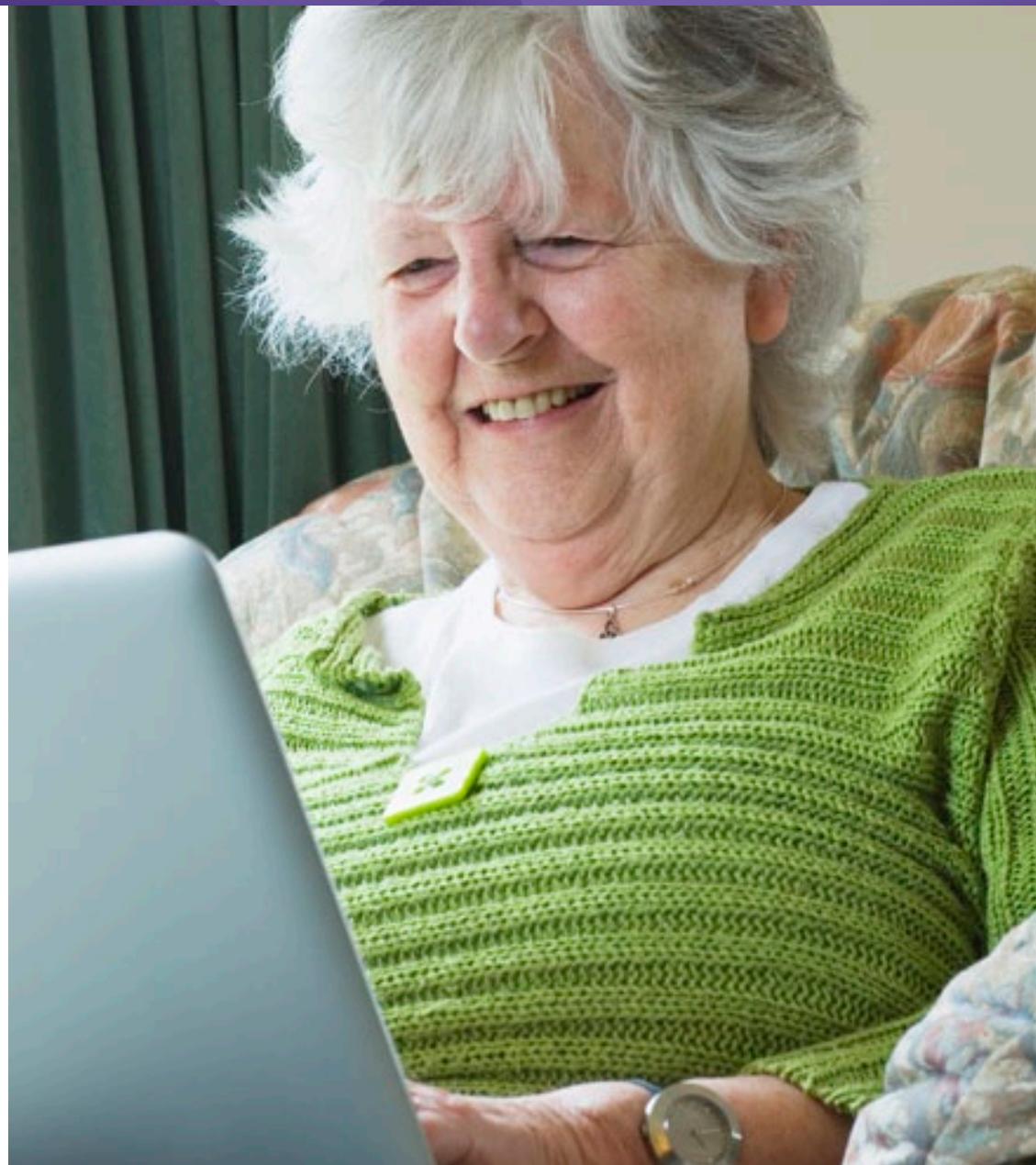


Patient Information Forum

Guide to Health Records Access



Patient Information Forum
Raising the standard of consumer health information
www.pifonline.org.uk



The Patient Information Forum

The Patient Information Forum is the UK membership organisation for people who work in consumer health information (CHI). We are independent, not-for-profit and cross sector. Our members include NHS organisations, both local and national, patient organisations, commercial companies, academics and policy-making organisations.

Our mission is to ensure that everyone can access relevant, high-quality information and support to help them understand their care and make confident, informed decisions about their health and wellbeing.

We believe in championing informed choice and helping people feel confident about the decisions they make. We, and our members, are passionate about the benefits of health information and constantly strive for excellence.

Our role is to:

- ▶ support providers of health information
- ▶ enhance the patient experience
- ▶ improve outcomes by raising the standard of consumer health information.

We campaign to raise the profile of consumer health information, encouraging organisations and policy makers to recognise the value and impact of good health information. We understand the needs of health information providers and support them in their work by fostering and enabling collaborative working; raising the standard of information; and facilitating the sharing of expertise.

Our members benefit from a range of services, including a weekly email newsletter, events, workshops and regional meetings, an annual conference, a query service and a range of resources and tools on our website.

For more information about the Patient Information Forum and membership please go to www.pifonline.org.uk



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This guide was informed by:

- ▶ An extensive literature review
- ▶ Interviews with clinicians, commissioners and opinion leaders
- ▶ An invitation to electronic health record suppliers to contribute case studies
- ▶ A consultation event with patients and the public held in February 2012
- ▶ A policy roundtable event held in March 2012.

This is a fast-moving field, and although we have tried to make it as evidence-based as possible, some views are of necessity informed by expert opinion.

The case studies included in this guide are not exhaustive, but represent the broad range of Personal Health Record and Record Access projects currently operating around the UK.

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PiF would like to thank all of the PiF members and other organisations who contributed case studies, perspectives and references for this guide. In particular, we would also like to thank the following for their input:

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As a patient lucky enough to have access to my GP record online, I am very keen that everyone else should be offered a similar service. There are countless advantages to

this new way of interacting with the health service, including becoming a better-informed, active patient, and feeling more in control of your health and care. I have been delighted to contribute to PiF's understanding of Personal Health Records and think this guide does a valuable job in spelling out what needs to be done to make access to electronic health records a reality for everyone.

Yvonne Bennett

Patient, Haughton Thornley Medical Centres

“ ‘Information is an essential service in its own right, allowing us to understand our own health, choose healthier lifestyles, and choose the treatment and support that is right for us.’¹

“ ‘The aim is for everyone to benefit - irrespective of whether we can access the internet, have other translation, communication or support needs - and for information to improve health and care and to reduce inequalities. This will mean that some of us will need extra support to use information as a core part of our care services.’¹



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¹ *The power of information: putting all of us in control of the health and care information we need.* Department of Health, 2012. <http://informationstrategy.dh.gov.uk>

This guide is about shared Personal Health Records (PHRs) - an exciting new development with enormous potential to facilitate a step change in the extent to which individuals are involved in managing, and making decisions about, their health. This guide is aimed at practitioners, managers and patient organisations in health and social care in the UK. It gives a vision for the future of Personal Health Records, and an understanding of some of the challenges and barriers which must be overcome in order to realise their full potential. It points to solutions to these barriers and is, in effect, a call to action.

The guide brings together the perspectives of policy makers, clinicians, suppliers and patients themselves. The case studies illustrate the current status of record access around the UK and the rest of the world.

Chapter 1 defines PHRs and explains the **different levels of access, patient co-production and cross-organisational integration** which are possible. It sets PHRs in the context of the development of record access in the UK and the newly launched Information Strategy for England.

Chapter 2 describes the **patient and citizen perspective** on PHRs. This includes the potential benefits, such as improved health and communication, but also some of the risks, such as concerns about safety, and widening health inequalities.

Chapter 3 discusses PHRs from the **health and social care professional perspective**. It explains some of the concerns about PHRs which have been barriers to their widespread uptake. It counters these with some of the benefits seen when PHRs are implemented in practice.

Chapter 4 describes the **benefits of PHRs from the commissioner and health system perspective**. It summarises what steps towards record access are included in the new Information Strategy for England, but also highlights important issues still to be tackled by all four UK health systems in order to give PHRs a chance to realise their full potential.

Finally, there are chapters with case studies, and further reading, useful resources, and a glossary of terms.

This guide is being published at a time when the health records landscape in the UK is changing at a rapid pace. We are keen to hear what you think of it and to learn from you about any areas that we may not have covered, or where PiF could usefully do further work. There is information at the end of the guide about how to feedback your comments to us.



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Shared Personal Health Records - a vision for the future

Box 1

Maria is a 39-year-old woman. After having two children she has put on a lot of weight so she is on a health kick. She is starting to run and cycle regularly and her smart phone automatically records her exercise from her pedometer and downloads it into her PHR. Her bathroom scales also transfer her weekly weigh-ins. And she uses her phone to keep a record of what she eats. When she logs on to her PHR she can see how many calories and how much fat she has had, and seeing this plotted against how much weight she has lost is really helping to keep her on track. When she saw her practice nurse recently they were able to look at the results together and the nurse then sent her some links to lifestyle advice, which she has stored in her PHR too.

One of Maria's sons has severe allergies and, since she has linked his GP, dermatologist, paediatrician and dietician together via his PHR, she is finding it much easier to keep

track of what's going on. Everyone can see when his appointments are, what tests are due, and the results as they come through. Maria is becoming a dab hand at taking photographs of his eczema flare-ups and saving them in his record. This helps her and the doctors to see which creams are working, and she is able to email them for advice, rather than always having to take time off work and school to go to the hospital. And she can order repeat prescriptions online and make appointments. The dietician has helped her put together a list of what food he can and can't eat, and it is even linked to specific brands. This is invaluable for friends, family and school to check what he can eat, and she can allow access to this document to whoever needs it.

Maria's elderly mother, who lives in sheltered accommodation, has been causing a lot of concern recently. She has mild dementia

and is confused at times. Unfortunately she has never been much good with computers so attempts at getting her to use an online health record have failed. But she has nominated Maria to be able to access her record, along with her community care team, so Maria can see when someone's going in to see her mother and what has been done. They make a note of her mood and mental state too, so when Maria takes her to see the doctor they all have a clear idea of how she is doing. There is even an app that links Maria, her family and her mother's local friends so that they can see when a visit might be welcome, or if any chores are needed.

Maria doesn't know how she would manage without all this technology. Imagine if she had to make an appointment every time she needed to speak to a health professional, or had to wait for letters to arrive from the hospital!



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Chapter One:

Putting record access into context

Information is pivotal to good-quality care. It allows us to understand how to improve our own and our family's health, to know what our care and treatment choices are, and to assess for ourselves the quality of services and support available.²

England's new Information Strategy embraces the way information and technology can positively change our lives. It recognises that information must drive better health, care and support.

In the Chancellor's 2011 autumn statement, the Government pledged that everybody in England will have online access to their GP records by 2015, as a first step towards wider access. The Information Strategy puts some detail around how this will be achieved. However, the Government has avoided central direction and so leaves the arena wide open for local innovation.²

“ ‘From a patient's perspective [using a PHR] means being an active partner in the doctor-patient relationship; your whole relationship changes. You've gone from being told what's happening - it becomes a discussion. It's a relationship that is based on trust. It's about having choices and being a happy patient, and making sure you are getting the best possible care. That's what I am experiencing now. Things are changing. We've got 'Choose and Book', there's lifestyle courses and things like the expert patient programme, and record access. We can order repeat prescriptions, and check our medications. And we can get into our actual medical records, so we can check results and X-ray reports online; we can read the letters, and we can also print

everything out and can even take that when we go and see another doctor... And in the community, if there's a district nurse coming to your house you can show them your latest blood results. And perhaps if you've got a family that's split up, say your parents are in sheltered accommodation and you're looking after them, and if they are agreeable, you can keep an eye on what's going on. And our time is important. It saves time to get results. And you can get your results translated if you can't speak English, or you can show them wherever you are in the world. And you can print everything out, like what's happened recently and your medicines, when you're going in to hospital, so that the information is there.'

60-year-old woman and keen PHR user



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² *The power of information: putting all of us in control of the health and care information we need.* Department of Health, 2012. <http://informationstrategy.dh.gov.uk>

Chapter One: Putting record access into context

Of course, having any access to our health records is a huge leap forward from where we are now. But access is not enough. Patients increasingly want to make active use of their records. The vision now is for shared PHRs - see box 2. These enable individuals to truly be at the centre of their care.

A shared PHR is a physical or electronic, patient-controlled copy of all the health information stored about an individual by health and social care organisations, to which the individual can add their own data.

There are many ways shared PHRs could become a reality. A patient could see their entire NHS record, and be able to annotate and add their own data, and share it with others. Or an individual could subscribe to a system they choose, collect their own information and import records from all their health providers. The options are numerous, but the vision is the same: people in control of their own data.

Why is the shared Personal Health Record so important?

PHRs are the greatest innovation in the field of health information for generations. As such, they herald an enormous cultural change for all of us. By understanding the power of PHRs and supporting their implementation and use, organisations that produce and provide health information are ideally placed to help make patients and the public more confident, empowered and informed.

“ ‘In a networked health information environment, various data holders, including consumers, keep multiple copies of health data. There is no default ‘source of truth’. Every piece of information must be evaluated based on many factors, including its source.’

Markle Connecting for Health Collaboration³

“ ‘Whether or not it reduces costs, it’s morally right.’ *PiF policy roundtable event*

International definition of PHR

Box 2

There has been lack of consistency in how the term PHR is used. The International Organization for Standardization has defined it as follows:

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

Health Informatics - Personal health records - Definition, scope and context. (ISO/TR 14292:2012)

³ Markle Connecting for Health common framework for networked personal health information. www.markle.org



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Chapter One:

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PHRs to support self management - the bigger picture

Box 3

PHRs are not an end in themselves, but just one of the tools needed to achieve the real prize - a step change in the extent to which people are able to manage their own health effectively and a change in the relationships between citizens and their clinicians and the NHS. Around 15 million people in the UK live with a long-term condition⁴ such as diabetes, depression, heart disease or arthritis, and this number is expected to double by 2030.⁵ Long-term conditions account for 70% of NHS spending.⁶ We know that people with a long-term condition, or at risk of developing one, can improve their health and quality of life by taking a more active role in their own care.⁵

Engaged patients feel more confident and empowered, have better clinical outcomes and make more appropriate use of health services. But to do this they need self-

management skills and access to information about their condition. They also need skilled support and motivation from their clinicians, and healthcare systems that operate very differently from those we have today.

Interventions to support self management include:

- ▶ Information
- ▶ Care planning
- ▶ Goal setting
- ▶ Decision aids
- ▶ Self-monitoring
- ▶ Education and peer support.⁷

PHRs can support the delivery interventions - but this needs to be designed in to systems from the outset. Offering simple 'access', the ability to view health records passively online, will not deliver the full potential of PHRs.

The Health Foundation has funded a number of major demonstration projects in this area - including the myRecord project and Co-creating Health. For a fuller discussion of self management, and how PHRs fit in, visit their website at www.health.org.uk.

Self management support can be viewed in two ways:

- ▶ as a portfolio of techniques and tools that help patients choose healthy behaviours; and
- ▶ as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership.⁸

⁴ www.dh.gov.uk

⁵ *Co-creating health: Evaluation of first phase*. London, The Health Foundation, 2012. www.health.org.uk

⁶ *Long term conditions compendium of information: third edition*. Department of Health, 2012. www.dh.gov.uk

⁷ *Evidence: Helping people help themselves*. London: The Health Foundation, 2011. www.health.org.uk

⁸ Bodenheimer T, MacGregor C, Shafiri C. *Helping patients manage their chronic conditions*. California: California Healthcare Foundation, 2005. www.chcf.org



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What is record access?

Under the 1998 Data Protection Act, everyone has a legal right to ask to see their NHS or private health records, using a Subject Access Request.⁹ In practice, this means applying to see the paper versions from each practice, hospital or care provider separately. Access may be denied if it is considered that it would cause serious harm to the patient,¹⁰ and patients will often need to pay to see a copy.⁹

But things are changing. As more and more health providers replace paper records with electronic versions, the aim is to allow patients to access these electronic records for themselves.



Health records - the current situation

In the NHS, each individual provider, such as a GP practice or hospital, tends to store information in their own systems, with little or no sharing with other providers.

Over the past ten years, the NHS in England, Wales and Scotland, and Health and Social Care in Northern Ireland, have attempted to develop the IT infrastructure to provide universal, structured, person-based electronic records - see boxes 4 and 5 overleaf. In England, the National Programme for IT, begun in 2002, was commissioned to connect over 30,000 GPs in England to almost 300 hospitals and give patients access to their personal health information. Although the programme delivered some significant improvements, such as a national secure broadband network and 'Choose and Book' (to choose hospitals and clinics and book appointments online), it is now being dismantled in favour of a decentralised approach to allow for local decision-making and innovation.

In general practice, where IT development has been largely bottom-up and clinically led, the implementation of electronic records has moved ahead of secondary care. Paperless records are now the norm, and correspondence from other parts of the system is routinely scanned and held electronically. There is widespread use of clinical coding systems (such as READ and SNOMED) that allow information from records to be extracted and summarised. The potential for allowing patient access to records is there. Some of the major GP software companies, such as EMIS, already have systems up and running. Other suppliers (including TPP) are conducting pilots.

Elsewhere in the NHS, comprehensive electronic records remain an aspiration. Many places, particularly hospitals and social care settings, still rely on paper records for all or part of care, alongside numerous electronic systems for specific functions, which may or may not integrate with each other. Staff have to wait for data to move around the system by fax and post; it is very difficult to know

⁹ NHS Choices www.nhs.uk

¹⁰ *Confidentiality*. London: General Medical Council, 2009. Endnotes, paragraph 16. www.gmc-uk.org



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how and when a patient is treated elsewhere; and it is virtually impossible for patients to see all information held about them, let alone have any control over what is kept in the record and who sees it. This remains a major barrier to online record access beyond primary care.

The exceptions to this are patient-held records - see box 6 overleaf. For years these have been used routinely in a few settings where patients are looked after by multiple providers. Generally, the patient is the custodian of the notes and has free access to them, but data is added only by professionals. Other cases, such as the RedBook, allow the custodian to add updates too.

Patient-held records demonstrate how, by patients controlling their own data, no single provider can prevent others from using the data, and records can be truly integrated.

National progress on record access

Box 4

England

The Government has pledged that all NHS patients will be able to access their personal GP records online by 2015. This will be commissioned locally rather than through national procurement. However, at present, only some 100 GP practices are offering online record access to patients so there is a long way to go. Meanwhile, in secondary care, access is limited to specific schemes and pilots.

Wales

Patients are being offered a 'My Health Online' account. These have been rolled out to 21% of general practices so far. Initially patients will be able to order repeat prescriptions, book appointments and update personal information. Subsequent phases will allow record access within about two years. There are no plans at the moment to offer access to secondary care records.

Scotland

There are two GP software companies which cover the whole of primary care and both offer a module that allows patient access to their records. However, there will be no mandatory national roll out of these. The Government is developing a citizen e-health strategy which will include (probably limited) record access.

Northern Ireland

There is a new Electronic Patients Records system being put in place. The software provider was announced recently and the first benefits are expected in the next year or so. The project is seeking to link up Trust records (including diagnostic testing) with out-of-hours services and GP systems. However, patient access to GP records is not part of the remit.



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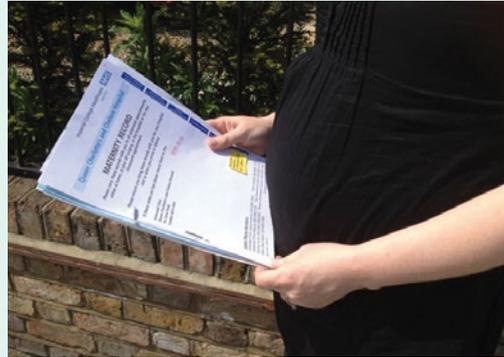
Summary records for emergency care **Box 5**

Around the UK, work is continuing to create an online record for each NHS patient, summarising their prescriptions and any allergies or adverse reactions to a medicine.

These records will only be used by health professionals at the point of emergency or out-of-hours care. Access is available throughout Scotland (Emergency Care Summaries), and is being rolled out across Wales (Individual Health Records), Northern Ireland (Emergency Care Records) and England (Summary Care Records).

Examples of patient-held records **Box 6**

- ▶ Maternity notes are kept at home by women and used by GPs, midwives and hospitals. Women can add their own birth plans and other information.



- ▶ The Red Book is a personal child health record, kept by the parent and used by them and any health professional involved in the child's care until they reach five years old.

- ▶ The new End of Life Care Co-ordination Record Keeping Guidance¹¹ includes the option of the record of a patient's preferences or decisions being kept on paper in the person's home or 'current' home.
- ▶ Gypsy and travellers health records are being piloted in a number of sites to ensure that members of the travelling community have their full record wherever they go.¹²
- ▶ The 'Copying letters to patients' initiative, launched by the Department of Health in 2002, aims to make patients routinely copied in to letters written about them between health professionals, although the scheme is not mandatory.

¹¹ *End of life care co-ordination record keeping guidance*. National End of Life Care Programme, March 2012. www.endoflifecareforadults.nhs.uk

¹² Sussex Traveller Health and Wellbeing Team. www.gypsy-traveller.org



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“ ‘I signed up to a [PHR] service so that I could see both my records and those of my children. It was useful to have my medical history in one place, and it was interesting if you understood them and knew what you were looking for. I consider myself educated enough to understand most of the terms in a medical report. Still, I found myself needing explanations for things that were measured differently from what I was expecting, or for things that were out of range (did I need to worry?), or simply for what to do next.

The [health provider] took the view that they'd only set up a meeting with you to discuss the results if there was anything to worry about but, in a way, having the

information raised a lot of questions in my mind even if the doctor decided there was nothing to discuss. And people end up with a lot of information that they may not properly understand for which they may start seeking answers in the wrong place, and about which they may worry unnecessarily.

A second risk is obviously confidentiality and safeguarding patient data. Would I sign up for something similar over here in the UK? Yes, as it would allow me to do the practical things and see/have my own records without having to go to the doctor's practice, should I need them.'

Healthy woman, just returned from living in the US



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Key features of a shared Personal Health Record

Box 7

1. Private and secure

- ▶ Patients and other users authenticated properly
- ▶ Clear limitations on identifying information held within the record
- ▶ Best practice system security

2. Transparent

- ▶ Audit trail of who has viewed and edited the record

3. Current

- ▶ Constantly synchronised with the health and social care providers' electronic health records (which remain their property even if the patient withdraws access to the shared PHR)

4. Comprehensive information

- ▶ Incorporates all relevant information from all the electronic health records about the patient held by any health or social care organisation
- ▶ Full access to health records, medical notes, current and past prescriptions, test results
- ▶ Secure messaging between patients and health professionals
- ▶ Transactions such as ordering repeat prescriptions or booking appointments

5. Controlled by the patient/citizen - who can:

- ▶ Decide who to share the record with (including healthcare professionals, carers and others)

- ▶ Withdraw that access to the record at any time and still keep their copy
- ▶ Add to, and annotate, the record
- ▶ Download or export the information to another device or format

They may also include functions such as:

- ▶ Setting agendas for appointments in advance
- ▶ Completing Patient Reported Outcome Measures and sharing other data with healthcare professionals
- ▶ Tailored education or support programmes, care plans, treatment goals, reminders.

Consensus of experts convened by PiF, 2012



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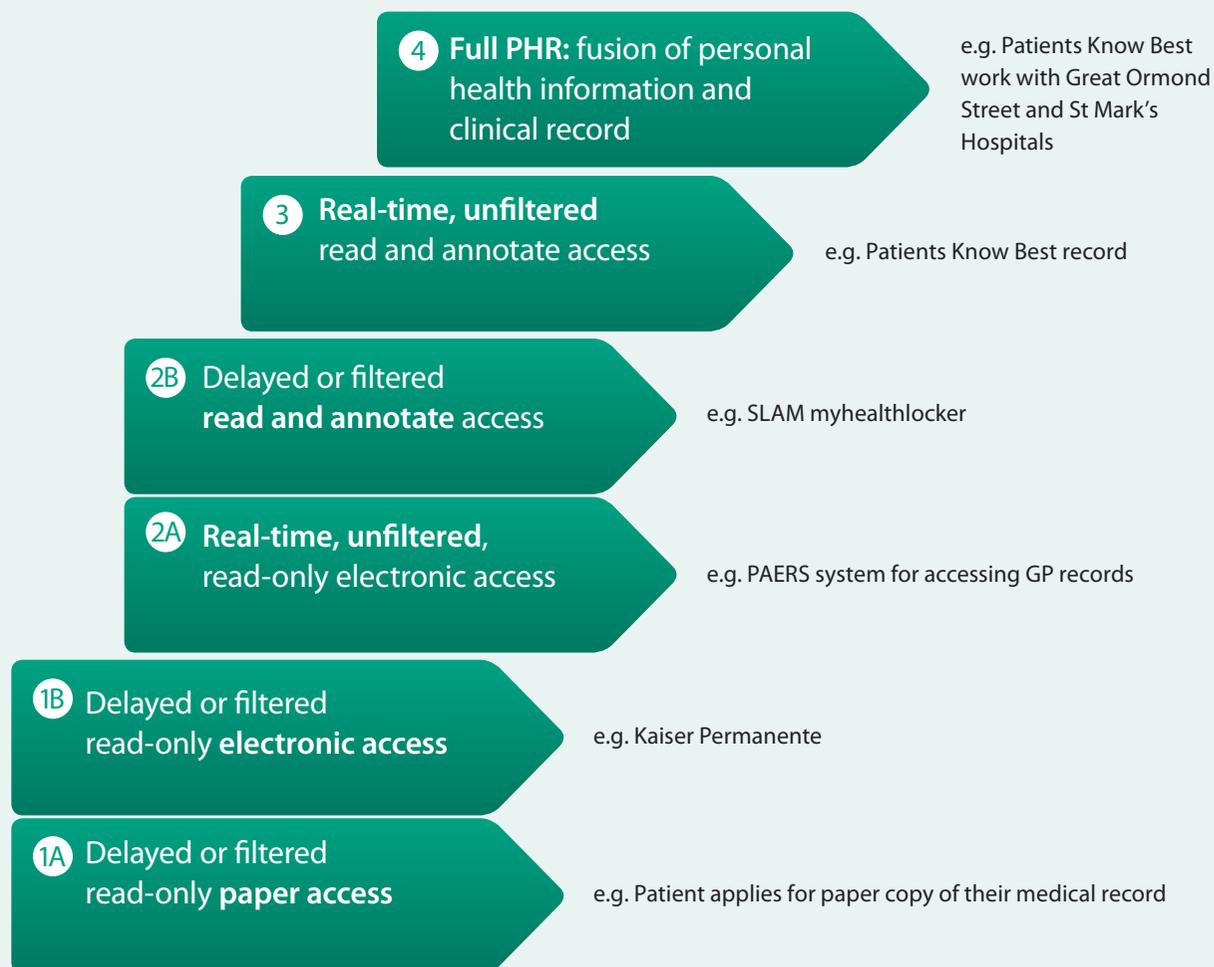
From record access to shared Personal Health Records

PiF has defined the essential features of a full shared PHR - see box 7 on previous page.

There are several levels of access to records along the road to this end point. Figure 1 outlines what these are and gives examples of solutions currently operating at each level - given as case studies in Chapter 7.

It should be noted that some delay in parts of the record being made accessible may be a good thing: the Record Access Collaborative guidelines recommend that potentially alarming test results should be communicated face to face, before patients are able to see them in their record.¹³

Figure 1 - Stages on the road to full Personal Health Records¹⁴



¹³ Record Access Collaborative. *Enabling patients to access electronic health records. Guidance for Health Professionals*. London: RCGP, 2010. www.rcgp.org.uk

¹⁴ PiF and Professor Iain Buchan, June 2012 [personal communication].



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Tethered PHRs

A distinction can be made between tethered and untethered records. A **tethered** record is a subset of data held by a specific healthcare provider, such as a GP practice. The user can access and update their data with varying degrees of control. Renal PatientView and the PAERS GP record access system are UK examples. By definition, a tethered record will not be comprehensive - only information held by one healthcare provider will be included - but if this is the GP practice, this will include at least the most significant correspondence and test results from other providers.

The tethered record can also enable a system that is interactive, allowing a closer and more personalised relationship between the citizen and the NHS.

Untethered PHRs

Given the disjointed nature of electronic health records in the UK, shared PHRs in their fullest form are likely to be provided through untethered solutions. An **untethered** PHR is controlled by the individual rather than an institution. Typically, it will be provided through a web-based platform which offers the patient an online space to keep data about their health - including data generated by the patient themselves - and synchronises with the patient's electronic health records held by different institutions (see Figure 2 overleaf). This requires the patient and the healthcare institutions' permission and relevant interoperability protocols to be in place.

Untethered records offer the potential for patients to share data from one healthcare institution or professional with another, including non-NHS providers - thereby

joining up the data into a full shared PHR. Untethered PHRs are at an early stage of development in the UK, but two providers, Microsoft HealthVault and Patients Know Best, have platforms which can offer them.

“I think the idea of a record you can correct, fill in blanks, submit your own readings and interactively manage your own condition (graphs against target of blood pressure etc.) has great potential... If you can link families round the back to allow tracking of genetic conditions then the potential is enormous.”

GP responding to DH Consultation on Record Access Support Needs 2012



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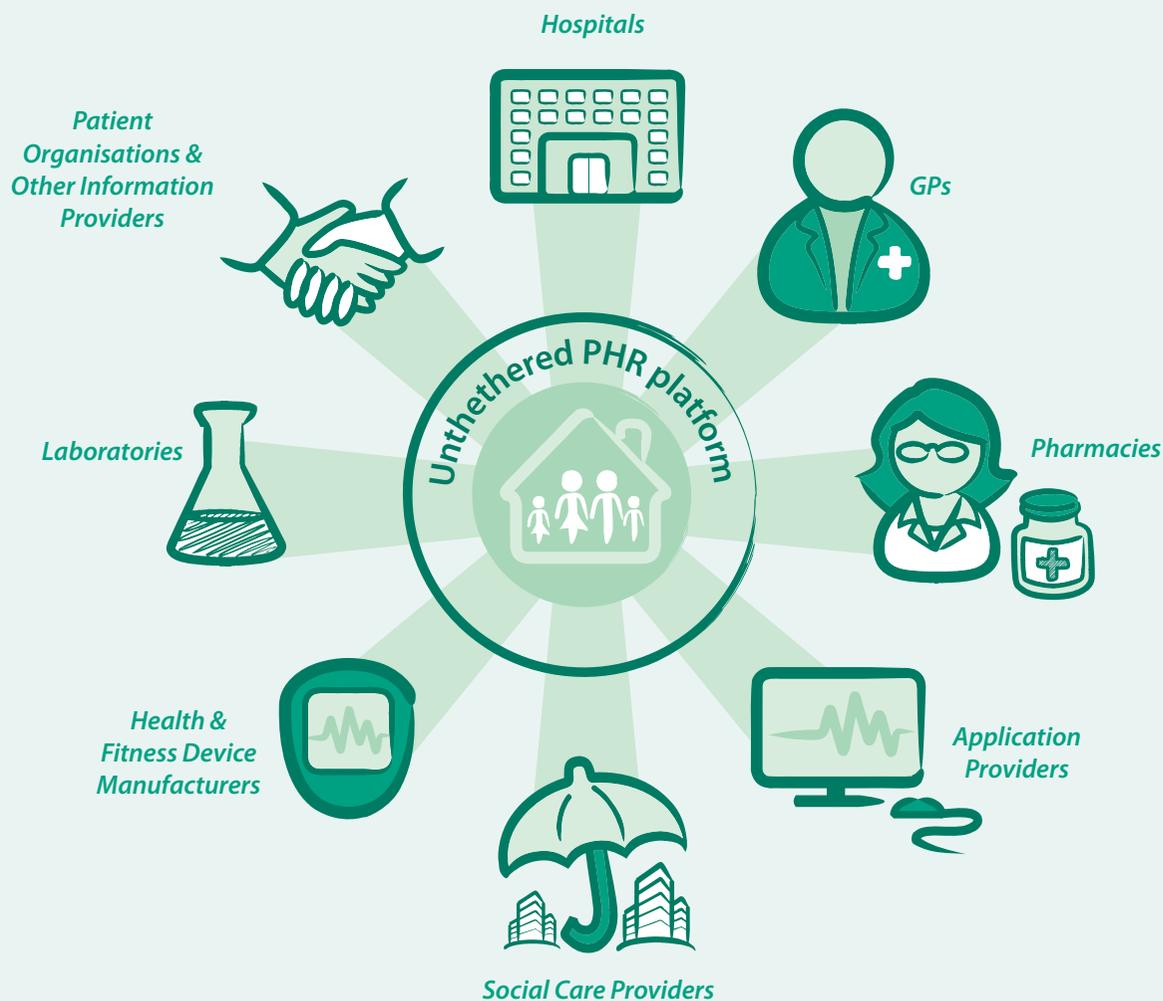
Chapter One: Putting record access into context

Beyond just offering patients the ability to access and add to their records, both untethered and tethered PHRs offer a vehicle for the development of innovative applications and add-ons to enable patients to track and interpret their data, and manage their health proactively. People can connect monitoring devices, such as blood pressure monitors, weighing scales, blood sugar monitors and heart rate monitors, to their computers and upload data directly into their record, helping them to increase their personal fitness or monitor a long-term condition, and share this data with health professionals.

PHRs also have the potential to play an important role in telehealth and telecare. The Whole System Demonstrator programme included elements of record access in most trial sites and has shown significant benefits.¹⁵

¹⁵ 3 Million Lives www.3millionlives.co.uk

Figure 2 - The 'untethered' PHR platform



Chapter One:

Putting record access into context

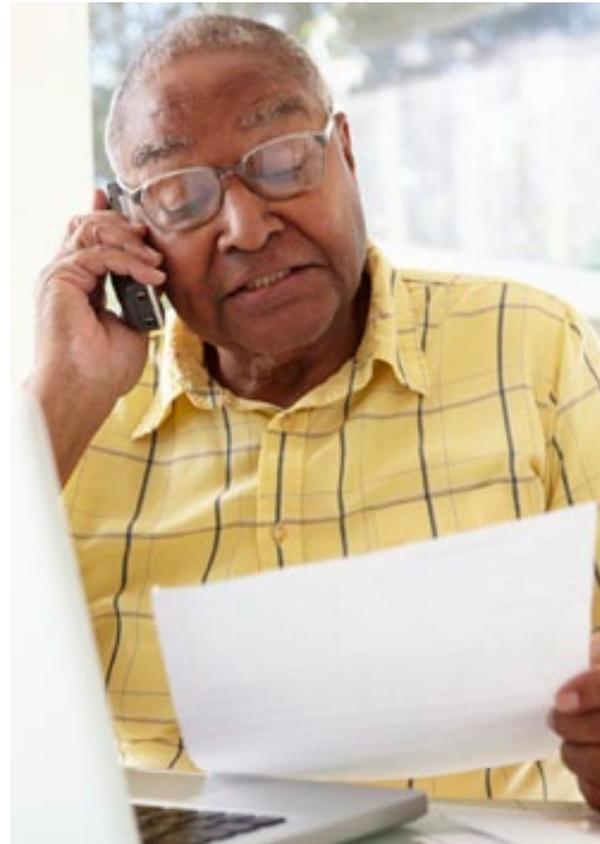
Shared social care records

Just as there is scope in the development of health records, there is great opportunity to similarly develop social care-related information. Healthcare informatics is now being recognised as a major contributor to care delivery and although this is less developed in social care, the two will need to evolve in parallel. Social care records have particular requirements and a wide remit covering a range of contributors and providers. The systems and information requirements can therefore be very different from those for clinical health services.

Social care records are very broad: they are about the person and those around them, giving a bigger picture that can include plans for the future.

The concept of an 'Adult Care Support Record' (ACSR) has been developed to address these requirements in adult social care.¹⁶ Similar developments are happening in children's services. The ACSR is similar to the PHR and encompasses part or all of

the definition of a PHR. But an ACSR is not thought of as a single, physical record. Rather, it is conceived as a virtual record, distributed across a range of systems and infrastructures.



Compared to PHRs, it is likely an individual will be far more involved in producing their ACSR, creating plans and commissioning services for him or herself. The ACSR will include all the relevant information about a person that relates to their care, some of which they hold and some of which is stored by the various agencies and providers who work with them and support their care. But it should all be accessible as if it were contained within a single system.

The ACSR needs to be accessed by three stakeholders:

- ▶ the individual (who needs the record, generates some of it, and may want to share it)
- ▶ practitioners (they must record and evidence their practice)
- ▶ organisations providing services (who will want to record finances, care, service transactions and planning, and decision-making).

¹⁶ ACSR framework guide. *The core adult care support record*. Strategic Improving Information Programme, February 2011. <https://nascis.ic.nhs.uk>



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Putting record access into context

Information needs to flow dynamically around this triangle, supporting a range of purposes rather than being held as static 'facts' in a single box. So, for social care, it is important to consider using integrated technology that shares information, and presents it in different ways to different people for different purposes.

Relatively few users will be able to view a complete ACSR. Usually access will be restricted to those parts of the record relevant to the user's role. This includes the person who the record is about as, very occasionally, there may be some components where access by that individual may not be appropriate - for example, when there are safeguarding issues, mental health concerns or third-party identities. In general, the person that the record describes should be aware of who has access to any component of it, and be able to restrict or withdraw that access.

For most people, it is probable that they will be the one who will retain the most complete view of their record, and it is likely

that they may wish to restrict access to some component, such as financial components or specific sensitive issues. For a minority, such as those with reduced capacity for decision-making, the holistic view of their record may be allocated to a carer or advocate.

The ACSR will have two aspects. The **person focus** will have information relating to an individual, to be accessed, updated and used by him or her (or their advocate) to identify and manage care. This may be linked to other customer and health records, but the social care component should be identifiable and access controlled through appropriate governance. It may include, for example, care and support plans, end-of-life plans, personal relationships, the person's finance data and service transactions.

The **organisation focus** is about the information relating to an organisation's interactions with the individual, to monitor effectiveness and efficiencies of service, and for safeguarding the individual and the community. There may be more than one organisational view of data, and the views

may overlap where agencies provide joint services and support. The organisation focus also includes parts of the record that it may not be appropriate to share with the individual. Access and control of this data needs to be strictly managed.

For most people going through life, PHRs are appropriate and relevant; a smaller proportion of people will also need an ACSR - recording additional data and services - that they can access and share with a much wider care support team.



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Chapter One: *Putting record access into context*

Conclusion

The UK is just starting out on the road towards full shared PHRs for all. There is tension between the ideal, defined here, and the more limited, but achievable, levels of access which are the immediate aim in the new Information Strategy for England, and elsewhere in the UK. The following chapters of this guide describe some of the benefits and challenges to realising the full potential of PHRs, and outline essential steps which are needed to turn the vision into reality.



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Chapter Two:

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“ ‘It is dangerous not knowing your own medical records. A PHR would help.’

PiF patient consultation

Public reaction to PHRs

When people are introduced to the concept of shared PHRs, reactions range from enthusiasm and excitement to scepticism and concern.

Of those who took part in the consultation event held to develop this guide, many eagerly welcomed advantages such as seeing exactly what is held in their record, accessing test results, and conducting transactions such as booking appointments and ordering repeat prescriptions.

However, people also raised concerns about security risks and third parties accessing records without consent. And while some can see the benefits of sharing a record with, for example, family and carers, some people want and need to be able to pick and choose who sees what.

There is also concern that not everyone is IT literate or even has access to a computer, although with the widespread use of smart phones the problem of internet access is diminishing.¹⁷ But, in pilots, there are examples of elderly people embracing new technologies, sometimes prompted by the offer of record access. Younger people, many of whom already live in a social media world, may find online access to records a natural progression. Also, patients with long-term medical conditions may leap at the chance of engaging more easily with health professionals. These groups may be more likely to engage quickly with this new model of healthcare and others will catch up.

“ ‘I wouldn’t want everyone I share my record with to know if I was thinking about a living will. Or who I want to share my records with.’

PiF patient consultation

“ ‘I fell down the stairs and broke my shoulder. It resulted in 8 visits to the fracture clinic which meant 8 letters to my doctor, none of which I received copies of, so that would have meant 8 appointments at the GP’s to find out what the letter said, and 8 telephone calls. So [seeing the letters online] saved me 11 hours. For the doctor, it saved 8 appointments. They estimate that the GP appointment costs £25 a time, so it actually saved the NHS £200. And not only that, because I wasn’t using those appointments there were 8 other appointments available for people that really did need to see a doctor.’

60-year-old woman and keen PHR user

¹⁷ Patients Know Best blog: blog.patientsknowbest.com



Chapter Two: The patient and citizen perspective

Potential benefits to patients

There are a range of potential benefits of personal access to records. A PHR can be helpful in maintaining health and wellness, not just treating illness¹⁸ and how it is used will vary depending on an individual's needs.

Already some patients are saving time by conducting online transactions such as ordering repeat prescriptions and making appointments. But as access is given to the records themselves, the wider benefits become apparent.

Improved health

PHRs give patients greater access to a wide range of credible health information, data and knowledge.¹⁸ This allows them to:

- ▶ achieve a greater understanding of health and illness¹⁹
- ▶ be more involved^{18,19}
- ▶ make informed choices and judgements^{20,21}
- ▶ improve their health and manage their conditions.¹⁸

By seeing advice in 'black and white' health messages are reinforced and patients are more likely to make real changes to behaviour - such as their eating habits and activity levels.²²

Through better sharing of information between primary, secondary and social care, patients may experience more seamless care and be better able to manage the transition between services.

In a survey by HealthSpace, the features selected by respondents that were most important to them centred on easier management and ownership of their own health, improving access between themselves and the NHS, and ensuring the NHS is fully informed about them and their needs.²³ It also indicated that an online health portal would be used most regularly by people with long-term and chronic health conditions, and carers.

¹⁸ Tang PC, Ash JS, Bates DW et al. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc* 2006; 13 (2): 121-6. www.ncbi.nlm.nih.gov

¹⁹ Record Access Collaborative. *Enabling patients to access electronic health records. Guidance for Health Professionals*. London: RCGP, 2010. www.rcgp.org.uk

²⁰ *Guidelines for electronic record sharing with patients*. Record Access Collaborative, 2010. www.record-access-collaborative.org

²¹ Abidi SS, Goh A. A personalised healthcare delivery system: pushing customised healthcare information over the www. *Stud Health Technol Inform* 2000; 77: 663-7. www.ncbi.nlm.nih.gov

²² Fisher B, Bhavani V, Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. *J R Soc Med* 2009; 102 (12): 539-44. www.ncbi.nlm.nih.gov

²³ HealthSpace Patient Survey Report, January 2010 [unpublished].



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Improved trust

Patients able to access their GP records feel reassured that their doctors are communicating fully and that nothing is hidden. This reinforces trust and confidence in GPs.²⁴

Better communication

Access to records has also been shown to provide reassurance and clarify poor communication, enabling patients to better understand the dialogue with professionals and its consequences.²⁴

Patients accessing their health records can make their contacts with general practice and hospitals as efficient as possible.²⁵ For example, reviewing the record at home after a consultation can assist memory and understanding, and improve adherence to treatments.²⁴

Online access to records also offers the chance to share records with whomever a patient wishes. This could be with close family members and carers, to enable them all to understand diagnoses, treatment options and care. Information can also be shared outside the immediate health setting - for example, to private providers or when travelling abroad.

Accessibility

Electronic record access is an opportunity to improve access for patients, especially those with disabilities.²⁵ People with visual impairments can use assistive-technology to help them read the records. Those with hearing problems can go back and see what has been recorded. People with English as a second language can check the details of their care with English speakers and use translation software if necessary.

Ownership

There is intrinsic value in the citizen having the health record. For example, at Great Ormond Street Hospital, control of the record can be handed over to the patient after their 16th birthday. This facilitates a more efficient handover to adult services; it also shows the patient that they are now responsible.²⁶



²⁴ Fisher B, Bhavani V, Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. *J R Soc Med* 2009; 102 (12): 539-44. www.ncbi.nlm.nih.gov

²⁵ Record Access Collaborative. *Enabling patients to access electronic health records. Guidance for Health Professionals*. London: RCGP, 2010. www.rcgp.org.uk

²⁶ www.guardian.co.uk



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“ ‘A lot of the local BME [black and minority ethnic] population travel a lot. They will often have tests repeated in India or Pakistan and come back with the results and ask for them to go in their notes. They want lots of test results. They would feel more reassured if they could see their records. Google Translate would be very good for this group too. A lot of PCTs are supposed to offer free records translation services when patients come from abroad and bring their records, but in reality it doesn't work well.’

GP from South East London

“ ‘I nearly fused the power [sic] in writing to state categorically that neither I nor my wife wished our details uploaded onto any sort of database, especially one as leaky as the NHS.’

Posted on bigbrotherwatch.org.uk

Challenges of PHRs

Despite the likely benefits, some people do not embrace the concept of using an electronic health record, and others see potential problems.

A study in the US to look at barriers to PHR adoption found that the primary problems were linked to the digital divide, low literacy and cultural differences.²⁷

Digital divide

eHealth literacy is the ability of people to use emerging information and communications technologies to improve or enable health and healthcare.²⁸ As people with high eHealth literacy use technology in a more sophisticated and comprehensive way, inequalities become greater and the people at the bottom of the digital divide benefit less.²⁸ In the UK, there are 9.2 million adults who have never accessed the internet, including 60% of those aged 65 and over.²⁹

Low literacy

There are low levels of basic literacy and numeracy in some parts of the UK, and over 1 million illiterate people in England.³⁰ For example, over half of older Bangladeshi and Pakistani women, and 20% of older men, are illiterate in any language.²⁹

²⁷ Bagchi A, Moreno L, af Ursin R. Considerations in designing personal health records for underserved populations. *Mathematica Policy Research; Issue Brief*, April 2007, number 1. www.mathematica-mpr.com

²⁸ Neter E, Brainin E. Health Literacy: Extending the digital divide to the realm of health information. *J Med Internet Res* 2012; 14 (1): e19. www.ncbi.nlm.nih.gov

²⁹ *The power of information - equality analysis*. Department of Health, 2012. www.dh.gov.uk

³⁰ *The skills for life survey*. Department for Education and Skills, 2003. www.education.gov.uk



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Language barriers

Cultural barriers, particularly language barriers, can prevent PHR uptake. In the US, PHR use is negatively correlated with low health literacy and cultural differences.³¹ Language barriers may mean that patients are not aware of, or are not recruited into, PHR schemes. Or they may not understand the information they find in a record. This is a particular problem if interpreters are in short supply. But provided the health institution can provide these patients with access, PHRs in fact have the potential to help with language barriers either

through the use of translation software, or through patients using bilingual relatives or friends to help them understand the contents.

Security concerns

Medical records hold extremely personal information. Details disclosed, maliciously accessed or lost represent serious infringements on someone's privacy.

In a survey by HealthSpace (see case study on page 54), a final open-ended option to add comments resulted in 26% of people saying they were concerned about security and risks of confidentiality breaches through record access.³²

Coercion

There are instances when individuals are forced to share their record with someone they don't want to - for example, if the patient is a child or an adult in an abusive relationship. There may also be situations when family members or carers insist on accessing or even annotating a vulnerable person's record. It is

the clinician's responsibility to check that there is no coercion as part of the access set-up and consent process.

Apathy or reluctance

Not everyone, particularly those who are young and healthy, see the relevance or advantages of accessing their own record.

Others may not have the time or skills needed to engage with record access. Some may feel obliged to engage with record access just to continue to access services, and may resent the burden this places on them.

Concern over record content

Health records may contain particularly sensitive information, or sometimes unknown information, so there is a risk that some people may be distressed by what they read. People may disagree with what is written. And some may not understand the terminology used, which could cause confusion. There is also a risk of misinterpretation - for example, with test results.



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³¹ Bagchi A, Moreno L, af Ursin R. Considerations in designing personal health records for underserved populations. *Mathematica Policy Research; Issue Brief*, April 2007, number 1. www.mathematica-mpr.com

³² HealthSpace Patient Survey Report, January 2010.

Chapter Two: The patient and citizen perspective

Further information to support understanding of records

Box 8

It is inevitable that people will come across information within their health record that they will not understand. It is therefore vital that they have quick links to other sources of information. The new Information Strategy for England includes a new, single 'portal', provided by Government from 2013, as a link to trusted information on health, care, support and public health.

The following are examples of web-based information which can support patient understanding of their health records:

www.patient.co.uk is the information service provided by EMIS for EMIS's Patient Access and PAERS iPatient. This gives information on a wide range of conditions and medicines.

The PAERS/EMIS system automatically links READ codes and test results in the record with relevant patient information leaflets in patient.co.uk. This makes understanding far easier. PAERS/EMIS iPatient will soon

enable patients to choose which external information provider they want to link with their record, offering the most relevant information for them.

Patients Know Best annotates test results using explanations from the Royal College of Pathologists, as well as allowing individual clinicians to link to local and international information sources.

Renal PatientView provides links to external sources such as patient groups, hospital websites and international professional organisations.

NHS Choices is a national resource providing information on conditions, treatments and healthy living. It has links to medicine guides and the evidence-based 'Map of Medicine' used by doctors to guide clinical decisions. It is paid for by the Department of Health and any PHR supplier is free to link to it.

Taking the hassle out of healthcare

Access to good information is an important part of making sure people stay healthy and get the best care. By making it easier for you to look at and share your health and care records, you will be able to take more control of your own care, and work with professionals to make sure that there is 'no decision about me without me'.

1. Accessing your GP records online will give you more control over your care
2. Booking appointments will be quicker and easier when you can do it online
3. You'll need fewer phone calls when you can communicate with professional teams electronically
4. You'll have less paperwork in your life when your healthcare letters are available online
5. You'll know where to go for health and care information when there is one trusted website
6. Services will do more to offer you support to use and understand information if and when you need it
7. You won't have to repeat yourself when your information is shared between health and care professionals
8. You'll be confident that your feedback is being listened to and helping to improve services
9. You will have more information to help you choose the best services and treatments for you

To find out more go to www.dh.gov.uk/informationstrategy

NHS
choices
your health, your choices



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NHS Care Record Guarantee

Box 9

The Guarantee³³ states that the NHS will make sure, through contracts and staff training, that everyone who works in or on behalf of the NHS understands their duty of confidentiality. All organisations providing care for the NHS, or on its behalf, must follow the same strict policies and controls.

The Guarantee also states that the NHS will make sure records are held securely and only make them available to people who have a right to see them. If it is found that someone has deliberately accessed records without permission or good reason, the NHS will inform the patient and take action.

“Switching on patient access alone is not enough, and potentially detrimental, if appropriate support structures are not in place for patients so that they understand and know how to use the information. This support structure must be in place, including a proper consent process.”³⁴



³³ NHS Care Record Guarantee. National Information Governance Board, 2011. www.nigb.nhs.uk

³⁴ Summary report - second phase. NHS Future Forum, 2012. <http://healthandcare.dh.gov.uk>

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Possible solutions

Despite the challenges, misconceptions and concerns, there is much that can be done to encourage patients to embrace record access. Many of these solutions are being explored by the myRecord project, funded by The Health Foundation.

Maximise enrolment

Healthcare providers and Government can:

- ▶ Actively promote record access, rather than just making the service available and waiting for patients to opt in. A year-long programme to encourage patients to use Renal PatientView tripled patient registration when doctors: encouraged enrolment; introduced the portal into care planning; and promoted it in all correspondence to GPs.³⁵
- ▶ Include marketing and support for minority ethnic groups.
- ▶ Provide users with 'Questions you need to ask before you engage'.

³⁵ *How-to Guide. Encouraging patient to use Renal PatientView.* NHS Kidney Care. www.kidneycare.nhs.uk

³⁶ Neter E, Brainin E. Health Literacy: Extending the digital divide to the realm of health information. *J Med Internet Res* 2012; 14 (1): e19. www.ncbi.nlm.nih.gov

- ▶ Concentrate on vulnerable and marginalised groups - such as those with chronic mental health conditions - who have measurably worse health outcomes across all areas.³⁶

PHR suppliers can:

- ▶ Actively participate in public awareness campaigns to convince patients of the benefits of PHRs, and educate and support patients to use PHRs to the full.

Reassure

Healthcare providers and Government can:

- ▶ Pay attention to informing and involving members of the public, to increase public confidence.³⁷
- ▶ Reassure users of the security in place to protect their data and who accesses it.
- ▶ Highlight the NHS Care Record Guarantee - see box 9.
- ▶ Use secure and trusted brands, such as the NHS.

³⁷ *Health on-line: public attitudes to data sharing in the NHS.* Scottish Consumer Council, 2005. www.statewatch.org

- ▶ Be vigilant for potential coercion. Third-party information may need to be anonymised - for example, when someone with an abusive alcoholic husband wants the GP to help him, but does not want to be identified.³⁸
- ▶ Issue guidance for patients on how to access their records safely. The Department of Health and the British Computer Society have commissioned the development of this guidance and aim to publish it at the end of 2012.³⁹
- ▶ Reassure users of the support and further information available to them - see box 8 on page 27 - and highlight positive feedback from patients using PHRs.

³⁸ Record Access Collaborative. *Enabling patients to access electronic health records. Guidance for Health Professionals.* London: RCGP, 2010. www.rcgp.org.uk

³⁹ www.mynors-suppliah.com



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Maximise accessibility

Healthcare providers and Government can:

- ▶ Ensure there are places, such as libraries and clinics, where those without computers can go to access their records.
- ▶ Provide training and support to help people understand PHRs and know how to use them. This could be via:
 - Helplines
 - Librarians, volunteers, clinic staff
 - Drop-in centres
 - Step-by-step guides
 - Expert patient programs.

In the above-mentioned Renal PatientView programme,⁴⁰ the first step in increasing the use of the portal was to ensure there was one single dedicated administrator trained to register new applicants and to reset lost or forgotten passwords.

- ▶ Balance security with ease of access - robust authentication processes are essential but if these are too onerous they can become a barrier to take-up. The low numbers of HealthSpace users was, in part, blamed on cumbersome registration and log-in procedures.⁴¹
- ▶ Introduce PHRs into national school curricula to reinforce the role of these records and the need for quality and accuracy.

PHR suppliers can:

- ▶ Include users in the design of services.
- ▶ Design technology that can be used by those with low literacy.
- ▶ Provide information sources alongside record access so that users can cross-refer when they come across anything they don't understand - see box 8 on page 27.



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⁴⁰ How-to Guide. Encouraging patient to use Renal PatientView. NHS Kidney Care. www.kidneycare.nhs.uk

⁴¹ www.ehi.co.uk

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Professionals' reaction to PHRs

Many healthcare professionals embrace the principles of shared PHRs. However, the BMA's response to the Information Revolution consultation in 2010 - see box 10 - reflects the concerns of many about the practicalities, the need to 'protect' patients from difficult information, and threats to confidentiality. There is also some debate about whether, in the long-term, PHRs will increase or decrease a clinician's workload.



BMA position

Box 10

The British Medical Association (BMA) welcomes the intention to improve patient access to NHS data but points out that it is often subjective, and often generated to be of use to clinicians rather than patients. For example, many notes are recorded as aides-memoires to healthcare professionals - they could be unhelpful or even alarming to patients, for example, when a doctor speculates on a possible diagnosis, which is an essential part of differential diagnosis.

BMA response to Information Revolution consultation (www.bma.org.uk)



RCN position

Box 11

The Royal College of Nursing (RCN) believes that all people, including children and young people, should be supported to control and manage their own health information according to their preferences and needs.⁴²

⁴² *Personal health records and information management: RCN briefing*. Royal College of Nursing 2012. In press.



Chapter Three: The health and social care professional perspective

Real benefits for professionals

Information in health records is set to become more readily available to individuals. This will be an essential part of a healthcare paradigm shift for professionals and consumers, towards informed, active patients involved in their care and decision-making (see box 3 on page 10).

“ ‘We talk the language of being patient-centred and empowering people. We have to live this out and move with the technology and allow them to have this access. We need to use patients more.’ *Psychiatrist*

Informed active patients

Access to PHRs will potentially make patients more informed, empowered, engaged, proactive and responsible. A Cochrane review of 36 trials found that self-monitoring and agenda setting (where patients can

record their agenda for a healthcare consultation in advance) reduced emergency admissions, A&E visits and unscheduled visits to the doctor.⁴³ And a study in the US found that access to health information through PHRs means patients know more about their health and take better care of themselves.⁴⁴

Increased opportunities for health promotion and prevention

Full PHRs have the potential to engage people in managing health risks, such as obesity and genetic risk factors, before they become symptomatic.

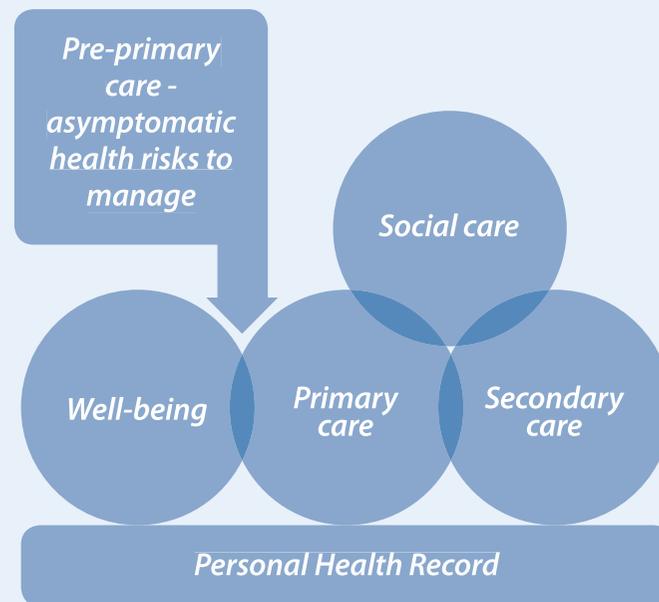
Figure 3 shows how PHRs can potentially join up data from patients themselves with health system data. Healthcare information will start to accumulate at a much earlier stage of disease than is the case with current medical records. This creates an opportunity for primary care and public health professionals to engage with patients who have mounting health risks, but who might not otherwise seek primary care help. This has been called ‘pre-primary care’.⁴⁵

⁴³ Gibson PG, Powell H, Wilson A et al. Self-management education and regular practitioner review for adults with asthma. Cochrane Database of Systematic Reviews 2002, issue 3. onlinelibrary.wiley.com.

⁴⁴ *Consumer and Health Information Technology: A national survey*. California Healthcare Foundation, April 2010.

⁴⁵ Buchan I. Informatics for Healthcare Systems. In Walshe K, Smith J (Eds.). *Healthcare Management*. Open University Press, 2011.

Figure 3 - The Personal Health Record joining data from different parts of the health and social care system⁴⁵



Chapter Three:

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Furthermore, when patients elect to share data with health professionals, they may find that this act of sharing helps motivate them to make the changes they need - for example, to lose weight or be more active.

Improved trust

If patients are able to see what is recorded about them, and are able to enter their own data, there is likely to be more trust between staff and patients.⁴⁶

Better communication

As patients become more informed and a relationship of trust develops, communication may improve and a stronger relationship between staff and patients may develop. Studies show patients are more prepared for appointments and ask more relevant questions when they have accessed their record.^{47,48}

There is substantial research exploring patients' unvoiced agendas in consultations,

and the benefits of tools like patient agenda forms.⁴⁷ Incorporating these in online appointment booking systems could be a powerful way of improving the effectiveness of consultations. PHR-mediated electronic communication between patients and health professionals can also improve the efficiency of telephone and face-to-face communication.⁴⁹

Communication can be improved across groups of care-givers, if given access (such as extended family, carers, social care).

There is also the potential to obtain meaningful and timely feedback from patients - on their symptoms but also on consultations and treatments.

“ ‘The only person who knows everything is the patient.’ **GP** ”



⁴⁶ Fisher B, Bhavani V, Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. *J R Soc Med* 2009; 102 (12): 539-44. www.ncbi.nlm.nih.gov

⁴⁷ *Consumer and Health Information Technology: A national survey.* California Healthcare Foundation, April 2010.

⁴⁸ Hamiton W, Britten N. Patient Agendas in Primary Care. *BMJ* 2006; 332: 1225. www.bmj.com

⁴⁹ Tang PC, Ash Js, Bates DW et al. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc* 2006; 13 (2): 121-6. www.ncbi.nlm.nih.gov



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Better care

Evidence and experience shows that allowing patients access to their medical records improves quality of care, safety, effectiveness and patient experience.⁵⁰ Having more data helps clinicians make better decisions⁵¹ and may increase the effective use of treatments and medicines. Sharing records with professionals in A&E and in outpatient clinics makes care safer and more efficient.

There is some discussion among doctors about whether improved outcomes are most likely in patients with modifiable behaviours - for example, people with diabetes or cardiovascular disease. PHRs could have a big impact, but only if patients engage with them fully to realise the benefits.

Savings

People with full record access may use services and consultations more effectively and efficiently, focusing consultations on what matters to them. They may also share data with clinicians, carers and family, reducing the need to repeat stories or phone the GP practice.⁵⁰

Efficiency savings may result from online transactions, such as repeat prescriptions, appointment bookings and sharing test results.⁵⁰



More accurate records

By allowing a patient to see and annotate their medical records, it is likely that they will correct mistakes and omissions. This could reduce medical errors and repetition of tests and procedures. It will also reduce the fragmented information that results from different records kept with each provider.

Joining the eRevolution

With the push for local innovation, clinical commissioning groups (CCGs) have the opportunity to develop systems that suit local needs. Offering ground-breaking PHRs, and other attractive services such as electronic transactions and communication, will give providers a competitive advantage and may attract patients and investment.

There is also an explosion of health applications, telehealth and telemedicine and the opportunity to link PHRs into these developments.

⁵⁰ Patient record access: turning it on, sharing the learning. The Health Foundation, 2010. www.health.org.uk

⁵¹ Tang PC, Ash Js, Bates DW et al. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc* 2006; 13 (2): 121-6. www.ncbi.nlm.nih.gov



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Challenges for professionals

Many professionals, even those that embrace the concept of record access, envisage problems with how it would work in practice - see box 12, overleaf.

Workload

There is concern that patients accessing records may result in more or lengthier consultations. For example, patients may need an explanation about what is contained in their record and what it means, and this will take time. In fact, seven doctors in a clinic for patients with congestive heart failure reported no change in their workload

“ ‘When discussing PHRs, 10% of GPs react with ‘over my dead body’, 5% say ‘yes’ immediately, the rest are convincible.’

Record Access project manager

during a randomised controlled trial in which patients were able to access their medical notes and test results and send and receive electronic messages with clinic staff.⁵²

Data from here in the UK, currently being finalised, shows that online record access, separate from booking appointments and repeat prescriptions, can save substantial numbers of telephone calls and appointments in primary care. It increases the capacity of primary care.⁵³ A study in the US reported that physicians found electronic messaging an efficient method for handling non-urgent communication with their patients.⁵⁴

Nevertheless, electronic communication is a new way of working and requires some fundamental changes in thinking and practice that therefore generates concern. And if this becomes a common way of consulting it will need to be properly reflected in reimbursement mechanisms, such as the Quality and Outcomes Framework and the Payment by Results tariffs.

Some clinicians think that all patient records need checking for third-party and sensitive information and ‘sanitising’ before a patient can have access. This presents a potentially huge workload, albeit a task that could be done by a trained non-healthcare professional. One approach has been to only open up access to recent records, rather than check back through years’ worth.



⁵² Earnest MA, Ross SE, Wittevrongel L et al. Use of a patient-accessible electronic medical record in a practice for congestive heart failure: patient and physician experiences. *J Am Med Inform Assoc* 2004; 11 (5): 410-7. www.ncbi.nlm.nih.gov

⁵³ Brian Fisher, personal communication

⁵⁴ Tang PC et al. PAMFOnline: Integrating EHealth with an Electronic Medical Record System. *AMIA Annu Symp Proc* 2003; 644-8. www.ncbi.nlm.nih.gov



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Communication

Health professionals may be resistant to the cultural changes and workflow changes that come as part of record access. Some also worry that their clinical interactions will be distorted if patients can see what they are writing, or that they may be exposed as uncertain or prone to error.⁵⁵ However, others point out that they already write with a view to record access and copying letters to patients, and have done so for many years. Many professionals already turn the screen towards patients as they type, as a means of reaching a shared understanding.

Experience shows that record access does encourage honesty, which can lead to occasional uncomfortable conversations with patients.⁵⁶ However, experience also confirms that many patients welcome and expect openness, and that health professionals are best advised to share these options and decisions with patients.⁵⁷ Record access is an additional route of information for patients but should not be a substitute for information communicated by professionals to patients.⁵⁶

⁵⁵ Fisher B & Britten N. Patient access to records: expectations of hospital doctors and experiences of cancer patients. *Br J Gen Pract* 1993; 43 (367), 52-6. www.ncbi.nlm.nih.gov

⁵⁶ Record Access Collaborative. *Enabling Patients to access electronic health records. Guidance for Health Professionals*. London: RCGP, 2010. www.rcgp.org.uk

⁵⁷ Liaw ST, Radford AJ, Maddocks I. The impact of a computer generated patient held health record. *Aust Fam Physician* 1998; 27 (suppl 1): S39-43. www.ncbi.nlm.nih.gov

⁵⁸ Pagliari C, Shand T, Fisher B. Embedding online patient record access in UK primary care: a survey of stakeholder experiences. *J R Soc Med Sh Rep* 2012; 3: 34.

GP attitudes to record access

Box 12

A recent study of 57 GP practices in England that had agreed to pilot a record access system revealed some of the barriers to uptake.⁵⁸

Of the 25 practices who had not adopted the system, explanations included: a lack of priority (in most cases it was regarded positively but had simply not yet been implemented); lack of internal agreement (e.g. only one GP advocate in the practice); perceived workload (e.g. time required to check records; patients seeking clarification); uncertainty about operating procedures or likely benefits (i.e. lack of information); lack of patient demand (e.g. service offered but no take-up); and security concerns.

None expressed concerns about litigation, citing confidence in the information held in their systems, although there was some uncertainty about their position if record access were to reveal third-party information. While confidentiality was a concern, inappropriate sharing by patients was felt to be potentially more problematic than a technical breach. The potential for medical records to confuse or upset some patients was also acknowledged. Overall, these non-users supported the principle of record access and regarded it as 'an inevitability', but felt that more information and support should be available to help them prepare to deliver this service.



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Potential liability

One of the main barriers for one UK record access pilot was fear that it would lead to more complaints and more work because of patients questioning the contents of their record.⁵⁹ However, evidence suggests that this is not a widespread problem in practice, and that barriers can be overcome if patients' concerns are recognised and understood, and adequate support and learning provided at an early stage.⁵⁹

Poor uptake and outcomes

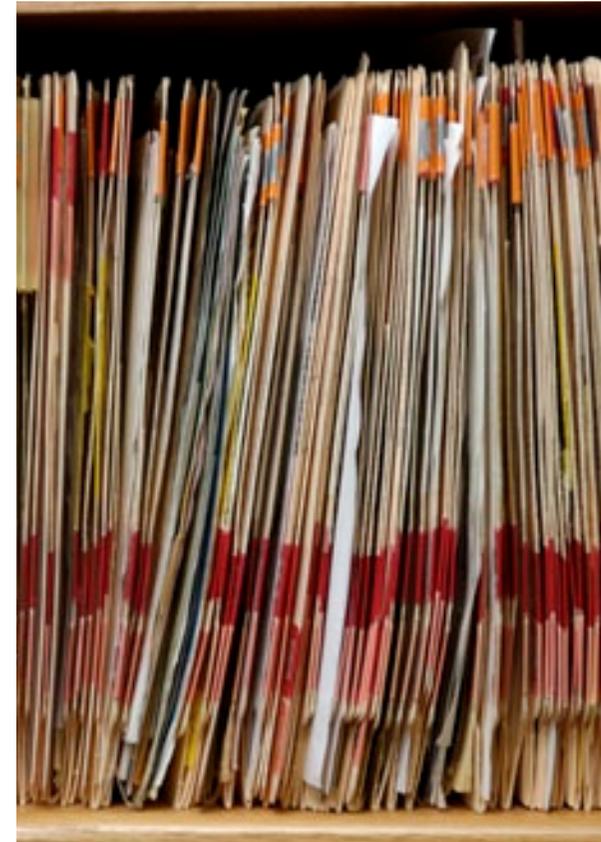
Providing the platform for PHRs isn't enough. Patients must be involved in keeping their record up-to-date and learning how to use its full potential.

PHRs may be embraced disproportionately by educated, savvy patients, resulting in a widening of health inequalities. In a health

survey in the US, higher-income individuals are the most likely to have used a PHR. But lower-income adults, those with chronic conditions, and those without a university degree are more likely to experience positive effects of having their information accessible online.⁶⁰

“ ‘Clinical records... are terse, technical and patient unfriendly. In the absence of a clinical interpreter confusion, apathy and (at times seriously dangerous) misunderstandings are certain to ensue.’

Clinician comment in DH consultation on Record Access Support Needs 2012



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⁵⁹ Patient record access: turning it on, sharing the learning. The Health Foundation, 2010. www.health.org.uk

⁶⁰ Consumer and Health Information Technology: A national survey. California Healthcare Foundation, April 2010.

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Royal College of General Practitioners (RCGP) position⁶¹

Box 13

The clinical record is currently written primarily for the health professional and for communication between health professionals. It is important that record access does not reduce the effectiveness of these traditional functions. It is important that health professionals still feel able to enter subjective thoughts into the record and this should be explained to patients when enabling access.

The need for clinical accuracy for health professional communication may also involve highly technical information, which must not be made less informative simply for the patient's ease of understanding. On the other hand, if the record is to become useful for patients, the clearer and more straightforward the writing the better.

These can appear to be competing claims, but in many situations there is no conflict.

Possible solutions

Although the concept of PHRs has been part of the health landscape for many years, implementation and widespread adoption has not happened. There has been significant inertia and even resistance from some. However, there is much that can be done to overcome barriers.

Incentivise or legislate

Record access should become standard practice.⁶² Legislation may be the only way that PHRs will be adopted universally. It has been suggested by some that PHRs could be included in the GP contract, or as part of the Quality and Outcomes Framework, creating a financial incentive for patient enrolment.

Set PHRs in the context of the broader paradigm shift

There is gathering momentum for a shift towards more engaged informed patients. PHRs will be central to this, to augment trust and improve safety - see box 3, page 10.

There is much that can be done to embed this culture shift into UK healthcare. Box 14 has tips on implementing a patient-focused shared decision-making programme. Also:

- ▶ The Royal Colleges, Medical Education England and universities can ensure this new culture is firmly part of healthcare professionals' curricula.⁶³
- ▶ PHR champions can influence colleagues using peer pressure and 'eminence-based medicine'. This can even be employed across specialities; for 30 years social workers have been keeping notes in a way that they envisage patients seeing, and they can share their experiences. The widespread use of electronic records in general practice means GPs are also more accepting of record access than those in secondary care.

⁶¹ Record Access Collaborative. *Enabling patients to access electronic health records. Guidance for Health Professionals*. London: RCGP, 2010. www.rcgp.org.uk

⁶² *The power of information: putting all of us in control of the health and care information we need*. Department of Health, 2012. <http://informationstrategy.dh.gov.uk>

⁶³ *Summary report - second phase*. NHS Future Forum, 2012. <http://healthandcare.dh.gov.uk>



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Manage concerns

Professional bodies, such as the British Medical Association and Royal Colleges, together need to tackle legitimate concerns about the introduction of PHRs. For example, guidance for professionals is needed on:

- ▶ Practical tips and guidance to make sharing records easier
- ▶ Myth busting - for example, patients can annotate but not edit their records
- ▶ Engaging other staff and getting expectations right - for instance, the status and attitude of practice managers is crucial
- ▶ Ensuring that the system enables practices to hide non-coded data before a certain date. This protects the professionals from inadvertent release of third-party data and old records having been written without patient access in mind
- ▶ Solutions to the problems of coercion. For instance, enabling patients to share only the data they choose
- ▶ How online messaging is to be properly managed and monitored. There needs to be clearly defined frameworks for professionals and patients, and it must be properly included in the reimbursement mechanisms.

Top tips for implementing self-management support⁶⁴

Box 14

1. Create partnerships across the healthcare system.
2. Frame self-management support within the wider context of national policy and local needs.
3. Establish clear purpose, aims, objectives and desired outcomes.
4. Spend time establishing your approach.
5. Ensure visible support from senior leaders.
6. Implement the training programmes and service redesign in an integrated way.
7. Recognise that embedding self-management support involves individual journeys.
8. Provide support to individuals.
9. Promote personal stories of success from both lay people and health staff.

⁶⁴ *Top tips for implementing self management support. Co-creating health programme.* London, The Health Foundation. www.health.org.uk



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Chapter Four:

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Net benefit to the health system

As the earlier chapters of this guide have shown, PHRs have the potential to deliver tangible health benefits. However, PHRs themselves are of limited benefit to healthcare systems. Their value is highest when they are implemented in the context of other, related developments:

- ▶ A step change in the extent to which patients play an active role in maintaining and improving their own health
- ▶ A move away from paper-based health records towards integrated electronic records, where information is recorded only once, at the point of care
- ▶ New technology used to reduce and streamline consultations, including the use of telemedicine, and telephone and online consultations
- ▶ Electronic transactions, such as appointment booking and repeat prescription requests.

In this wider context, the main benefits of PHRs have been identified as:

- ▶ Reduced face-to-face contacts between patients and healthcare professionals, and more efficient consultations - for example, because information which has already been recorded does not need to be repeated
- ▶ Improved health outcomes through earlier diagnosis and reduced errors
- ▶ Net savings in administration costs, including the cost of the paper transfer of information and telephone calls.

There are a number of costs to implementing PHRs, including:

- ▶ Record access software, which may be part of an electronic health record system, but may also be provided through 'untethered' platforms (see page 17)
- ▶ Identification at initial registration and ongoing authentication processes
- ▶ Training for administrative and clinical staff
- ▶ Training, support and information for patients about how to use the system, including an ongoing 'Help' facility

- ▶ Checking records for sensitive or third-party information before giving access to patients.

Taking all this into account, as the Department of Health Information Strategy Impact Assessment shows,⁶⁵ even with relatively conservative assumptions, there will be a **net benefit to society** from the wholesale implementation of these changes. The Assessment values the net benefit in England at more than £5 billion over 10 years. The record access elements of the benefit relate to GP records only, and are based mainly on a pilot study, yet to be published.⁶⁶

Evidence from the US shows the potential benefits of PHRs to purchasers of healthcare include lower costs of managing long-term conditions, lower medication costs, and lower health promotion costs.⁶⁷ The greatest area of benefit is likely to be in the management of long-term conditions, where lifetime costs are highest. The US's 2009 stimulus package includes a \$36.5 billion nationwide investment in electronic health records because they believe they will improve health and save money - see box 15 on page 44.

⁶⁵ *The power of information impact assessment. Department of Health, 2012. www.dh.gov.uk*

⁶⁶ Fitton C, Fitton R, Fisher B et al. Examining the business case for Electronic Health Records Assess in two English General Practices. Publication date and journal yet to be decided.

⁶⁷ Tang PC, Ash Js, Bates DW et al. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc* 2006; 13 (2): 121-6. www.ncbi.nlm.nih.gov



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Chapter Four: The commissioner and health system perspective

The Information Strategy for England

England's new Information Strategy, *The power of information*,⁶⁸ puts an ambitious aspiration for record access in the opening chapter. It restates the pledge that everyone will have access to their GP records by 2015, along with the means to book appointments and request repeat prescriptions electronically. A timetable for access to records beyond primary care is not specified.

The Strategy highlights important pieces of work needed for the widespread adoption of record access.

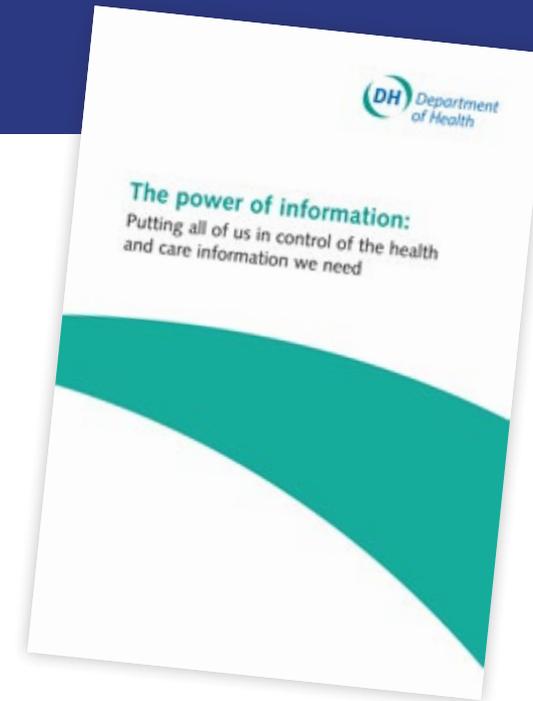
- ▶ Dame Fiona Caldicott is leading a review into the balance between protecting confidentiality and the sharing of health and social care information.⁶⁹
- ▶ A group led by the RCGP, including the National Commissioning Board, BMA and patient organisations, has been convened to develop a plan to roll out access to patient records by 2015, as recommended

by the Future Forum.⁷⁰ This will include guidance on issues such as third-party information, data security, education and development for patients and clinicians, and technical standards that need to be in place so that records can be accessed safely.

To pave the way for PHRs, which involve the joining up of data, there is a need for national information standards to enable interoperability across health and social care systems. The Information Strategy for England defines a modular approach to developing these standards.

The Strategy also gives a combined role to the Department of Health, National Commissioning Board and Public Health England to create an overall roadmap to ensure the implementation of standards to enable data sharing.

Nevertheless, the Strategy firmly avoids central direction and is clear that local commissioners and providers will need to take a lead.



“Supported by guidance, commissioners should be able to commission the local provision of information, and the support to use it, at stages in the development of our care journeys so that information becomes to be seen as an integral and necessary part of every service.”⁶⁸

⁶⁸ *The power of information: putting all of us in control of the health and care information we need*. Department of Health, 2012. <http://informationstrategy.dh.gov.uk>

⁶⁹ National Information Governance Board for Health and Social Care. Press release, 2012. www.nigb.nhs.uk/ig-review

⁷⁰ *Summary report - second phase*. NHS Future Forum, 2012. <http://healthandcare.dh.gov.uk>



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Making PHRs a reality

There has been enormous progress in policy terms on record access in recent times but, despite this, there are concerns that providers will pay lip-service to the principles and do the minimum they can to 'tick the record access box', rather than offering full PHRs. The figures quoted on the extent of access today need to be read with caution: some 60% of GP practices today have the technological capability through their electronic health record systems to offer access, but in fact fewer than 0.8% of practices do (around 100 practices in England⁷¹), and in even the most successful of these, only 14% of patients are registered for access⁷² (and a smaller proportion still will be using it regularly). There is therefore a mountain to climb to achieve the 2015 pledge - i.e. access is not the same as use.

As for the full shared PHR - linking records from different institutions with patients' own data - there are almost no examples in the UK to date, and it is clear that this will not be the focus of the health system until after 2015.

The risk is that, over the next few years, both uptake, and the difference made to health outcomes, will be seen as poor, and the detractors will win the day.

PiF's view is that four areas need particular attention in order to avoid these risks.

1. Articulate the benefits clearly to patients and the public

Patient interest in health records is growing, but take-up is still very slow. For example, in the myRecord project, practices are typically recruiting just 1-2 patients per practice per week.

Citizens will need to be involved in setting up the systems that will answer their needs and particularly the needs of those with low health literacy and particular conditions. A big marketing campaign will be needed to showcase the benefits to different groups of individuals. Patient organisations will have a major role to play in championing the benefits of and promoting uptake of PHRs.

2. Create the business case for clinicians, providers and commissioners

Like any change, deploying PHRs requires time and effort, with an associated cost. The business case around record access to date is based on a small number of pilot GP practices, where the clinicians are enthusiasts. Clinicians and healthcare organisations are likely to remain sceptical about the benefits of PHRs unless fully-costed business cases and deployment examples are developed.

3. Undertake baseline evaluation

From the beginning, commissioners and providers must integrate empirical systematic evaluation and learning. Consideration should be given now to the key metrics that should be expected to see change over the next decade as PHRs are deployed, and baseline data should be collected so that progress can be tracked. This must include patient-orientated outcomes including quality of life, health literacy, and activation levels.

⁷¹ DH Study of Support Needs to facilitate record access, 2012 (unpublished).

⁷² Haughton Thornley Medical Centre website statistics, December 2011. www.htmc.co.uk



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4. Define the revenue models which will enable technical readiness

The Information Strategy Impact Assessment⁷³ identifies Clinical Commissioning Groups (CCGs) in England as bearing the burden of the costs of record access but, currently, it is unclear how the funding flows will work, or what the revenue model should be for providers of PHR platforms. UK Governments are not commissioning or paying for PHR services centrally. Local providers and CCGs will need to decide how best to pay for new services. Commissioning support organisations may have a role to play too.

Electronic health record suppliers are at various stages of developing their record access interfaces. For GP systems, access is relatively straightforward, and the biggest UK supplier already has a well-established system, with other competitors in the process of developing theirs. The revenue model for these systems is relatively straightforward; they are an add-on to existing electronic health record systems which may be charged for or offered free of charge.



However, enormous benefits accrue when patients have the opportunity, through a PHR platform, to integrate information from different parts of the health and social care system with applications to suit their circumstances and their own data. Suppliers of such platforms will be looking for return on investments and, with many providers involved from across the health and social care system, it is less clear who will pay. For example, would a hospital in the future need to subscribe to numerous different PHR platforms or portals so that patients could choose between several when accessing their electronic health record?

New revenue models may have to be considered, such as generating income via targeted advertising, selling anonymised data to commercial partners, or providing applications which end users pay for. There are numerous ethical issues which arise from these ideas. Without a clear framework defining what revenue models are acceptable, providers may not have the financial incentives needed to innovate in this field. There is a tension between allowing local innovation and procurement, and ensuring that solutions are made available on an affordable basis that allow patients access to records from all parts of the health system.

“ ‘We’re a million miles away from meaningful access to all records everywhere.’
GP commissioner ”

⁷³ *The power of information impact assessment*. Department of Health, 2012. www.dh.gov.uk



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Chapter Four:

The commissioner and health system perspective

Developments around the world

Box 15

The **US** is far ahead of the UK in terms of the number of patients accessing their records. There, 10% of people surveyed in 2010 said they have some form of personal health record (although their definition is broader than the one we use here), up from 3% in 2008.⁷⁴ Much of this access provision is via providers, such as Kaiser Permanente and the Department of Veterans Affairs. The US stimulus package has focused partly on the introduction of a nationwide network of electronic health records. They believe this will improve health and save money. The US's HITECH Act (Health Information Technology for Economic and Clinical Health) has up to \$36.5 billion available out of the \$916.1 billion healthcare budget.⁷⁵ This will be largely distributed through incentive payments to hospitals, physicians and qualifying providers for 'meaningful use' of certified electronic health records.⁷⁶ This includes giving patients timely electronic access to their health information; patient-specific education resources; and electronic reminders for preventive or follow-up care.⁷⁷

In **France** health information systems are also being redeveloped to improve, for example, information sharing, electronic prescriptions and decision aids. At the heart of this is the Dossier Medical Personnel (DMP) - a public-funded national electronic health record available to any French citizen. The user can enable or disable emergency access; receive information from their health professionals; add their own data; control all accesses by health professionals; and nominate their doctor to manage their record. 2012 plans include accelerating uptake by incorporating DMP as a quality payment indicator, to develop training and education, and to leverage patient access.

In **Denmark** the Sundhed.dk portal collects and distributes healthcare information among citizens and professionals. It was commissioned to bring together information from all parts of the health service; offer a shared platform for communication; give insight and transparency to empower patients; and give providers easy access to patients' medical history. Every Danish citizen has their own personal page. Here, the citizen can find accurate and up-to-date healthcare information - for example: treatments and diagnoses from the hospital patient record; book appointments with his GP; get repeat prescriptions; monitor drug compliance; survey waiting lists and quality ratings of hospitals; register as an organ donor; and get access to local disease management systems in out-patient clinics. Health professionals can also get secure and controlled access to the personal data of patients they are actively treating.

⁷⁴ Markle 2010 survey on Health in a Networked Life. www.markle.org

⁷⁵ www.usfederalbudget.us/health_care_budget_2013_1.html

⁷⁶ Washington Healthcare News, November 2009. www.wahcnews.com

⁷⁷ www.hitechanswers.net



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Chapter Five: Conclusions

Healthcare increasingly exists in an online, electronic environment. While patients' records have not been at the forefront of this, there are many advances being made in this field and the advantages are becoming clearer. The future looks set to embrace health record access in some form or another.

Allowing patients access to their records should form part of a shift towards confident, empowered, informed patients. Information is an intervention in its own right and record access must become standard practice so that everyone can benefit from the information revolution.

Ultimately, record access at the individual institution level is not enough. We should aim for shared PHRs for all service users, which enable them to link and contribute to information about them from all parts of the health and social care system.

For this to happen there needs to be clarity about funding models, intra-operability and information governance.

Commissioners and providers need to plan for this, and the needs of patients and users must be foremost. Careful design is crucial to make the service accessible to all, regardless of literacy skills.

At national level, a clear road map is needed to define the path to PHRs, and progress tracked and rewarded through the structures being put in place by the National Commissioning Board.

Patient organisations should campaign for the development of shared PHRs, and also help communicate the benefits of these to their members. They can also contribute to the development of information systems to best suit their members. Designers of self-management courses should also include record access in the course content.

Information producers should include the benefits of record access when they are producing information. They should also consider how best to tailor their output for integration into online information systems.



“It's about being an active partner, having choices, and a relationship with the doctor based on trust. It's about being a happy patient!”

Patient accessing records at Haughton Thornley Medical Centres



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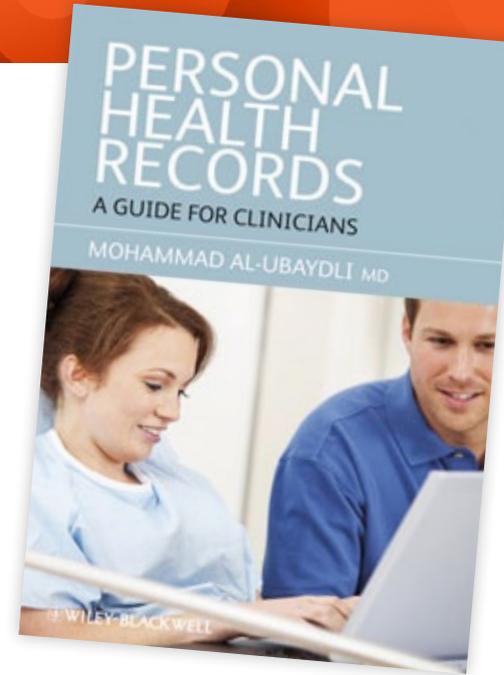


Chapter Six: Useful resources and glossary

Useful resources

- ▶ **Arran and Ayrshire patient portal evaluation**
www.axiomconsultancy.co.uk
- ▶ **Department of Health England's 2012 Information Strategy**
www.dh.gov.uk
- ▶ **Dr Peter S's blog** as a GP implementing record access
<http://gprecordaccess.blogspot.co.uk>
- ▶ **Houghton Thornley Medical Centres website**
www.htmc.co.uk
- ▶ **Markle Connecting for Health**
A public-private collaboration in the US. Their goal is to improve people's health and healthcare through innovations in information technology. This includes opinion surveys, frameworks (for example, on networked information and PHRs) and research.
www.markle.org

- ▶ **Personal health records: a guide for clinicians** by Mohammad Al-Ubaydli.
This book has been written by a doctor who has developed his own personal health records software for patients and doctors to interact. The book explains how to get the best from the patient's records and how to put the information to good use, helping both the patient and the clinician to a more effective and efficient outcome in any clinical situation.
- ▶ **Record Access Collaborative**
A network of organisations and individuals who are interested and supportive of record access. It aims to raise awareness and increase uptake of record access, support the development of national standards, and offer information and evidence about current developments.
www.record-access-collaborative.org



- ▶ **Renal PatientView evaluation**
www.kidneycare.nhs.uk
- ▶ **Personal Health Records - putting patients in control?** by 2020Health (in press)
www.2020health.org



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Chapter Six:

Useful resources and glossary

Patient information on record access

There are still relatively few publications for patients about electronic record access, but a number of information resources have been developed about record access in general, for example:

- ▶ **How to see your Health Records** published by NHS inform in Scotland
www.hris.org.uk
- ▶ **How do I access my Medical Records?** on NHS Choices
www.nhs.uk
- ▶ **Leaflets about the Summary Care Record and The Care Record Guarantee** published by Connecting for Health in multiple languages
www.connectingforhealth.nhs.uk

- ▶ **Requesting amendments to health and social care records** published by the National Information Governance Board
www.nigb.nhs.uk
- ▶ **Patient access to records** information pack published by NHS North West as part of their Patient Access to Records Programme.
- ▶ **Records access. An introduction for patients and clinicians** produced by Coastal Medical Group, supported by North Lancs PCT.
www.coastalmedicalgroup.co.uk

Glossary of terms

- ▶ **Adult Care Support Record (ACSR)**
The record kept about an individual in social care; similar to the PHR, but distributed across a wider range of systems and infrastructure.
- ▶ **Application (App)**
Software for specific purposes. Usually 'app' refers to software for mobile devices such as phones.
- ▶ **Authentication**
Process of determining if a user is who they claim to be.
- ▶ **Clinical Commissioning Groups (CCGs)**
The new health commissioning organisations which will replace Primary Care Trusts in April 2013. They will be responsible for planning and buying healthcare.
- ▶ **eHealth**
Healthcare supported by information and services via the internet or related technologies.
- ▶ **eHealth literacy**
The ability of people to use emerging information and communications technologies to improve or enable health and healthcare.



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Chapter Six:

Useful resources and glossary

▶ **Electronic patient record / electronic health record**

The electronic record kept about an individual by any health or social care organisation, such as general practice, hospital, social care, pharmacy or private health provider.

▶ **Interoperability**

The ability of systems to work with other products or systems.

▶ **Patient**

In this document we have used the term patient to mean anyone who uses health or social care services.

▶ **Patient Reported Outcome Measure (PROM)**

Standard measures, reported on by patients, about how they are feeling or what they are able to do. They can also be measured during treatment or a trial.

▶ **Personal Health Record (PHR)**

A health record which may be stand-alone or may integrate health information from multiple sources, and for which the individual manages and controls the content and grants permissions for access by, and/or sharing with, other parties.

▶ **Portal**

In the context of electronic records, a portal is the way a user accesses and interfaces with a records system via the internet, sometimes pulling information from a number of sources.

▶ **Record access**

Access to records, either the paper version or electronically.

▶ **Secure messaging**

Communication, similar to email, that protects sensitive data.

▶ **Smartphone**

A phone offering a range of built-in applications and internet access.

▶ **Telehealth / telemedicine / telecare**

The use of telecommunication equipment and information technology to provide clinical care to individuals at distant sites and the transmission of medical and surgical information and images needed to provide that care.

▶ **Tethered record**

A record that is a subset of data held by a specific healthcare provider, such as a GP practice. By definition, a tethered record will not be comprehensive because information held by only one healthcare provider is included. The user can access and update their data with varying degrees of control.

▶ **Untethered record**

A record controlled by the individual rather than an institution. Typically, it will be provided through a web-based platform which offers the patient an online space to keep data about their health - including data generated by the patient themselves - and synchronises with the patient's electronic health records held by different institutions. Untethered records offer the potential for patients to share data from one healthcare institution or professional involved in their care with another. They also offer a vehicle for the development of innovative applications and add-ons to enable patients to track and interpret their data, and manage their own health proactively.



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This is a pilot run by the National Brain Tumour Registry and brainstrust, the brain cancer charity.

The aim is for a patient information portal to provide cancer patients in England with access to the data about their care held by the National Cancer Registry and allow them to comment, add to or share this information. Patients will also have access to more information about their care; this will allow them to take an active part in the decisions about them and, should they

wish, seek opinions or advice from others. The portal will also allow patients to enter information about their quality of life which can feed into both their clinical care and wider information about the effect of brain tumours on patients' lives.

The pilot is starting small, using data in the National Brain Tumour Registry. The pilot will be run in partnership with a range of brain tumour charities and the charities will play a major role supporting the patient community and guiding the development and content of the portal.

A key element of the pilot will be to ensure that the technology, processes and systems can easily be scaled to cover all cancers sites.



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Cerner Patient Portal is a secure online portal currently used across 164 acute and primary care organisations in the US. It brings together a patient's health information into one place and is designed to allow individuals to access and connect with their care team easily, boosting patient loyalty and helping providers achieve operational efficiencies. Features include:

- ▶ Secure messaging between the patient and their care team
- ▶ Home Device Connectivity to capture data on approved home and lifestyle devices (e.g. pedometers, scales, glucometers, blood pressure cuffs) for use in the patient record and other services
- ▶ Medication Management to view prescriptions, and record medicine compliance and effects
- ▶ eVisits/eConsultation. A healthcare professional can respond while viewing the patient's actual record and have immediate access to past problems, current medications, allergies and test results



- ▶ Individual or groups challenges - such as weight loss or physical activity (i.e. number of steps or miles walked). This is done through a connected application and the data can be viewed by their doctor.

Cerner has noted a number of barriers and solutions over the last 10 years:

- ▶ PHRs need to be connected to a provider. Programs that have limited interaction between individuals and their providers have low adoption
- ▶ Users want to connect with their data automatically. Showing individuals a view of the



electronic medical record that their physicians are using eliminates timely data entry, plus gives them a level of transparency they enjoy. Using digital devices to automatically send data to a person's record further eliminates self-entry. Programs that rely on self-entering medication, test results, conditions and health information have low adoption

- ▶ Doctors and nurses should recommend the portal/PHR. Adoption grows dramatically if the care team not only uses but advocates the system
- ▶ Involve the individual in their care plan. Connect condition management tools to the individual so that they can track their progress
- ▶ The novelty of simply having access to your information is not enough. For the system to be widely adopted it needs to drive health improvement.

EMIS Patient Access www.patient.emisaccess.co.uk

Case study 

EMIS is one of the main GP software companies in the UK. Patient Access is its own patient module. It offers online services to over 1.36 million active patients. In Scotland it is paid for by NHS Scotland. It is used by more than 231,500 patients.

Practices that use the EMIS system for clinicians can turn on whichever parts of the Patient Access module they wish. Patients may then:

- ▶ view, book or cancel appointments
- ▶ request repeat prescriptions
- ▶ view their GP medical record, including letters, consultations, test results, prescriptions
- ▶ send secure messages
- ▶ update contact details
- ▶ pre-register if they are new to the surgery.

Practices have reported a dramatic reduction in administration time and overheads as Patient Access is fully integrated with the EMIS clinical system. What's more, EMIS says Patient Access can significantly reduce missed appointments and free-up practice telephone lines for patients without internet access.

Patient.co.uk is the information service provided by EMIS for EMIS's Patient Access. This gives trusted medical information, accredited by the Information Standard, on a wide range of diseases and conditions.



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eRedbook www.eredbook.org.uk

Case study **D**

This is an electronic version of the existing, paper-based Redbook - a national standard Personal Child Health Record. It will be created, updated and maintained via an online application by either the custodian of the eRedbook, or the relevant healthcare professional.

The eRedbook will store personally identifiable data on Microsoft's HealthVault system, for privacy- and security-enhanced data storage. In the future there will also be bolt-on modules that can allow specialist sections to be included (such as on epilepsy or Down syndrome) and translated versions.

While the paper version of the Redbook is still being used, the e-version will run in

parallel. Data added to the paper version using a digital pen and other devices, such as tablets, will be automatically added to the e-version.

Potential benefits over the paper version include having it always available and up to date; improved data collection for research; better parental engagement; improved information sharing and reduced information duplication; and improved healthcare commissioning.

eRedbook is still undergoing pilot testing. Results are expected in spring 2013.

 *Your digital redbook*
Personal Child Health Record



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Haughton Thornley Medical Centres

Dr Amir Hannan at Haughton Thornley Medical Centres has set out to make records as accessible as possible to patients. He started offering online access to health records and other services, including appointment setting and re-ordering of repeat prescriptions, in 2006. Since establishing a patient information portal in 2008, the take up of online services has accelerated, with patients also benefiting from a trusted source of health information via the web which links to rich sources of information from a range of providers.

Access is via EMIS Patient Access and there are now over 1,900 patients registered for record access. Dr Hannan has found that accessing records online reduces the need for GP and practice nurse appointments, gives patients the opportunity to view tests results and other aspects of their records when travelling as well as from home, and supports shared decision-making.⁷⁸

“ [During a pre-op interview at the hospital] the health worker asked my wife for a list of her current medication. We did not have this information with us. However, I was able to use the hospital computer, and bring up my wife’s repeat prescription. The health worker was quite amazed that this could be done. She was able to print off the medication list. It saved her time writing the list, and eliminated any chance of error.’

HTMC patient

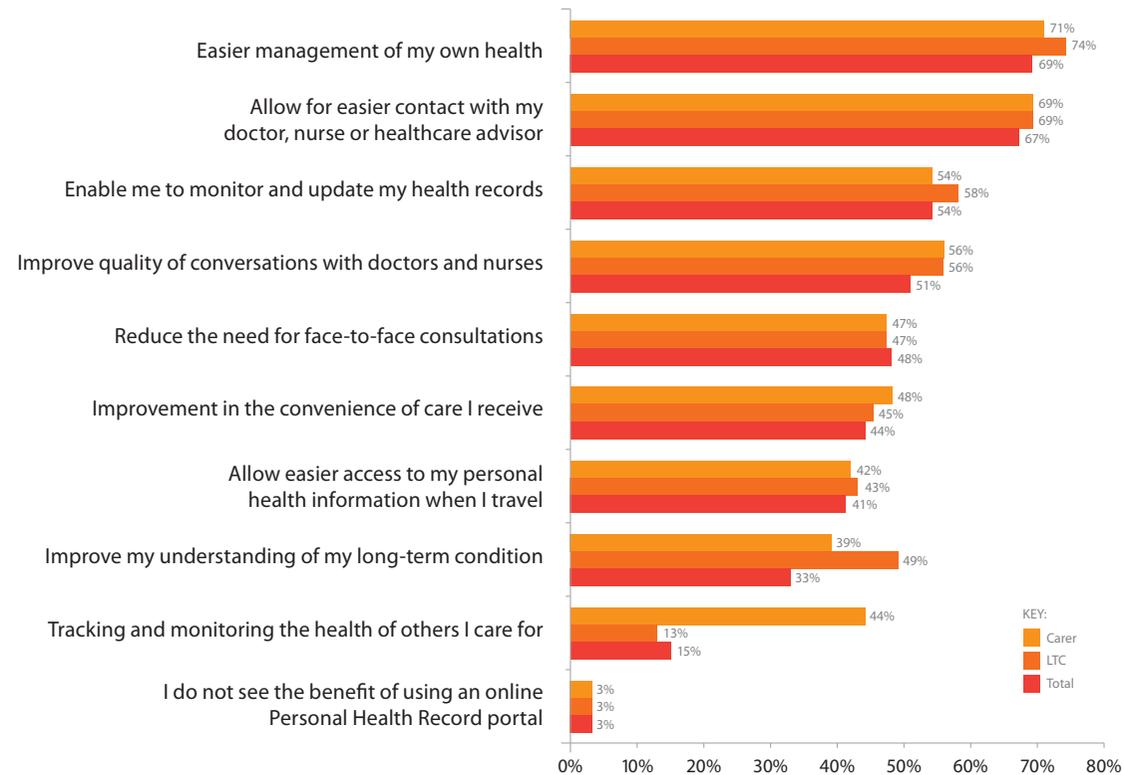
⁷⁸ <http://informationstrategy.dh.gov.uk>





This NHS England patient portal provides basic services such as an online personal health organiser, a diary and address book, and appointment booking through 'Choose and Book'. There are also advanced services such as access to Summary Care Records (for patients in areas where these have been created) and HealthSpace Communicator (a pilot scheme that allows patients to communicate electronically with their healthcare staff). January 2010 figures showed almost 80,000 people had registered for a basic HealthSpace account but uptake has been disappointing and it is being closed down.

What do you see as the main benefit of using an online health portal like HealthSpace?⁷⁹



⁷⁹ HealthSpace Patient Survey Report, January 2010.



Kaiser Permanente www.kp.org

Case study 

Kaiser Permanente is one of the US's largest healthcare and health plan providers. HealthConnect is the healthcare provider's electronic health record system. This is linked to its PHR, My Health Manager on kp.org. There are 3.9 million members registered for My Health Manager - 63% of eligible members. Users can:

- ▶ access their medical records, including allergies, past visit information, immunisations and ongoing health conditions
- ▶ view test results
- ▶ email physicians and other care givers
- ▶ order repeat prescriptions
- ▶ schedule and manage appointments
- ▶ receive healthcare reminders.

In 2011, Kaiser Permanente members viewed 29 million lab test results, sent 12 million emails to providers and refilled 10 million prescriptions through kp.org.

According to a 2010 Kaiser Permanente study,⁸⁰ secure patient-physician email messaging improves the effectiveness of care for patients with diabetes and hypertension. Usage of kp.org is also associated with member retention and satisfaction. In a 2012 survey, 72% of members surveyed agreed that the website helps them get the care they need, and 86% said they would recommend kp.org. In one region, members using the online appointments feature were 33% less likely to not attend appointments than members booking through the facility.



Users in the Northwest region had 7-10% fewer office visits and made 14% fewer telephone contacts than members not using My Health Manager.

Kaiser Permanente expanded the access of My Health Manager to mobile devices, such as smart phones, in early 2012. In April 2012, 15% of traffic to kp.org came from mobile devices.



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⁸⁰ Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. *Health Affairs* 2010; 29(7): 1370-5. <http://content.healthaffairs.org>

Looking Local <http://lookinglocal.gov.uk>

Case study 



Owned and managed by Kirklees Council, this bespoke technology allows multi-platform publishing on interactive TV (Sky and Virgin), mobiles and smart phones (including applications), and Wii and Facebook.

Looking Local enables public sector partners to deliver services and publish information on channels and devices that they might not be able to offer alone. Its specific focus is on digital inclusion and using new and popular technologies to widen access.

There were 1.83 million sessions on Looking Local in 2011, up 36% on the year before.

Nearly 8 million people across the UK do not have access to the internet, so PHRs and all other electronic services are not available to them; many of the people offline have the highest reliance on health services and the wider public sector. However 57% of homes can

access services via Sky & Virgin (over 14 million homes). Research into mobile and smartphones shows that 91% of UK adults have a mobile and nearly 50% of adults now own a smartphone. One third of adult smartphone users say accessing the internet on their phone is more important than internet on any other device and reports are showing that people in lower socio demographic groups are bypassing the home PC option and buying smartphones to go online and make calls.

Partners include:

- ▶ **EMIS** - Patients can log into Patient Access to see their medications, make an appointment or order a repeat prescription
- ▶ **NHS Scotland** - Patients can access: services from NHS 24, NHS Inform, Care Information Scotland and Scottish Backs; health questionnaires; GP appointment booking; access to local health services; information from the Health A-Z; seasonal health advice; news, health and wellbeing guides; as well as links to local support organisations. Around 350 patients a week are using the service

▶ **NHS Choices** - Patients can access a range of health information, from local health service listings to a Medical A-Z, Live Well advice and the latest health news.

▶ **Individual health organisations** have also developed their own services:

- **NHS Sefton CCG** uses Looking Local to offer a range of information and services including GP appointment booking, repeat prescription ordering, local health news and information on healthy living, specific conditions and information for carers. This local content is enhanced by local and national partners including the British Lung Foundation, Diabetes UK and the British Heart Foundation. In 2010-2011, 200 people per week accessed the service
- **Baywide CCG** in South Devon uses Looking Local to bring information and services together from 21 GP practices. Patients can make appointments and order repeat prescriptions, as well as get information on local services and news.



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MyALERT www.alert-online.com/myalert

Case study 1



MyALERT is a US clinical software company and MyALERT is their PHR provision. MyALERT allows citizens to access information on their medical record, and to register their own health-related details via the internet. There is also a mobile phone version. Current number of users is around 12,500.

Doctors can use MyALERT to monitor a user's health condition and provide advice to help promote healthier living.

Functions include:

- ▶ personal tools
- ▶ health management trackers
- ▶ risk assessment forms
- ▶ scheduling features.

Other main features include:

- ▶ having all information and clinical data in one place
- ▶ allowing users to actively participate in the documentation of their health status by registering and editing information related to problems, allergies, lab test results, medication and immunisations
- ▶ connection to healthcare institutions.



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Developed by NHS Scotland and University of Dundee, this is the official NHS Scotland information portal for people with diabetes and their carers. By May 2012 there were around 755 registrants. Usage of the website has doubled over the last twelve months and work continues to raise awareness across the health service and through patient groups. My Diabetes My Way builds upon the NHS Scotland shared diabetes record (SCI-DC) which captures data from primary, secondary and tertiary care, specialist screening services and laboratories.

Service users can access:

- ▶ all of their available information regardless of the many locations in which their care takes place
- ▶ test results - the most popular section of the website
- ▶ tailored information leaflets, videos and interactive tools to help them learn more about diabetes and how the condition can be managed effectively.

The experience of My Diabetes My Way illustrates some of the barriers and solutions to PHR deployment:

My Diabetes My Way experience of PHR deployment:

Barriers	Solutions
<p>Staff Awareness If front-line staff are not driving a PHR initiative, they may have little interest in engaging, or may not have heard about it. Dissemination via clinical networks was not as straightforward as anticipated.</p>	<p>The team began by delivering presentations at staff training events and clinical network conferences and by ensuring the project was referenced in strategic documentation (e.g. diabetes action plan). However, the most effective way of pushing the initiative has been to target patients themselves.</p>
<p>User Awareness Making patients aware of a PHR initiative is a challenge, particularly when one clinical site is not directly targeted. This is made even more challenging when staff awareness is low.</p>	<p>Word of mouth is an incredibly efficient tool but is not sufficient on its own. My Diabetes My Way have advertising materials in all hospital diabetes clinics in Scotland, the web address is on some screening letters and the team present at local patient groups and conferences. Articles have been published in local and national media and there are plans to have cards inserted with prescriptions when people with diabetes collect their medicines from any Scottish pharmacy.</p>
<p>Technical Skills In an older population, such as those with type 2 diabetes, computers are still not commonly used and in some cases people are scared or simply not interested in using them.</p>	<p>National statistics from August 2011 show that ~85% of people in the UK have access to the internet at home or elsewhere. Those who are not computer literate should speak to family members or friends who are, or find out about training at their local library.</p>
<p>Motivation Some may not have the motivation to 'self-manage' and prefer to continue with the paternalistic healthcare model.</p>	<p>This is a long-term challenge - part of the wider paradigm shift described on page 10 (box 3).</p>
<p>Health Literacy Displaying clinical results does not necessarily make them understandable - either for the latest results or for data histories. Line graphs are not necessarily the most effective way of showing trends or how well someone is doing.</p>	<p>The system aims to present data in ways that allow users to better interpret their information - for example, personal target charts.</p>



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myhealth@QEHB www.uhb.nhs.uk

Case study **K**

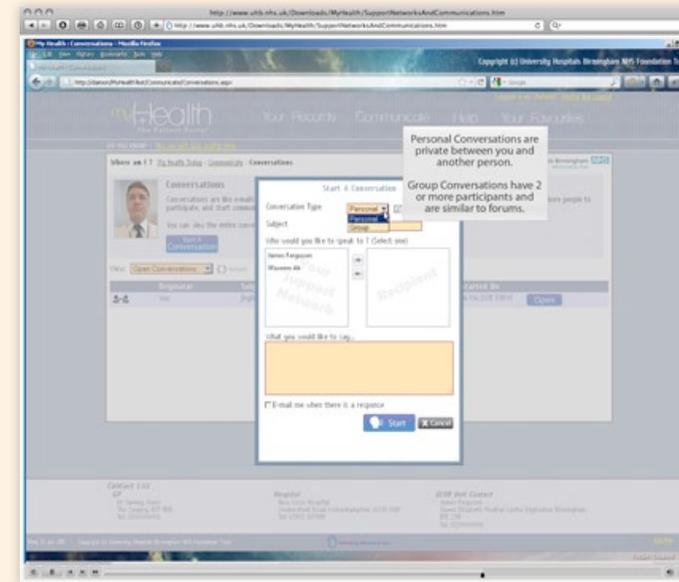
University Hospitals Birmingham NHS Foundation Trust is about to roll-out its bespoke web-based patient records portal, which allows those with long-term conditions to view and update their medical records.

The myhealth@QEHB portal was piloted with patients with a long-term liver condition. But from July 2012, patients receiving treatment in specialties such as diabetes and prostate cancer will also have access to the system.

Patients can log in to their personal home page, My Health Today, which will include:

- ▶ Diagnosis, medication, test results, discharge letters, admissions to hospital, details provided in clinical appointments, and contacts

- ▶ Links to reliable information about their treatment and condition
- ▶ Options to connect with other patients and medical practitioners to create their own support network
- ▶ A 'Recent activity' area to keep the user up to date with alerts and so users can see what they have done, what they need to do, and what others in their support network have chosen to share
- ▶ The option to submit information direct to their consultant, and store and share files pertaining to their health on the system.



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myRecord

Case study L

The myRecord project is a collaboration between the NHS Alliance, The Health Foundation, InHealth Associates, NHS Lewisham, NHS Berkshire East PCT and clinical commissioning groups, the RCGP Informatics Group, Diabetes UK and PAERS. So far approximately 450 patients have signed up in the two test bed sites/practices where the team is working closely to test what interventions are most successful in recruiting patients.

The aim is to give Lewisham patients access to their medical records online, offering support to signed-up patients and practices, and working to see what helps and what gets in the way. The team has engaged with patients, GPs, the Lewisham record access facilitator and a range of PCTs and commissioning groups.

Patients and practices will become increasingly involved as partners during the course of the project, as record-access champions and co-designers. This is a programme to work with practices to create an attitudinal shift to make online record access the norm.



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NHS Arran and Ayrshire Patient Portal

Case study **M**

The development of this online patient portal was led by GP Jim Campbell. The Scottish Government provided funding for NHS Ayrshire and Arran to develop it further. The purpose of the portal is to allow patients, particularly those with long-term conditions, to take more control of their own health by a combination of online services and self-management, including:

- ▶ Information on medicines
- ▶ Repeat prescription ordering
- ▶ Access to elements of the health record, such as test results
- ▶ Appointment requests
- ▶ Recording own measurements (such as blood pressure, blood sugar) and mood
- ▶ Goal setting
- ▶ Secure messaging between healthcare professional and patients
- ▶ Approved links about their particular health conditions.

After a six-month pilot in two GP practices, an independent evaluation of the portal was published in May 2011.⁸¹ During the pilot, 391 patients registered to use the portal, and 50% of these went on to use it. The majority of survey respondents were using the portal to order prescriptions (86%). In addition to this, over one-third (37%) were using it to view information from their health records (such as allergies, test results and alerts). Nearly a quarter were also using it to monitor their blood results. The majority of respondents (81%) felt they had benefited from using the portal. They said that they had benefited from being able to:

- ▶ Order repeat prescriptions more easily
- ▶ Reduce the time and cost of telephone calls to their surgery
- ▶ Track their health
- ▶ Access services more easily and conveniently.

A focus group with patients with long-term conditions (diabetes and COPD) indicated that they would have concerns about the credibility of information they found on the internet, but they had confidence in the approved information offered in the portal. They also said they found it reassuring to be able to see what information was contained within their own medical records and check its accuracy.

The pilot evaluation estimated that, assuming the portal had operated for 12 months, it would have possibly achieved a total saving of £69,194. This is based on 2% of the GP practices' population using the portal, and 5% of the GP practices' long-term conditions patients using the portal. These cost reductions were based on savings that might arise from, for example, fewer outpatient, day-case and practice nurse appointments, and fewer emergency admissions, of patients with long-term conditions.



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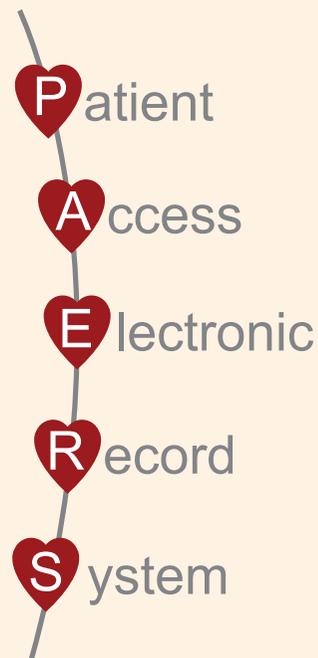
⁸¹ NHS Ayrshire & Arran: Evaluation of on-line patient portal. Axiom Consultancy (Scotland) Ltd, May 2011. www.axiomconsultancy.co.uk

PAERS (Patient Access to Electronic Record Systems) is an independent company set up by three doctors to enable patients to access their GP record. Currently all EMIS practices can offer this service through PAERS. The secure online service is free and patients can access it from a web-browser anywhere in the world, including through their mobile. So far there are about 100 practices signed up.

Details include:

- ▶ full and summary medical record, with links to information and education on diagnoses, support groups, test results and medicines
- ▶ consultations
- ▶ test results (if they are normal)
- ▶ current medications
- ▶ vaccinations
- ▶ letters
- ▶ patient information leaflets.

It is also possible for patients to view their record through a kiosk in the surgery. Authentication is via fingerprint identification. Information can only be seen by the patient directly in front of the screen, and cannot be overlooked by those nearby. This service has a cost.



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Set up by a clinician passionate about patients accessing their own records, this online PHR is totally in the patient's control and is already integrated into the NHS secure network. First, a patient registers with PKB and then invites whoever she wants to access it - for example, health professionals, social care workers and family, inside or outside the NHS - allowing them all to work together as a team.

- ▶ Anyone from the team can upload and share information
- ▶ Secure messaging between patients and clinicians is integral to the system
- ▶ Information shared includes letters, results, prescriptions and medical notes
- ▶ Health data can be sent and received - for example, daily blood sugar results
- ▶ The system allows for online consultation, stored in the patient record.

Great Ormond Street Hospital is using PKB to help look after children with gastrointestinal failure. Each patient needs complex care spread across London. Using this portal, the local hospital, GP surgery, community nurses and home healthcare companies are all able to use the same health record. PKB is also being used in Torbay Hospital in Devon to allow patients receiving care from the cystic fibrosis, surgery and speech therapy teams to receive test results and conduct online consultations. It is also working with a patient group, The Thalidomide Trust, to provide its patients with their own PHR. And in the US, PKB is being used in a trial looking at whether giving gastroenterology patients access to their records saves healthcare costs.



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

“ ‘I need quite regular contact, day-to-day, because things change on a daily basis with the feeding; sometimes I need it reviewing quite urgently. So say I'll see someone from neurology, gastric, nutrition, physios and everyone really on a weekly basis. When I was younger you really had to get into contact with doctors because you would constantly be on the phone and then they wouldn't be able to get back to you and then you'd have to try and send an e-mail to someone and they necessarily wouldn't get that e-mail. It was just really hard to keep in touch. It's just really brought the talking with doctors into the 21st Century really, it just makes living with a medical condition a lot more easier, so it just feels like you have an equal say on your care.’

Patient using PKB



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Renal PatientView is an online portal initiated by the Renal Information Exchange Group and further developed by NHS Kidney Care. There are now over 19,000 registered patients. The portal enables NHS kidney patients to:

- ▶ view their test results
- ▶ get information about their disease and treatment
- ▶ add their own data such as blood pressure, glucose and weight readings
- ▶ use an online discussion forum.

GPs and, with the patient's permission, other healthcare workers can also log in to see this information - this is particularly useful for non-specialists involved in the care of renal patients, or when patients are looked after in more than one centre. Funding is from the Government in Scotland or, elsewhere, a small annual charge to participating renal units.

Renal PatientView

A recent evaluation⁸² showed nearly all patients found it valuable to have access to information from their own health record available over the internet. Most patients (94%) found the results section the most useful, followed by information on their medicines (47%), letters (43%) and 'Enter my own results' (38%). Of the functions used the most, the results section was visited the most, followed by the patient's information, medicines and patient details.

Most users of Renal PatientView (88%) felt that it made them feel more in control of their medical care; 86% found it gave them a better understanding of their kidney disease; 79% found it helped them communicate better with their doctors; 77% were reassured

about treatment; and 75% felt more involved with decisions about their care. Only 5% felt confused by the lab results and 14% worried about things they read.

Professionals felt that patients who use Renal PatientView were more informed; more involved in treatment decisions; more prepared for hospital visits; and better able to communicate with their doctors and follow their recommendations. Professionals also felt that their patients' use of Renal PatientView had not increased their workload.



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⁸² Renal Patient View: A system which provides patients online access to their test results. Final report. NHS Kidney Care, February 2012. www.kidneycare.nhs.uk

South London and Maudsley NHS Foundation Trust (SLaM) Case Study

SLaM (a national centre for psychiatric care), local GPs and Microsoft worked together to develop a limited PHR, which is stored online on Microsoft's HealthVault. The programme, called myhealthlocker, was launched in May 2012. Service users can securely collect, store, edit and manage their own health information from a variety of sources. They can select what information is shared and who they share this with.

Service users can open a myhealthlocker account and agree with their health worker exactly what information about their care it is helpful to have access to. This could include:

- ▶ their SLaM careplan, which the patient can contribute to
- ▶ information about medicines, emergency contact details and health records
- ▶ a health journal to keep track of symptoms, sleep patterns, behaviours and emotions
- ▶ access to resources and tips on staying well and managing their health and wellbeing
- ▶ clinicians and patients contributing to records directly to work collaboratively on care and treatment. This encourages a two-way flow of information between patients and clinicians
- ▶ the patient and care worker deciding what information to share with each other, and can also share part or all of this with a family member or carer.

“ ‘Rather than the clinician holding on to the records, it is about the service user having the records. It's about being able to see them, it is about being able to understand what's written about them, and also, more importantly actually, to be able to write about themselves. It's about bringing their experience and sharing it with clinicians, rather than vice versa... several of the service users have focused on how exciting it is actually for them to feel in control, to enter into a dialogue they have initiated and recorded and they can own and add to, rather than feeling they are the recipient of a dialogue from the other side.’ *SLaM doctor*

“ ‘For the last few years I've been diagnosed with schizophrenia so there's a lot of paranoid feelings which stops me getting involved in things. After a few years the gap between seeing the care workers and the consultants got longer and longer; this was one of the things I realised about myhealthlocker - if it had existed then I would have found out what the changes were going on. When I first heard about myhealthlocker it looked very interesting. It seemed like it was going to be very useful because of instant access to it, because of the way there's an input from the professionals and it seemed very easy to use. With myhealthlocker I check my messages via email and so on every day so even if it is something really simple it does have a significant effect in terms of bringing me back in with other people. My expectation is that it is going to have a major impact on the sense of isolation. Once there is a point of contact it made a lot of difference.’ *SLaM patient*



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Chapter Seven: Case studies

TPP SystmOne www.tpp-uk.com

Case study 



TPP is a clinical software company supplying SystmOne - single networked health records - to 120,000 users in the NHS. SystmOne is accessible to any

healthcare professional anywhere, across a range of disciplines from over 1800 GP practices, plus areas such as child health, community care, urgent care and palliative care. SystmOnline is a free web-based service within SystmOne that provides patients with the ability to:

- ▶ access their medical record
- ▶ arrange appointments
- ▶ order prescriptions
- ▶ complete questionnaires
- ▶ update personal details
- ▶ ask questions.

So far there has been widespread uptake of transactional elements of online patient access, such as booking appointments and ordering repeat prescriptions. TPP is now beginning to pilot the wider functionality of patients' record access.



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TRIBAL

Tribal is a technology provider. Its Patient Relationship Management system is a secure patient portal helping patients manage their own health and long-term conditions in their own homes, supported by healthcare professionals.

For example, Tribal's paediatric diabetes portal for University College London Hospitals NHS Trust is a secure portal for patients to:

- ▶ find information about conditions
- ▶ book appointments
- ▶ access their care plan

- ▶ set agendas for future meetings
- ▶ transfer data from glucose monitoring and insulin pump settings
- ▶ check on their progress (for example, their haemoglobin concentration) and compare values with peers and standards; this may allow early detection of events that might lead to an admission
- ▶ use two-way multi-lingual communication via new channels such as email, text message and Twitter, as well as traditional letters
- ▶ receive training and educational information
- ▶ share information with approved third parties, such as schools.

Tribal has evidence showing that its Patient Relationship Management system cuts healthcare professional administration by 25%, and need for outbound telephone calls by 50%, as well as increasing the ratio of patients to specialist healthcare workers by more than 30%.



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Chapter Seven: Case studies

University Hospital Southampton Case study NHS Foundation Trust

UHS is about to start piloting the use of Microsoft's HealthVault to deliver online access to hospital services and to achieve the vision of 'no decision about me without me' for its patients. The study will start with patients with irritable bowel disease but there are plans to include other groups, such as pregnant women with diabetes, and patients with respiratory problems or other long-term conditions. During the pilot, patients will get:

- ▶ access to their discharge summaries and upcoming appointments
- ▶ ability to securely communicate with their clinicians in a similar way to email
- ▶ the option to keep a health journal.

In the longer term, patients will also get:

- ▶ lab results
- ▶ clinic information
- ▶ specific information about their condition.

University Hospital Southampton 
NHS Foundation Trust



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The US Department of Veterans Affairs is a government-run benefit system for military veterans, their families and survivors. It is the US government's second largest department and runs medical facilities, clinics and benefits offices.

My HealtheVet is the VA's record access service and provides an online gateway to benefits and services. All users can enter their own information. Those with upgraded accounts are able to:

- ▶ view their self-entered information
- ▶ access parts of their official VA health record
- ▶ view their military service information

- ▶ view VA appointments
- ▶ check lab results
- ▶ access trusted health and medical information
- ▶ order repeat prescriptions and view prescription history
- ▶ email the VA healthcare team.

VA have also developed the 'Blue Button'. This is on the health record webpage and by clicking on it the user can download any information into a simple text file or PDF that can be read, printed or saved on any computer. It gives complete control of the information without any special software, enabling the data to be shared with anyone, such as providers, caregivers and family.



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