ8rlives	Sensors and monitoring devices, focus on respiratory	Yes		80,000				Yes
	SENSOR I								Yes
	SENSOR II								Yes
Bodymap Apps	Fibro Map	Apps for tracking, monitoring and reporting a patient's health condition	Yes		>3,000				No
	My LDN								No
	My Pain Manager								No
ClinicYou	ClinicYou	Practice management platform with patient portal	Yes		>11,700	>500			Yes
Cerner	Cerner	Integrated health record with patient access	Yes	Yes					Yes
Coordinate My Care	Coordinate My Care	Currently an e-palliative care system, but plan to provide patient access	Yes	Yes	23,900	750			Yes
dataByZed	My Medical	An app for patients to view/maintain their medical records	Yes						Yes

Supplier	Product	Description	Supplier provided information	Implementer provided information	N of registered users	Average N of uses per month	N of health/care professional users	N of organisational customers	Can health/ care records be accessed via the PHR?
EMIS	Patient Access	PHR linked to Apple Healthkit, which enables self-management through linkage with apps and medical devices as well as Patient Access services	Yes		Patient Access: 1.5 million PHR: 11,000				Yes
Epic	MyChart	Gives patients controlled access to the same Epic medical records that their doctors use, via a browser or a mobile app		Yes					
Epilepsy Society	Epilepsy Toolkit	App to support patients with epilepsy, providing information and tools, eg medication adherence	Yes						No
Get Real Health	My Health Record	Allows University Hospital Southampton NHS Foundation Trust patients to co-manage their healthcare online		Yes	600				
Graphnet Health	CareCentric	Health and social care record for citizens	Yes	Yes				40 trusts 1,100 GP practices	Yes

Supplier	Product	Description	Supplier provided information	Implementer provided information	N of registered users	Average N of uses per month	N of health/care professional users	N of organisational customers	Can health/care records be accessed via the PHR?
Inform Health	HIV portal	Gives HIV patients access to records, eg to results and to communicate with clinicians	Yes						No
InterSystems	Personal Community	Self-service transactions – appointments, repeat prescriptions, viewing/updating care record and care plans	Yes						
Leeds Teaching Hospital Trust	Leeds Care Record	Sharing of appropriate patient information across health and social care services in Leeds		Yes					
Liquidlogic	Liquidlogic Autonomy Portal	Supports online social care assessments that in turn may provide the user with a variety of information/options governed by their responses; also online two-way interaction between the user and the local authority	Yes					10+ social care providers	Yes
Medelinked, How are You? Axsys	Medelinked	'Standard PHR functionality'	Yes						No

Supplier	Product	Description	Supplier provided information	Implementer provided information	N of registered users	Average N of uses per month	N of health/care professional users	N of organisational customers	Can health/care records be accessed via the PHR?
Medopad	Medopad	Chemotherapy app for Apple Watch	Yes					1 trust	No
Microsoft	HealthVault	PHR platform, eg used for eRedbook, Digital Life Science's (DLS') A Better Plan and myhealthlocker	Yes					6 trusts 2 GP practices 1 local authority 1 social care provider	Yes
MyRightCare UK Ltd	MyRightCare	Palliative care planning system, with patient access	Yes					4 trusts 50 GP practices 2 commissioners 2 local authorities 1 social care provider	Yes
NantHealth UK	Fusion fx Patient Portal	Portal for patients to use to access healthcare records and capture and share their own information	Yes		145,000	66,000			Yes
NHS 24 / Scottish Centre for Telehealth and Telecare / Atos Collaboration	SmartCare Person Held File	Provides users with an integrated view of their health and social care records as well as self-entered information		Yes	10–50				Yes

Supplier	Product	Description	Supplier provided information	Implementer provided information	N of registered users	Average N of uses per month	N of health/care professional users	N of organisational customers	Can health/care records be accessed via the PHR?
NHS Scotland	MyDiabetesMyWay	NHS Scotland interactive diabetes website to help support people who have diabetes and their family and friends		Yes	10,000	1,600	2 user support staff 4 health board staff monitoring mailboxes for secure messages		
Nourish Care Systems	Nourish	Domiciliary and care home record with patient access	Yes		600				No
OLM Systems Ltd	MyLife	Access to social care record	Yes					>25 local authorities 1 social care provider	Yes
Patient Access to Electronic Record Systems (PAERS) Ltd	iPatient	Patient access to GP record, appointment booking, secure messaging	Yes						
PatientView	PatientView	Shows patients their latest test results, letters and medicines, plus information about diagnosis and treatment; allows setting up of alerts, monitoring of symptoms and downloading of records		Yes					Yes

Supplier	Product	Description	Supplier provided information	Implementer provided information	N of registered users	Average N of uses per month	N of health/care professional users	N of organisational customers	Can health/ care records be accessed via the PHR?
Patients Know Best	Patients Know Best®	Self-management and access to patient records, appointment booking etc	Yes	Yes				61 trusts 32 GP practices 4 commissioners 2 social care providers	Yes
Sitekit	eRedbook	Digital personal child health record	Yes		1,340			1 CCG	Yes
	Self Care Framework	A set of services to allow patients/ professionals to interact and share information from apps/devices etc	Yes					7 NHS boards in Scotland 1 CCG	Yes
South London and Maudsley NHS Trust	myhealthlocker	Allows mental health patients to access their care plans, keep track of how they are feeling, and access health and wellbeing resources		Yes					
Swansea University	UK Multiple Sclerosis Register	Access to patient records and patient recorded outcome measures for multiple sclerosis patients	Yes						No

Supplier	Product	Description	Supplier provided information	Implementer provided information	N of registered users	Average N of uses per month	N of health/care professional users	N of organisational customers	Can health/care records be accessed via the PHR?
The Exchange Foundation	Puffell /TimeCheck	Personalised digital tool supporting individuals to set and track goals related to health and wellbeing; TimeCheck offers additional functionality for individuals to record their feelings, preferences and needs via video and messaging	Yes		5,000			8 commissioners 5 local authorities	No
TPP	SystmOne	Patient Access services	Yes						Yes
Two-Ten Health	SALUD	Clinical records system for dental patients, based in teaching hospitals		Yes		450	450		
uMotif	uMotif	App for patients to self-manage and access information on their condition	Yes		1,000			10 trusts	No

Appendix 2: Electronic records access broken down by supplier

Types of information from electronic records that patients/citizens can access via the PHR and what they can do with the information

PHR	Medications/ prescriptions	Vaccinations	Allergies	Summary of medical conditions	Investigations	Patient history	Family history	Letters/ documents	Care/ support plans	Assessment/ examinations	Referrals/ appointments	Screenings	Consultations
Liquidlogic Autonomy Portal								- View	- View - Add new information	- View - Add new information			
Patients Know Best®	- View - Add new information - Annotate		- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate		- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate
Self Care Framework	- View - Add new information	- View - Add new information	- View - Add new information	- View - Add new information		- View - Add new information	- View - Add new information		- View - Add new information		- View		
eRedbook	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate
Graphnet CareCentric	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View	- View - Add new information	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate
PAERS i-Patient	- View	- View	- View	- View	- View	- View	- View	- View	- View	- View	- View	- View	- View
Microsoft HealthVault	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate

Types of information from electronic records that patients/citizens can access via the PHR and what they can do with the information

PHR	Medications/ prescriptions	Vaccinations	Allergies	Summary of medical conditions	Investigations	Patient history	Family history	Letters/ documents	Care/ support plans	Assessment/ examinations	Referrals/ appointments	Screenings	Consultations
My Medical	- View - Annotate	- View - Annotate	- View - Annotate	- View - Annotate	- View - Annotate	- View - Add new information - Annotate	- View - Annotate	- View - Annotate	- View - Annotate	- View - Annotate	- View - Annotate	- View - Annotate	- View - Annotate
EMIS Patient Access	- View	- View	- View	- View	- View	- View		- View	- View	- View - Add new information	- View	- View	- View
Cerner	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate	- View - Add new information - Annotate
Fusion fx Patient Portal	- View - Add new information	- View - Add new information	- View - Add new information	- View - Add new information	- View	- View - Add new information	- View - Add new information	- View - Add new information	- View - Annotate		- View - Add new information		
Activ8rlives, SENSOR I and SENSOR II	- View - Add new information	- View - Add new information	- Add new information										
MyLife									- View - Add new information	- View - Add new information	- View - Add new information		
ClinicYou	- View	- View	- View	- Add new information	- Add new information			- Add new information	- View	- View	- View	- View	- View
MyRightCare	- View	- Add new information - Annotate	- View - Annotate	- View	- View	- Add new information - Annotate	- Add new information - Annotate	- View	- View - Add new information - Annotate	- View			- View

Appendix 3: Communicating with care providers, broken down by supplier

PHR	Online consultations via PHR	Communicating with care teams via PHR	Booking appointment via PHR	Communication methods
		Communicating with care providers		
Puffell/TimeCheck	Operational	Operational	Not available	Secure messaging Audio Video Instant messaging Discussion forum
Liquidlogic Autonomy Portal		Operational	Not available	Secure messaging
Patients Know Best®	Operational	Operational	Operational	Secure messaging Video Discussion forum
Self Care Framework	Under development	Operational	Under development	Secure messaging Audio
eRedbook	Offered but not yet implemented	Operational	Under development	Secure messaging
Medelinked, HowAreYou, AxSys	Operational	Operational	Operational	Secure messaging Video Instant messaging Discussion forum
CareCentric	Not available	Operational	Offered but not yet implemented	Secure messaging Audio Discussion forum

PHR	Communicating with care providers			
	Online consultations via PHR	**Communicating with care teams via PHR**	**Booking appointment via PHR**	**Communication methods**
i-Patient	Under development	Not available	Operational	Secure messaging
HealthVault	Operational	Operational	Not available	Secure messaging Video Instant messaging Discussion forum
Nourish	Not available	Operational	Not available	Secure messaging Audio
My Medical	Not available	Under development	Under development	Secure messaging
Patient Access	Under development	Operational	Operational	Video Discussion forum
Cerner	Operational	Operational	Operational	Secure messaging
Fusion fx Patient Portal	Under development	Operational	Operational	Secure messaging
Inform HIV portal	Under development	Under development	Under development	Secure messaging Instant messaging
uMotif	Under development	Operational	Under development	Secure messaging
FibroMapp, My Pain Manager, myLDN	Offered but not yet implemented	Offered but not yet implemented	Offered but not yet implemented	Secure messaging
Activ8rlives, SENSOR I and SENSOR II	Not available	Not available	Not available	Instant messaging Discussion forum

	Communicating with care providers			
PHR	**Online consultations via PHR**	**Communicating with care teams via PHR**	**Booking appointment via PHR**	**Communication methods**
MyLife	Under development	Offered but not yet implemented	Under development	Secure messaging Instant messaging
UK MS Register	Not available	Under development	Not available	Secure messaging
Epilepsy Toolkit	Not available	Not available	Not available	
ClinicYou	Operational	Operational	Operational	
MyRightCare	Offered but not yet implemented	Operational	Not available	Secure messaging Instant messaging Discussion forum

Appendix 4: Medication services broken down by supplier

PHR	Ordering repeat prescriptions via PHR	Medicines reconciliation	Medicine adherence	Getting more medication information
Puffell/TimeCheck	Not available	Under development	Operational	Not available
Liquidlogic Autonomy Portal	Not available	Not available	Not available	Not available
Patients Know Best®	Not available	Operational	Offered but not yet implemented	Not available
Self Care Framework	Not available	Not available	Operational	Operational
eRedbook	Not available	Not available	Not available	Under development
Medelinked; HowAreYou; AxSys	Not available	Not available	Not available	Operational
CareCentric	Under development	Not available	Not available	Offered but not yet implemented
i-Patient	Operational	Not available	Not available	Operational
HealthVault	Not available	Not available	Operational	Operational
Nourish	Not available	Not available	Not available	Not available
My Medical	Not available	Under development	Not available	Not available
Patient Access	Operational	Under development	Not available	Operational
Cerner	Operational	Operational	Operational	Operational
Fusion fx Patient Portal	Operational	Not available	Under development	Operational

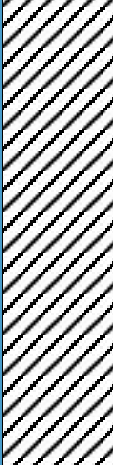| PHR	Medication services			
	Ordering repeat prescriptions via PHR	Medicines reconciliation	Medicine adherence	Getting more medication information
Inform HIV portal	Under development	Under development	Under development	Under development
uMotif	Under development	Operational	Under development	Under development
FibroMapp, My Pain Manager, myLDN	Offered but not yet implemented	Operational	Offered but not yet implemented	Operational
Activ8rlives, SENSOR I and SENSOR II	Not available	Operational	Offered but not yet implemented	Operational
MyLife	Not available	Not available	Not available	Offered but not yet implemented
UK MS Register			Under development	Not available
Epilepsy Toolkit	Not available	Not available	Operational	Operational
ClinicYou	Not available	Operational	Not available	Not available
MyRightCare	Not available	Offered but not yet implemented	Under development	Operational

Appendix 5: Self-care and shared care services, broken down by supplier

PHR	Self-care and shared care								
	Linking to monitoring devices	Recording information to help monitor/track health condition	Setting personal goals	Setting agenda and prompts	To-do lists/reminders	Recording information to be used in an emergency/crisis	Care and support planning	Rating services of care providers	Recording health outcomes
Puffell/TimeCheck	Under development	Operational		Operational		Under development		Not available	Operational
Liquidlogic Autonomy Portal	Not available	Not available	Operational	Not available	Under development	Operational	Offered but not yet implemented	Offered but not yet implemented	Not available
Patients Know Best®	Operational	Operational	Offered but not implemented	Offered but not implemented	Offered but not yet implemented	Operational	Offered but not yet implemented	Not available	Operational
Self Care Framework	Operational	Operational	Operational			Operational	Operational	Not available	Operational
eRedbook	Operational	Operational	Operational	Operational	Operational	Operational	Operational	Not available	Operational
Medelinked, HowAreYou, AxSys	Operational	Operational	Operational	Operational	Operational	Operational	Operational	Not available	Operational
CareCentric	Operational	Operational	Operational	Operational	Offered but not yet implemented	Offered but not yet implemented	Operational	Under development	Operational
i-Patient	Not available	Not available	Not available	Not available	Not available	Operational	Not available	Operational	Not available
HealthVault	Operational	Operational	Operational	Operational	Operational	Operational	Operational	Operational	Operational
Nourish	Under development	Under development	Under development	Operational	Operational	Operational	Operational	Not available	Operational
My Medical	Not available	Not available	Not available	Not available	Not available	Offered but not yet implemented	Not available	Not available	Not available

Self-care and shared care

PHR	Linking to monitoring devices	Recording information to help monitor/ track health/ condition	Setting personal goals	Setting agenda and prompts	To-do lists/ reminders	Recording information to be used in an emergency/ crisis	Care and support planning	Rating services of care providers	Recording health outcomes
Patient Access	Operational	Under development	Not available	Not available	Not available	Not available	Not available	Not available	Not available
Cerner	Operational	Operational	Operational	Operational	Operational	Operational	Operational	Operational	Operational
Fusion fx Patient Portal	Under development	Operational	Operational	Under development	Operational	Operational	Operational	Operational	Operational
Inform HIV portal		Under development	Under development	Under development	Under development	Under development	Under development	Under development	Under development
uMotif	Operational	Operational	Operational	Operational	Operational	Operational	Operational	Not available	Operational
FibroMapp, My Pain Manager, myLDN	Offered but not yet implemented	Operational			Operational	Operational	Not available	Not available	Operational
Activ8rlives, SENSOR I and SENSOR II	Operational	Operational	Operational	Operational	Under development	Under development	Under development	Not available	Under development
MyLife	Offered but not yet implemented	Offered but not yet implemented	Offered but not yet implemented	Not available	Not available	Not available	Offered but not yet implemented	Offered but not yet implemented	Not available
UK MS Register									
Epilepsy Toolkit	Not available	Operational	Not available	Operational	Operational	Not available	Not available	Not available	Not available
ClinicYou	Not available	Not available	Not available	Not available	Operational	Offered but not yet implemented	Operational	Operational	Operational
MyRightCare	Offered but not yet implemented	Operational	Operational	Under development	Under development	Operational	Operational	Under development	Offered but not yet implemented

Appendix 6: Information and support services broken down by supplier

PHR	Information and support		
	Finding out about illness/condition	**Information on treatment/care options**	**Getting support**	**Finding out about local services**

PHR	Finding out about illness/condition	Information on treatment/care options	Getting support	Finding out about local services
Puffell/TimeCheck	Operational	Under development	Operational	Operational
Liquidlogic Autonomy Portal	Not available	Not available	Operational	Operational
Patients Know Best®	Operational	Operational	Operational	Operational
Self Care Framework	Operational	Operational	Operational	Operational
eRedbook	Operational	Operational	Operational	Operational
Medelinked, HowAreYou, AxSys	Operational	Not available	Not available	Not available
CareCentric	Offered but not yet implemented	Operational	Operational	Operational
i-Patient	Operational	Not available	Operational	Operational
HealthVault	Operational	Operational	Operational	Operational
Nourish	Not available	Not available	Not available	Not available
My Medical	Offered but not yet implemented	Offered but not yet implemented	Not available	Not available
Patient Access	Operational	Operational	Operational	Operational
Cerner	Operational	Operational	Operational	Operational
Fusion fx Patient Portal	Operational	Operational	Under development	Operational

PHR	Information and support		
	Finding out about illness/condition	Information on treatment/care options	Getting support	Finding out about local services
Inform HIV portal	Under development			Under development
uMotif	Operational	Operational	Under development	Operational
FibroMapp, My Pain Manager, myLDN	Operational	Not available	Not available	Not available
Activ&rlives, SENSOR I and SENSOR II	Operational	Offered but not yet implemented	Offered but not yet implemented	Not available
MyLife	Operational	Operational	Operational	Operational
Epilepsy Toolkit	Operational	Operational	Not available	Not available
ClinicYou	Operational	Operational	Not available	Operational
MyRightCare	Operational	Operational	Under development	

Appendix 7: Literature review

1 Literature review methods

1.1 Databases searched

Literature on PHRs was searched on computerised databases: PUBMED, CINAHL and MEDLINE (via NHS Athens). Searches were carried out from August 2015 to the end of September 2015. Studies published after this date were not included in the literature review.

Searches were carried out using medical subject headings mMeSH) terminology in the above databases, eg ('patients'[MeSH Terms] OR 'patients'[All Fields] OR 'patient'[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, in some instances specific UK-based PHR projects were identified using search engines to identify published literature. References from the initial literature search were also reviewed for identification of further sources of literature.

1.2 Types of studies included

Systematic reviews, randomised controlled trials (RCTs), case control/cohort/cross-sectional studies as well as other descriptive studies were included in the literature review. Although the systematic reviews were classified as a high level of evidence and mentioned accordingly in the review, case studies and reports were included to cover a wide range of studies.

1.3 Inclusion and exclusion criteria

Studies were likely to be included if they were based in the UK. Since the vast majority of the literature was from the USA (66 in the USA vs 6 in the UK), case studies of various UK-based projects were included to strengthen the local population evidence base.

Finally, searches were carried out particularly for recent studies (post 2012), because there has recently been a significant increase in the number of PHR projects as well as better availability of the technology itself. In certain cases, larger UK-based studies prior to this date were included to strengthen the UK-based evidence.

1.4 Data extraction and analysis

A specific data extract form was designed to collate data from the included studies using patient- and system-specific measures. In addition, data regarding the study date, country, population demography and design of the PHR system were collected to add context to the results.

2 Measures used for analysis

A Patient-specific measures

1 Patient adoption

This includes the types of actions that were taken to:
- recruit patients
- encourage initial usage
- encourage continued use.

(For example, GPs meeting with patients to promote the system, and use of incentives to encourage patients to use PHRs.)

2   Patient use

This includes scenarios in which patients used the PHR, such as:

- types of PHR pages accessed or functionality used (eg viewing blood test results or adding a blood pressure reading)
- the setting for use (eg accessing medication during an acute illness).

3   What worked well

This includes what motivated patients to adopt the PHR (eg patients feeling empowered about their health condition).

4   Benefits

This includes improvement in patient experience in managing their disease or related outcomes. Where available, this outlined who benefits the most from the use (eg better management of blood glucose control in diabetic patients, or significantly better control in one ethnic population).

5   Disbenefits

This includes any instances where the use of the PHR could result in an adverse health outcome (eg patients falsely believing that their PHR activity will automatically be acted upon).

6   Barriers

This includes patient-specific obstacles to implementation and adoption of PHRs (eg difficulty in understanding the terminology used in the system). It also includes a note of how the barriers were mitigated or authors' views on how they could have been mitigated.

B   System-specific measures

('System' in this review is not limited to the health record itself, but encompasses the healthcare system in which the PHR is implemented.)

1   System implementation

This includes measures taken to facilitate the implementation of the PHR, both in terms of the health/care system (eg forming a network or a multidisciplinary team to manage the PHR) and the PHR itself (eg patient participation in designing the PHR).

2   What worked well

This identifies which aspects of the system implementation and adoption worked well and encouraged use of the PHRs (eg responding to patients' questions on a timely basis).

3   Benefits

This includes benefits to the NHS/organisations in terms of time and cost savings.

4   Disbenefits

Contrary to the above benefits, this includes loss in terms of time or cost to the organisation.

5   Barriers

This includes challenges to the design, implementation and use of the system. It also includes description of how the barriers were or could be overcome.

Study ID Fisher 2009 – Patient Access to Electronic Records System (PAERS)

Country	**Year**	
UK	2005	

Study population	43 patients aged between 20 and 71 years Median age: 40 years Patients who had accessed the PAERS system were selected. Of a total of 159 patients selected, 43 patients decided to take part. This included 8 patients with long-term condition, 10 with mental health issues and 16 pregnant women. Of the 43 participants, 35 were women, 33 patients were white British and 11 patients were from other ethnic groups. Ethnicity was not recorded for two patients.
Study design	Focus groups, telephone interviews and one-to-one interviews
System details	PAERS system, which offered details of consultation, prescriptions, letters, investigation results, allergies and vaccinations. Links to patient information related to their condition were also provided. The system included a kiosk in the waiting room that provided patient access to the above. Note that pregnant women who were included in the study used paper records.

Patient measures

Use	Patients accessed the PHR between once and twice, on average. Use was higher if the patients had long-term conditions. Some patients used it for curiosity.
Worked well	Accessing the PHR, patients were able to trace the cause of their symptoms and compare test results. Hence, patients were able to link their symptoms to previous conditions and promoted health awareness.
Benefits	Patients felt more in charge of their health and felt like partners in their healthcare.

System measures

Barriers	There were negative comments regarding the technical difficulties when patients first started using the system.

Study ID Phelps 2014 (Renal Patient View)[29]

Country	**Year**	
UK	2014	

Study population	11,352 patients registered from 37 UK adult centres 77% patients were aged between 35 and 74 years 60% were male
Study design	Case report
System details	Renal Patient View enables patients to view blood test results, clinician letters and information resources on a web browser. There was no financial incentive for patients to use the system.

	Patient measures
Participation	Initial promotion was by way of patient consultations and local advertising. Age and treatment group were significant in determining the initial participation to the PHR system. Middle-aged patients were more likely to complete a first logon than younger (<34) and older (>75) registrants. In addition, patients with transplant were more likely to log on than patients 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 be done by their parents. Patients from addresses associated with the greatest deprivation were more likely to not complete a first logon (OR 1.24, 95% confidence interval (CI) 1.08–1.42) compared with registrants of middle-ranked deprivation. Patients from addresses 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 of middle-ranked deprivation.
Use	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 • there were a median of 14 (mean 42.7) logons over 0–42 months • lapsing users had a median of 4 logons • persistent users had a median of 26 logons. Early lapse was associated with individuals who were aged over 75 years and those with greater deprivation, and was less likely in transplant recipients. Late lapsing was associated with those aged over 75 years and those receiving treatment by hospital haemodialysis. Greater deprivation was associated with a substantially reduced probability of continuing PHR use at 6 months, but subsequent rates of attrition were similar in all deprivation groups. Greater early attrition in older patients and haemodialysis patients was followed by a continuing higher rate of attrition than in the young and those with transplants. Most logon events occurred on weekdays and between 8am and 10pm. There were fewest logons on Sundays.
Worked well	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.

Study ID Ambrose 2014 (Patients Know Best®)[12]

Country	**Year**	
UK	2014	

Study population	119 patients (50 male, 69 female) Median age: 49 years (range 17–85 years, mean 48 years) 31/57 patients (54.4%) were over 50 years of age 5,015 unique electronic conversations recorded via telephone
Study design	Survey
System details	Assess patient satisfaction with the health record Patient Knows Best® is an electronic PHR that gives patients access to interact with clinicians. This study looked at the use of the system by patients receiving home parenteral nutrition.

Patient measures

Use	The following were found to be most useful by patients: • discussions by contacting the healthcare team online • monitoring the test results. Patients used the PHR to contact doctors and nutrition nurses more than dietitians or administrators.
Benefits	In total, 51/58 (87.9%) patients felt at least 'somewhat confident' or found it 'somewhat helpful' working online with clinicians through the PHR. Overall, 32 (62.7%) of these responded that the PHR was 'very/extremely helpful'.

System measures

Worked well	The PHR was developed by clinicians and iteratively improved over years to meet patients' needs. A key feature is the timely provision of blood test results.

Study ID Bhavnani 2011 – Patient Access to Electronic Records System (PAERS)[34]

Country	**Year**	
UK	2011	

Study population	A postal questionnaire was sent to adults aged >18 years who had registered to use the PAERS system at their GP surgery. Three GP surgeries: two in south-east London and one in Manchester offering kiosk-only access, online internet access only or both methods. A total of 213 of 610 patients consented and returned the questionnaire. The overall response rate was 35%. The response rate from the practice offering online access to records only was higher than practices offering either kiosk access only or both methods at 45%, 27% and 28% respectively. Mean age was 55 years, with a range of 18–97 years, the majority were aged between 45 and 65 years. Just over half the sample was female and 91% defined themselves as white. Self-reported health status indicated that the majority of

	respondents (108/51%) had been generally well but had an ongoing condition, illness or injury that required regular medical treatment.
Study design	Survey The questionnaire asked closed, open and Likert scale type questions
System details	PAERS provides a secure log-in system, which enables patients to access and navigate around their full GP electronic medical record autonomously, providing information to help patients' understanding of medical terminology. Patients can access their consultation record, their results, their letters (to and from the practice) and patient information leaflets. Patients access the system over the internet or via a kiosk in their general practice.
Patient measures	
Use	In total, 185 of 213 (86%) respondents had accessed their records and, of these, 125 (67%) looked at their records via the internet and 55 (30%) used the kiosk. A small minority (five respondents/3%) used both methods. The most frequent users tended to have a condition, illness or injury that required regular medical treatment. Those in poorer health used records access more than those who reported good health (Spearman's ρ=0.232, p=0.02). There were no significant relationships between the number of uses and age or ethnicity. The majority of respondents indicated that they used record access to look at test results, read letters to and from those involved in their health/care, to check what had been written about them and to look at information concerning past treatments
Worked well	Over half of the sample (112 (54% CI: 47–60%)), reported that they wanted to share their records with other health/care providers.
Benefits	One hundred and thirty-eight respondents, ie 76% (95% CI: 69–82%) felt more involved in their health/care because of record access, and 111 respondents, ie 62% (95% CI: 54–68%), felt that they understood better what had previously been discussed at appointments because of record access. Sixteen (9%) of respondents were more worried about their health because of record access, compared with 118 (65%) who disagreed with this statement (95% CI: 58–72%). A total of 67 of 158 patients (42% (95% CI: 34–51%)) reported that record access had made a difference to their medicine taking by ticking at least one of the options given. From this group, no one thought that record access made them less likely to take medication. Most (83%, n=56) thought that the record access helped them understand why they needed to take the medications. Approximately 25% (n=17) felt that record access made them more likely to take their medications. Fifty-six of 88 patients, ie 64% (95% CI: 53–74%) reported that record access had made a difference to following lifestyle advice by ticking at least one of the options given. From this group, none of the patients thought that record access made them less likely to follow lifestyle changes advice. A total of 32 of 56 patients (55%) reported that the record access helped them to understand why they needed to follow advice and also made them more likely to follow advice. Seventy-four respondents (41% CI: 33–48%) disagreed or strongly disagreed with the statement 'there is more chance of

Barriers	inaccurate information being included in my records'. Only 32 (17%) agreed with this statement and 76 (42%) neither agreed nor disagreed.

Just over half of respondents (99 of 182 (55% CI: 47–62%)) disagreed or strongly disagreed with the statement 'I am worried about unauthorised people having access to my electronic record'. A total of 46 (26%) respondents agreed or strongly agreed with this statement.

One hundred and thirty-six of 182 (75% CI: 68–75%) respondents felt more confident in their GPs as a result of electronic records.

One hundred and fourteen of 182 (63% CI: 55–69%) disagreed or strongly disagreed with the statement 'reading electronic records may lead to misunderstanding of information'.

Overall, 92 (51% CI: 43–58%) felt that looking at records beforehand saved time during appointments.

A total of 28 of 213 respondents (13%) had registered to use the system but had not accessed their records. The main reasons for not accessing records concerned:

- Overall, 82% included technical difficulties, for example difficulty logging on, network problems and forgotten passwords.
- Five (18%) reported not using the system because they did not have health problems.
- Of the 185 patients who had looked at their records, 82 (44%) had experienced technical difficulties. For 29% (52) of patients, these were while logging on.
- In total, 33% (n=56/169) of patients reported difficulties with understanding the content of their medical records. The most commonly reported difficulties were understanding abbreviations, medical words and terminology, and the meaning and significance of test results.
- Sixty-three (38%) had found errors. These included medical events or procedures not being recorded and inaccurate information about allergies and health conditions.

Study ID Hannan 2010 – Patient Access to Electronic Records System (PAERS)[19]		
Country	UK	
Study population	**Year**	**2010**
	Patients were in one practice: Haughton Thornley Medical Centre. Overall, 7% of the practice (800/12,164) had taken the access to the health records. Most patients were in the 45–74 years age group.	
Study design	Case report	
System details	The system included a web portal, use of different languages, talks on various awareness programs, out-of-hours advice, health seeking behaviour for teenagers, as well as booking appointments and ordering prescriptions.	

Patient measures	
Participation	Patients who were interested in the project had a structured discussion describing the health record. In addition, a DVD of the structured discussion and videos were put on YouTube. Posters, articles in newspapers, on radio and TV were used. However the greatest impact was clinicians asking patients during consultations.
Worked well	There was not a single reported problem resulting from patients having gained access. Various measures were undertaken to help implementation.
Benefits	Overall, the patient views were positive and encouraging. These included: • feeling empowered, maintaining a healthy life • understanding their medical condition • monitoring information and sharing it with healthcare professionals • ordering repeat prescriptions and booking appointments • viewing medical history and linking to useful websites • up-to-date information on latest health/care advice and public health information • checking records prior to consultations.
Disbenefits	Errors in records were found and were corrected. No further information was given on these.
System measures	
Implementation	Nurses in the vaccination clinic reminded mothers to get access. Doctors asked patients at each point of contact. The local care record development board consisting of clinicians, managers and patients were involved in the project – this encouraged further practices to use the system. A Caldicott Guardian was used to hold a series of meetings with the public and the local press to explain the importance of the information sharing process. The local library had set up a 6-week IT course to teach patients basic internet skills.
Worked well	Various measures to help implementation were undertaken.

Study ID Cunningham 2014 MyDiabetesMyWay[14]		
Country	**Year**	
UK	2014	
Study population		People with diabetes were sent a registration form and letter, and 2 weeks later non-respondents were contacted by phone. Overall, 4,716 patients had completed the enrolment process (out of the 6,528 individuals registered to access the data): 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).

Study design	Case report – 3 years
System details	MyDiabetesMyWay is the NHS Scotland interactive website for people with diabetes and their carers. It contains a variety of validated multimedia resources aimed at improving self-management. These include traditional information leaflets, interactive educational tools, and videos describing 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 aged 16 or older.
Patient measures	
Use	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 laboratory results (18.2 per patient). The most accessed graph was for HbA1c levels (4 per patients).
Barriers	Barriers to non-usage (primary care pilot study): • 58.5% were simply not interested or felt they already had the information they needed • 41.5% described technical barriers including non-availability or access to a computer or the internet.
System measures	
Implementation	Activities to increase recruitment involved a campaign 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 the users. These discussions were moderated.

Study ID Price 2015[30]			
Country	Varied	**Year**	2015 (literature search between 2008 and 2014)
Study population	Patients with 'chronic diseases': 12 studies that included diabetes, 3 on hypertension, 5 on HIV and 1 each for asthma, ITP, multiple sclerosis, cancer and glaucoma.		
Study design	Systematic review, 23 studies including 7 RCTs 18 US, 3 Canadian, 1 Dutch and 1 French studies		
System details	Varied Access included eight types of features, including viewing and/or editing heath data, tracking care information, setting targets, communicating with health/care professional or carers. None of the studies had all eight features incorporated in the system.		
Patient measures			
Use	Patients with diabetes were more likely to use the system.		

Worked well	Identifying not only the patients who were likely to use the PHR but also certain diseases that those patients had eg those with diabetes are likely to have more uptake compared to those with other conditions.
Benefits	Most of the benefits were realised by patients with diabetes. There was evidence of no benefit in cancer, multiple sclerosis and ITP patients. Benefits were found in 16 of the 23 studies. However, these varied according to whether the results were validated or not. Of the six studies that had patient-reported benefits, 5/6 showed benefits of using PHR. However, among the validated results, only 50% (5/10 studies) showed benefit of using PHRs.
Disbenefits	Only one study reported harms in use. Healthcare professionals reported that patients were under the wrong assumption that they were continuously being monitored by the professionals and that they therefore did not report any change to their health conditions.
Benefits	Patients were able to easily communicate with healthcare professionals through the system.
Worked well	In the systems that were connected regionally with the electronic health record (17/23), 76% showed benefit from use of the PHR. However, in standalone PHRs, benefits were seen only in 50% of the studies (3/6).

Study ID Leusignan 2014

Country	Varied	Year	2014

System measures	
Study population	Primary care setting patients
Study design	Systematic review including 143 studies (17 studies were experimental in design); 10 databases were searched
System details	Varied

Patient measures	
Participation	Patient online access has a low uptake, and the effect on face-to-face utilisation of healthcare was equivocal.
Use	Use of prescription, test results, messaging healthcare professionals, referrals and appointments were the most beneficial.
Worked well	Female adult patients were more likely to use the PHRs. Patient contact emails were compact and brief. There was better patient satisfaction if healthcare professionals responded quicker to patient concerns. 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.
Benefits	Four studies reported an increase in patient adherence and attendance at clinic visits. There was better patient experience and satisfaction (in 16 studies). There was better communication with healthcare professionals (13 studies). While online access allows patients to reflect on their records and prepare for the next consultation, there was no evidence

	of improved health outcomes. 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. 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.
Disbenefits	Eight studies reported patients identifying error in medication lists and drug reactions. A significant number of discrepancies with some potential for severe harm were identified.
Barriers	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 other 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 were disadvantaged by lack of access to the internet while others reported no such barrier.
System measures	
Worked well	There was an appropriate framework of governance and guideline development before the systems are in place. Only six studies reported healthcare professionals wanting training, and only in two studies did they feel they lacked skills for use of the system.
Benefits	Both healthcare professionals and patients reported saving time.
Disbenefits	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 potential for severe harm in the intervention group compared with controls (0.03 intervention vs 0.08 control per patient, adjusted relative risk (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.
Barriers	Healthcare professionals needed support staff to filter messages. 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 reactions, and this could impact negatively on the doctor–patient relationship.

Study ID Ennis 2014 – 'myhealthlocker'[16]		
Country	**Year**	
UK	2014	
Study population	Primary care patients: total of 121 users in South London.	

Overall, 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 (47.8%) were aged 35–44; 5 (21.7%) were aged 45–54 and six people (26.1%) were aged 55–64.

Study design	Focus groups and preliminary survey
System details	PHR designed with and for those with severe and enduring mental health problems.
Patient measures	
Participation	An initial focus group showed that patients were interested in knowing about their diseases, and that they wanted more empowerment. Weekly drop-in sessions in the local community help patients with the use of system and general computer literacy.
Worked well	Use of focus groups prior to the design helped developers to customise the PHR according to patients' wishes. Several other patient reported outcomes measures (PROMs) were added based on the focus groups. Patients who were excellent in computer literacy were asked 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 the layout of the site was clear (mean 4.0, n=19), there were 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).
Barriers	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. Some patients needed basic training for computer use – eg navigation and use of a mouse. Black and ethnic minority patients needed more help to use the PHR. Patients had usability problems – including font size, navigation and understanding the content of the PHR.
System measures	
Benefits	The focus group identified that patients needed minimal interface. After initial training, the patients had no difficulty completing the PROMs.

Study ID Robotham 2015 – 'myhealthlocker'[31]

Country	Year
UK	2015

Study population	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. Overall, the sample included 58 people: 32 participants used the electronic PHR.

Study design	This was a 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	The 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 complete PROMs. These data are sent automatically to the clinical record, where they can be read both by patients and their clinician.

Patient measures	
Participation	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, teach basic computer skills and introduce them to the features of the electronic PHR. Patients who attended drop-ins but who had no other way of accessing the internet were lent mobile devices.
Use	Younger people (aged below 35 years) appeared to be less likely to use myhealthlocker than those aged 35 and over. Usage did not differ by gender (Fisher Exact test=.017, df=1, sig=1), by diagnosis (Fisher Exact test=.096, df=1, sig=1), length of time using services (1 year or less versus longer service history (n=44; Fisher Exact test=1.1, df=1, sig=.36).
Worked well	According to participants' responses to the feasibility survey (n=32), all but one said that they found the site useful, and 27 thought 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 the login process was 'simple' (only four found it 'complicated').
Benefits	There was improvement when comparing participants' last completed PROM (mean=45, standard deviation (SD)=14) against their first completed PROM (mean=40, SD=9). These differences were significant using paired t-test (t=-2.6, df=26, 2-sided sig=.016).
Barriers	Participants reported 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 above had been measured on 5-point Likert scales where a lower score represents a more positive response. Additional comments referred to limitations in how the results of the PROM were presented: '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 Shah 2014 – Patient Access to Electronic Records System (PAERS)[32]		
	Year	
Country	UK	2014
Study population	Patients who assessed their records at least twice in 12 months. Total: 226 patients across two NHS general practices, one with majority white populations and the other majority Asian. The response rate was 61% in the former and 8% in the latter.	
Study design	The study was a cross-sectional audit of the online record access service for patients that involved self-completion of a survey questionnaire by patients in two NHS general practices. Data were collected between 22 July 2011 and 14 August 2011. Manor House Surgery in Glossop and Haughton Thornley Medical Centres in Hyde, both located in Tameside and Glossop Primary Care Trust in the North of England, were the practice research sites of this study.	
System details	Using the PAERS via a secure login, access could be gained to a record of consultations, results, letters to and from the practice and information leaflets.	
Patient measures		
Participation	Patients had been informed about the possibilities of record access through information on and off line, meetings with doctors after surgery, and through YouTube videos. There had also been extensive local media coverage of the initiative.	
Use	Opportunity to obtain test results online, rather than by ringing the surgery, was welcomed. It was clear that the provision of test results online was a valued facility: the process was trusted and provided reassurance.	
Worked well	The initiative was promoted prior to launch, both via the doctors and media coverage. Patients reviewed the content for more than the intended purpose eg use of printed letters at the time of emergency. Proactive patients used their access to prepare prior to their consultations.	
Benefits	Checking past activity including test results and outcome of consultation.	
Disbenefits	Future actions: the PHR enabled patients to support decision making by seeking further information about their condition.	
Barriers	There was a perceived limitation of content. There was a delay in the content being available to the patient after the consultation. Some patients were unable to interpret medical abbreviations in medical consultations.	
System measures		
Worked well	The PHR enabled new unplanned activities when patients accessed their records – reminding patients about their consultation and printing letters in the case of emergency, raising discrepancies and self-monitoring.	
Benefits	Patients associated having online access to their medical records with savings both for themselves and for their healthcare providers. Patients reported saving themselves time (eg less need to take time off work for appointments) and money (eg for petrol or phone calls). There was an awareness of the possibility of savings for doctors' time through freed-up appointments slots.	

Study ID Mukoro 2012[26]		
Country	**Year**	
UK	2012	

Study population	Overall, 257 (50%) validated responses were received from the 507 users. In total, 70% survey respondents were aged 26 to 65 years: the majority (39%) was in the 51 to 65 year age group. Respondents were mostly male (60%) and white British (87%). In total, 88% had home access, and 71% used the system for patient responders (89%).
Study design	Evaluation study – web analytics, surveys and interviews Both quantitative and qualitative data were collected and analysed.
System details	Renal PatientView enables patients to view blood test results, clinician letters and information resources on a web browser.

Patient measures	
Use	Patients were most likely to use it for a recent test (88%), or if they were worried about a result (62%). Overall, 56% used it after a visit to their hospital or GP. In total 45% of patients reported accessing it when blood pressure (BP) was abnormal (45%) versus 20% when BP was normal. It was found that 49% will use the system only if reminded.
Worked well	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 they enter onto the PHR. Patients get timely information and update on their PHRs, which enabled them to be better prepared for consultations and instigate communication with healthcare staff. Real-time update of test results is vital – patients report peace of mind, reducing unnecessary anxiety. Overall, 28% of patients were concerned about security initially, with only 15% being concerned after using it.
Benefits	In total, 88% felt more in control of their medical care: 86% agreed or strongly agreed that the PHR gave them a better understanding of their illness. Overall, 79% communicated better with their doctor and were reassured about treatment. Visual display of 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%).
Barriers	Only a self-selected group of interested patients used the system. There should be more consideration to who gets access to patient information – eg patients wanted their healthcare professionals at the renal unit to have access to their information.

System measures	
Worked well	Access to the site is controlled by the patient who may choose to give permission for family, health/care professionals and
Barriers	There was a lack of usability for some patients eg initial log-in process was found to be 'a bit protracted'. Restricted access to content was perceived by some patients.

Barriers	others to view their data.
	Only a few of the patients were aware of all the functions of the PHRs eg not all patients were aware of entering their own data.
	The forum was moderated; however patients and professionals were not aware of this.

Study ID Swift 2014. The brain tumour patient information portal[33]

Country	UK	Year	2014
Study population	57 brain tumour patients and carers Sheffield and Winchester		
Study design	Case report		

Patient measures

Barriers	Challenges described by authors: accuracy, clarity, security, stress and confidentiality

System measures

Benefits	Benefits described by authors: closure, reassurance, knowledge, empowerment, access to research and understanding

Patient measures

Study ID Leeds Hypertension PHR Project Briefing 2015[24]

Country	UK	Year	2015
Study population	One patient identified from one GP practice with risk of high hypertension		
Study design	EMIS web portal		
System details	PHR platform for patients to access and store their health data on the app and feed the data to a PHR which can be shared with the local GP.		

Patient measures

Participation	Initial implementation involved setting up the patient access account and downloading the app for the patient and demonstrating how to take a blood pressure reading, and how to input and view results on the system.
	It was also ensured that the patient was fully aware of what is expected of them and had ongoing support.
	There was a weekly contact programme with the patient to ensure that the equipment was functioning and the patient was still engaging in the project.
Worked well	Uptake from the patients was phenomenal, with over 10,100 patients using the service within the first 6 months.

Benefits	Patients felt able to filter health data. Benefits of the system were: being able to view it at all times and ease of use. It was also noted that there was increasing confidence in the quality of the blood pressure readings, better control of health and easing of anxiety with better understanding of the disease.	
System measures		
Worked well	The ability of the data to be imported into the EMIS web was considered valuable.	
Benefits	The ability to view the results prior to the consultation meant that time could be focused on other discussions.	
Barriers	Initial uptake from the clinicians was slower – they were struggling with clear examples of how the PHR could be adopted in real use cases.	

Study ID Pagliari 2012[28]

Country	Year
UK	2012

Study population	Of the 57 centres originally enrolled in the pilot, only 32 (56.1%) had proceeded with implementation, of which 16 (50%) returned questionnaires. In total, 42 questionnaires were received from 14 practice managers; 15 clinicians; and 13 patients. All patients completing the questionnaire were aged 41 years or over with 46.2% falling between the ages of 71 and 80 years. Of these, 79.9% reported having a long-term condition and 30% indicated that they were receiving specialist care.
System details	GP software supplier EMIS online record access system
Study design	Survey – questionnaires contained closed, open and scaled items, tailored to user group (manager, GP and patient), covering reasons for enrolment, implementation methods, perceived benefits or drawbacks for patient care or workload, system usability and support requirements
Patient measures	
Participation	Most centres had recruited patients using waiting room leaflets or posters (71.4%), or opportunistically during consultations (57.1%).
Use	All but one patient had been using record access for 10 or more months. Most (84.6%) had viewed their record six or more times since registering, and 30.8% had viewed it more than 10 times. Most (84.6%) had used the system once or more within the preceding fortnight. Reported uses included accessing test results (84.6% of respondents) or clinician letters (53.8%), checking condition (53.8%), and supporting hospital consultations (53.8%); for example through reviewing records beforehand or sharing records during the clinical encounter. Most had shared their record with a spouse, partner or other family member (76.9%).
Worked well	Overall, 38.5% of patients indicated that record access had improved their trust in the health/centre and their confidence in sharing information or decisions with their doctor, while 61.5% indicated that it had not affected these factors.
Benefits	While most clinicians (66.7%) did not perceive that record access had changed the way patients manage their health, 26.7% did (one did not complete this item). Narrative responses revealed a belief, by some, that it had increased patients'

	involvement in the monitoring and management of their conditions; for example, through viewing results and seeking information before coming to see a clinician. All patients found record access 'somewhat useful' (38.5%) or 'very useful' (61.5%). Most believed it had improved their knowledge of their condition (92.3%) or their understanding of its clinical management (76.9%). Overall, 76.9% believed it had helped them to manage their health through encouraging them to take medication on time (23.1%), follow lifestyle advice (46.2%) or become aware of how their behaviour is influencing their health (46.2%).	
Disbenefits	A total of 46.2% of patients indicated that record access had improved their satisfaction with the health centre and 46.2% indicated that it had made no difference. One reported a negative influence.	
Barriers	Perceived barriers included patients' concerns about security, lack of interest, poor understanding of potential benefits and insufficient time for receiving instruction. Patients were typically enrolled by completing a consent/registration form. Organisational challenges included the time required to complete the registration process and review patient notes.	
	System measures	
Benefits	Overall, 79.9% of clinicians felt that record access could be provided without creating a significant additional burden on the health centre. A total of 86.7% perceived no adverse effect on consultation length and 13.3% stated that it had decreased this. Furthermore, 66.7% believed that it had not affected the frequency of consultations, and 13.3% felt that it had reduced the frequency.	
Barriers	Non-usage was addressed. Explanations included a lack of priority (in most cases it was regarded positively but had simply not yet been implemented), lack of internal agreement (eg only one GP advocate in the practice), perceived workload (eg time required to check records and patients seeking clarification); uncertainly about operating procedures or likely benefits (lack of information); lack of patient demand (eg service offered but no take-up) and security concerns (privacy).	

Study ID Jilka 2015[20]		
Country	**Year**	
Varied	2015	
Study population	Varied	
Study design	A systematic search was conducted using Web of Science to identify review articles on the impact of PHRs. Search was limited to English-language reviews 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'. Eight review articles were used in the final analysis.	
System details	Varied	
	Patient measures	
Use	The most common reasons why patients wanted to look at their medical records were to see what their physician said about them (74%), to be more involved in their health/care (74%), and to understand their condition better (72%).	

Benefits	Health outcomes/behaviour include diet, alcohol intake, medication changes and smoking or exercise habits, and are different to 'clinical outcomes', which refer to outcomes that can be empirically tested such as HA1c levels. Giardina et al's 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. Goldzweig et al[17] found most positive changes with 75% (6/8) of studies in their review reporting a positive change as a result of PHR access. Self-efficacy involved various aspects that encompass a patient's beliefs about how they feel, including patient involvement, communication, and patient empowerment as a result of PHR access. Overall, the changes as a result of PHR use across all self-efficacy domains was 67% (31/46) positive, comprising patient involvement (67%, 10/15), patient empowerment (78%, 18/23) and patient communication (38%, 3/8).

System measures

Benefits	In one study, using PHRs for writing all inpatient orders significantly lowered patient charges and hospital costs. Three studies that demonstrated how PHRs in the USA could provide a positive return on investment, providing evidence of major financial benefit. De Lusignan et al[15] found that half of the studies in their review (13/26) showed PHRs have a positive impact on changes to workload or workflow (ie a decrease in workload). Poissant et al's review focused on the effects of PHR access on healthcare professionals' documentation time. They found that that decreased documentation time in a PHR project is not likely to be realised, especially for physicians. From a total of 23 studies included in their review, they found that 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.
Disbenefits	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 examined the impact of PHR on time-efficiencies of physicians. Poissant et al found that using a PHR system increased physician documentation time by 17%. Of their studies, 60% (6/10) reported significant results in the direction of 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 and paper documentation time. Ferreira et al report 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.
Barriers	The poor uptake of electronic health records (EHRs) may be driven by healthcare professionals who are wary of patient access to medical records, fearing it may cause patient anxiety. De Lusignan et al[15] found eight studies where physicians feared that PHR access without a physician available to interpret the information might cause patients to worry. Although these risks are low, doctors have concerns about shared medical records and 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 handwritten notes.

Study ID	Mold 2015[25]	
Country	**Year**	
Varied	2015	
Study population		
Users tended to be slightly older (t-test, p<0.001), or middle-aged (50–65 years), and were more likely to be female (X2, p=0.002), (OR 1.15; 95% CI=1.10 to 1.19). Users also tended to have much greater overall morbidity (OR 5.64; 95% CI=5.07 to 6.28). Differences were also observed between insurance types, with users of messaging being less likely to be funded by Medicaid insurance than commercial insurance (OR 0.81, 95% CI=0.68 to 0.96). African–American and other non-white ethnicities (42.9% and 50.3%, respectively, p<0.01) were less likely than white and Asian patients to use online access (73.6% and 93.4%, respectively); and so were females of lower socioeconomic status.		
Study design		
Systematic review Primary care setting From the 176 papers sourced, only 17 papers were experimental in design, or cohort studies. Nine studies were RCTs (including one randomised control pilot study with qualitative element), and four were cohort studies (including one retrospective cohort study, one cross-sectional cohort study, one retrospective cohort and matched controlled study). Three were cluster randomised control trials. One study was defined as using a quasi-experimental non-randomised design. Most of these studies originated from the USA (n = 13), with three studies being undertaken in Norway, and only one from the UK.		
System details		
Varied		
Benefits	**Patient measures**	
Patients were more satisfied with automated communication of test results (OR 2.35; 95% CI=1.05 to 5.25; p=0.03) and with online information about their treatment or condition (OR 3.45; 95% CI=1.30 to 9.17; p=0.02); compared with those who accessed this information in person or by telephone. Some patients (34%, n=68/200) felt better able to express their concerns in writing; 36% (n=72/200) felt it was easier to communicate about difficult topics). Patients who were given access to their medication list online corrected more than twice as many medication discrepancies with potential for severe harm (0.03 versus 0.08 per patient, adjusted risk ratio 0.31, 95% CI=0.10 to 0.92; p=0.04). Children in the intervention group received 95.5% of immunisations compared with 87.2% in the control arm (n=105 parents; p=0.044). In total, 42 patients provided with online prompts were significantly more likely to receive influenza vaccines (22.0%, n=50/227 versus 14.0% control; p=0.018); and undergo mammography than control groups (48.6%, n=51/105 versus 29.5%; p=0.006). No significant improvement was noted in uptake rates of other screening tests. Online access to consultation notes was also found to increase reported medication adherence as 60–78% (n=5,391) of		

Barriers	patients taking medications reported increased adherence. Patient portal users had fewer visits over the study period, compared with the control group (average of 2.9 versus 4.3 visits; $p<0.0001$).Similarly, annual visit rates decreased by 9.7% (0.23 visits per member) in a cohort study; and in a matched-control study the decrease was 10.3%, or 0.25 visits per member per year ($p<0.001$). The control group reduction for the matched-control study was 3.7%, or 0.08 visits ($p<0.003$). Only 1–8% (n=5,391) of patients stated that viewing consultation notes caused confusion, worry, or that they felt offended by note comments.
	System measures
Benefits	In one cohort study about the implementation of a video to support the use of a patient's portal, during office visits 12 of 13 (92%) support staff agreed that it was easy to use, and six (46%) agreed that the technology did not take up more time. Findings from four RCTs indicated the reduction of face-to face consultations, while findings from other study designs (cohort and quasi experimental trials) found an increase. Only one paper suggested that telephone call volume can decline, with the intervention group seeing a reduction in the annual number of visits and telephone calls by 28% (intervention n=74; OR 3.19; 95% CI=2.44 to 3.94 versus control n=92; OR 4.45; 95% CI=3.60 to 5.29; $p<0.032$), and a total reduction in the number of calls to the GP of 10%.
Disbenefits	Many patients would not be willing to pay for, or only placed a low value on, online services, such as online communication with clinicians. Those who had communicated with their clinician electronically for at least a year had a lower willingness to pay than those who did not have access ($p=0.0028$). Clinicians (n=99) concerned that access to open notes would lengthen visits, reported a minor rise in consultation rates across three study sites (0–8%), and spent more time addressing patients' questions outside of visits (0–8%). Clinicians also reported changes in how they recorded clinical information, with between 3% and 36% of clinicians (n=99) changing record content to allow for online access, and 0–21% reporting taking more time writing notes. In a post-intervention survey, a significant difference was found in time spent writing or dictating notes between practice size, with 4 out of 37 clinicians (10.8%) in smaller practices spending more time writing notes compared with 7 out of 24 clinicians (29.2%) in larger practices ($p=0.019$). Face-to-face contact also increased in a before-and-after study of online test result viewing and secure messaging with clinicians. There were 87,206 users of the system and 71,663 non-users. Office visits rose by 0.7 per member per year (95% CI=0.6 to 0.7; $p<0.001$) in the patient group enrolled in the online system. There was also a significant increase in rates of after-hours clinic visits (18.7 per 1,000 patients per year 95% CI=12.8 to 24.3; $p<0.001$), emergency department encounters (11.2 per 1,000 patients per year 95% CI=2.6 to 19.7; $p=0.01$), and hospitalisations (19.9 per 1,000 patients per year 95% CI=14.6 to 25.3; $p<0.001$) for patients who used the online system compared with non-users. Results of a before-and-after study assessing online access to health records found a significant increase in the per member

	rates of telephone encounters, with a small rise of 0.3 per member per year (95% CI=0.2 to 0.3; p<0.001) in the patient group enrolled in the online system. Similar outcomes were found in a matched-control study, when telephone contact rates increased by 16.2% (0.32 contacts per member) in the secure messaging arm compared with 29.9% (0.52 contacts per member) for the matched control group (four studies indicated no change in telephone consultation volume. Two studies indicated no difference in telephone consultations between the intervention and control groups).
Barriers	Clinicians had concerns about the additional burden and workload from online access but found their fears only partly realised. Few intervention clinicians felt that emails were too lengthy (14.6%, n=43; p=0.04) or were concerned about incomplete information (10%, n=43; p=0.11).

Study ID Greenhalgh 2010 HealthSpace[18]

Country		**Year**
UK		2010
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.	
Study design	Case report	
System details	The NHS in England; 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 may 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.	

Patient measures

Participation	Between 2007 and October 2010, 172,950 people opened an advanced account, compared with 5–10% of the population anticipated in the original business case. In total, 2,913 (0.13% of those invited) opened a basic HealthSpace account.
Barriers	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. None entered any health data onto it and none intended to continue using 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 its functionality aligned poorly with their expectations and self-management practices. The main concern of participants was the fundamental design of the HealthSpace technology and the mismatch between this and their expectations. Despite background literature and explanations by researchers making 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[22]

Country	Year
Varied	2012

Study population	In total, 18 unique studies of chronic diseases were included in the review. 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%). Types of diseases include – diabetes, heart failure, chronic obstructive pulmonary disease (COPD), cardiovascular, cancer and mixed groups.
Study design	Systematic review: RCTs published between 1990 and 2012, web-based and interactive interventions for chronic diseases. All studies were from 2000 or later, with most after 2005. 12 US-based studies, 2 Canadian and 2 Norwegian studies, and 1 from Australia and Korea. Two studies were of high quality, 13 studies were of moderate quality and 3 were low quality, as per the authors' classification based on a 13-point rating system. Only seven described method of randomisation.

Patient measures

Benefits	Significant positive effects on patient empowerment were reported in four studies and positive physical activity was reported in two studies. 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.

Study ID Osborn 2010[27]

Country	Year
Varied	2010

Study population	Type 1 and type 2 diabetes patients (17 studies focused only on diabetic patients; 1 focused only on type 1 diabetes mellitus, 8 only on type 2 diabetes mellitus and 8 studies included both group of patients.
Study design	Systematic review: 26 studies included 2,436 patients including 271 patients for usability studies. Study times were between 3 months to 12 months durations. In total, 26 publications were included. RCTs (8), quasi-experimental studies (4), pre-post evaluations, portal system design and function and qualitative studies of

System details	Varied
	Patient measures
Benefits	usability were included in the systematic review. An RCT, 12-month duration, including 104 patients in the USA with chronic disease, showed significant improvement in cognitive status (+0.8% in control group vs -1.0% in intervention group) and functional level (19.4 vs 20.0) in the intervention group receiving home electronic portal compared with usual home health/care. However patient satisfaction and self-related health were not significant. The total number of urgent visits were significantly reduced (+5 vs -83); however there was no difference in the total number of nurse visits during the study period. An RCT in the USA including both type 1 and type 2 diabetes mellitus patients (n=104) showed a significant reduction in HbA1c levels between control group and an intervention group receiving web-based care management (-1.2 vs -1.6%) in 12 months' time. In addition, there was significant difference in HbA1c reduction between high users and low users (-1.2 vs -1.6%). There was also a significant better reduction in the triglyceride levels and increase in HDL levels in the intervention group. Usage of a type 2 diabetes portal in an RCT was higher when the information was personalised to individual patients (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[17]		**Year**	
Country	Varied	**2013**	
Study population	Chronic health conditions included 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		
	Patient measures		
Worked well	Acceptance of portals was higher in younger, computer literate and more enthusiastic patients. Patient satisfaction was generally high among the portal users.		
Benefits	In one RCT evaluating diabetes care, patients receiving a web-based and nurse care management had significantly lower HbA1c compared with the control group (Ralston 2009). 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 LDL levels between the groups after 12 months of		

access to an electronic PHR (Grant 2008), while a different RCT showed lower HbA1c at 6 months but not at 12 months (Tang 2013).

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 adherence to medical advice but no difference in adherence to medications (Ross 2004).

System measures	
Disbenefits	The study also found significantly high emergency department visits in the intervention group (20 vs 8 visits), with no difference in hospitalisations.

Study ID Robotham 2015[31]		
Country	**Year**	
UK	2014	

System measures	
Study population	In total, 31 staff delivered early intervention services for people with psychosis. Most of the participants were either care coordinators or clinical psychologists. Overall, 100 patients were identified, aged between 18 to 47 years (mean age of 26 years). The majority of participants were of black and minority ethnic groups. The majority of staff were white, female participants. A total of 100 consultations were used for analysis.
Study design	There was 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.
System details	Linking health record to research register

System measures	
Implementation	Only 66% of consultations mentioned the health records and most of them (94%) had reference to research. In addition, only 12% of the patients recollected that the information provided will be used from the health records. 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 • stipulating the sign-up process.
Barriers	Clinicians always 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)[13]

Country	Year
UK	2012

Study population	Twelve liver medicine patients in 2012 Note that the use of the system was reported to be over 8,200 patients in 2014–15.
Study design	Case report
System details	Web-based system with access to QEHB clinical record and online support for patients offered by the University Hospitals Birmingham NHS Foundation Trust. The web-based system provides patients with chronic health conditions access to key parts of their clinical records including test results. Patients can also input data into the system and share them with the clinician.

Patient measures	
Worked well	The system was developed by the local hospital IT and informatics staff with input from the clinicians and patients.
Benefits	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]'.

System measures	
Worked well	Clinical leadership and executive sponsorship is vital.
Barriers	Cultural change for many clinicians that was more of a barrier than the use of the technology itself.

Study ID Johnson 2014[21]

Country	Year
UK	2014

Study population	Inflammatory bowel disease (IBD) patients
Study design	Case report
System details	Every patient is offered a personalised website:

- secure and safe
- instant IBD symptomatic assessment
- instant management advice
- direct alert system to the IBD team
- library of advice leaflets
- direct portal of access to the hospital specialists
- access – worldwide
- integration with the National IBD Registry
- integration with hospital results system
- iPhone and Android apps.

Benefits	System measures
	• 520 patients on IBD-SSHAMP • No admissions • Only three hospital outpatient appointments made • Approximately 600 routine outpatient appointments saved to-date • £69,000 in outpatient appointments saved alone • Aiming for 800 patients by the end of 2014 • £130,000 in gross savings

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