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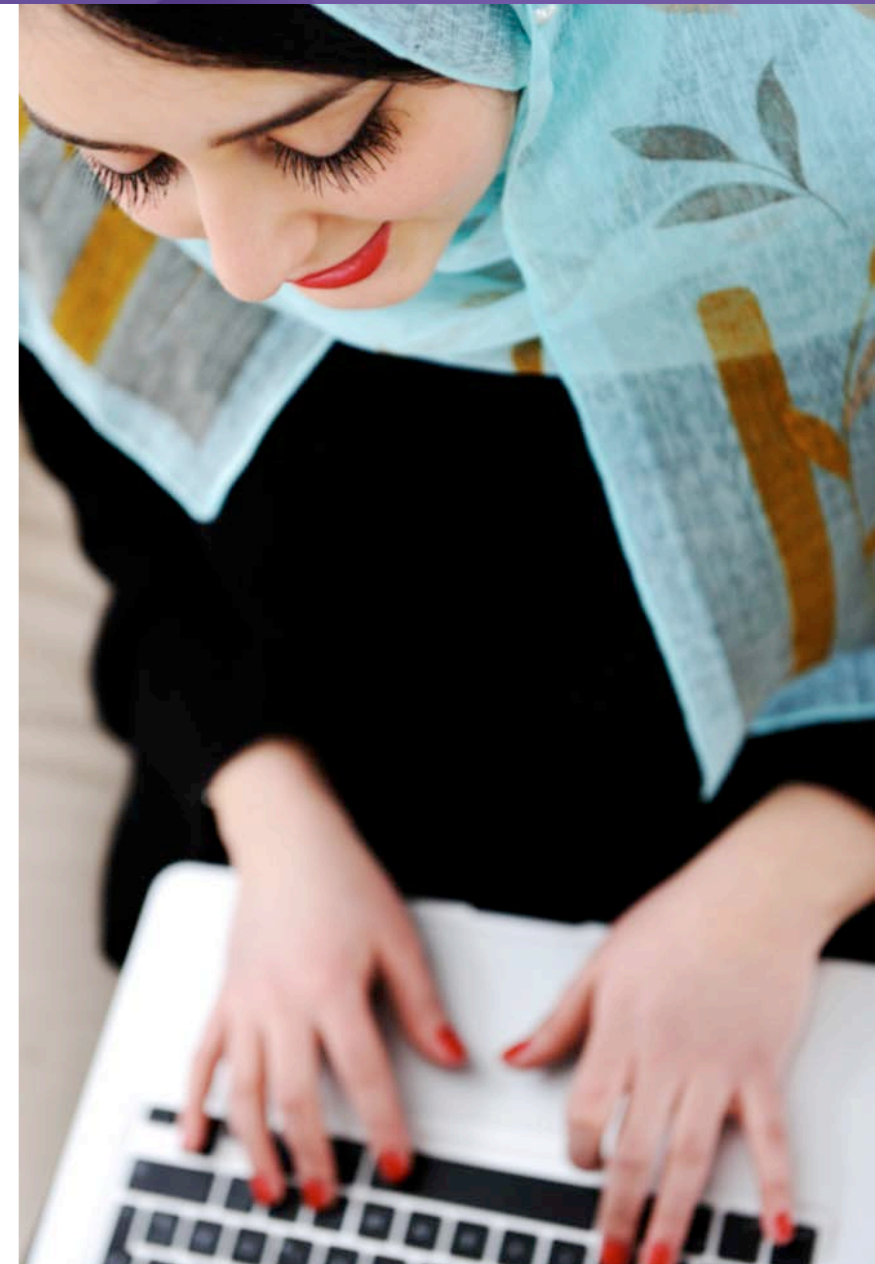
Patient Information Forum

# Personal Health Records: Learning from voices of experience



Patient Information Forum

*For everyone involved in health information and support*



## The Patient Information Forum

The Patient Information Forum (PIF) is the UK membership organisation and network for everyone working in, and involved with, healthcare information and support.

We are committed to improving the healthcare experience of people across the UK. We do this by supporting individuals and organisations to provide person-centred, high-quality and accessible information, which supports people to understand and make informed decisions about their health, wellbeing and care choices.

PIF is a non-profit, independent organisation with members in all healthcare sectors and in every country in the UK.

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-  [patientinformationforum](https://www.linkedin.com/company/patientinformationforum)

**Personal Health Records: learning from voices of experience**

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# About this guide

This guide is for anyone who would like to find out about Personal Health Records (PHRs). This could be if...

- ▶ you are keen to live a healthy lifestyle, and stay fit and well
  - ▶ and you are wondering whether PHRs might help you
- ▶ you have a long-term condition or other health need
  - ▶ and you are wondering whether PHRs might help you to understand your own situation, self-manage your care, and liaise with health and care professionals
- ▶ you would like to help someone else – perhaps a friend or relative – with their health and care
  - ▶ and you are wondering whether PHRs can help you to understand that person's needs and how best you can help
- ▶ you create or provide consumer or patient health information and support
  - ▶ and you are wondering whether PHRs can help you to reach patients, carers, service users and the general public

- ▶ you are using an mHealth app, wearable or another health-related device
  - ▶ and you are wondering about how they might interact with PHRs
- ▶ you are a health and care professional
  - ▶ and you are wondering how PHRs might help you to deliver safe and effective care
- ▶ you are an NHS or social care manager or commissioner
  - ▶ and you are looking for information that helps you to plan for, commission and implement PHRs.

While researching this guide, it quickly started to feel as if there are two parallel universes.

One is inhabited by people who know almost nothing about PHRs and haven't used them, people who seem underwhelmed by PHRs and uninterested in them.

Another, much smaller, universe is inhabited by people who know a great deal about PHRs, people who speak passionately about the potential benefits of PHRs and the challenges we face in ensuring they work well for everyone. By exploring the experiences and

opinions of people who care passionately about making a success of PHRs – people who have first-hand experience of developing or using them for personal or professional reasons, or both – we hope that this guide will give you a flavour of how PHRs could impact people's lives.

It builds on information in existing reports such as the Royal College of Physicians' ['Personal Health Record \(PHR\) Landscape Review'](#), 2020health.org's ['Personal Health Records: Putting patients in control?'](#), the Nuffield Trust's ['Delivering the Benefits of Digital Health Care'](#) and PIF's 2013 [Guide to Health Records Access](#) – without unnecessary duplication of content.

As we can't write every section from every perspective, and as we all engage with health from a personal perspective (as well as some of us from a professional one), we've written much of the content from the perspective of someone who is using their own PHR for their own personal reasons.

We start by exploring what sorts of PHRs are available and who might want them. Then we discuss aspects of PHRs that people highlighted as being the most important, concluding with a checklist of key things to consider.



### Can you help to build understanding?

This guide provides a snapshot of the experiences of people who are currently using or working with PHRs. When researching the content, we interviewed people on a one-to-one basis, attended talks at UK eHealth Week (May 2016) and an event organised by Sitekit, who produce the eRedbook. We also consulted publications that people told us were particularly interesting.

The guide is not, therefore, a comprehensive academic review of PHRs and we recognise there are experiences and views that we have not been able to include.

Please do share information on any research or projects that would add to the knowledge-base in this resource, via our ['invitation to feedback'](#), and we will do our best to include it on the PIF website.

'With my NHS number as my pin, I'd like to be able to see all my records on my mobile phone, with seamless integration between primary and secondary care. I'd like to be able to contribute to those records and be in control of them.'

**Michael Seres**

'Your PHR should be so helpful that it's as prominent in your life as your bank account. It should be your Facebook. You should be looking at it as often as you can.'

**Declan Hadley**

'Even your cat is now getting a personal health record, so get on with it. That's my message.'

**Adrian Byrne**

'It turns out that the only people who know how the whole system works are the patients... Only they cross the organisational boundaries, a fact that underlines the wisdom and importance of efforts to give patients control of their own medical records.'

**Fiona Godlee, writing in the BMJ<sup>1</sup>**

<sup>1</sup> Editor's Choice. Integrated care is what we all want. Fiona Godlee [www.bmj.com/content/344/bmj.e3959.full.print](http://www.bmj.com/content/344/bmj.e3959.full.print)



National Information Board

We are very grateful to the National Information Board for the grant they provided to support our development of this guide as part of their 'Building a Digital Ready Workforce' Programme.

PHRs are an integral part of the National Information Board's ['Personalised Health and Care 2020 - A Framework for Action'](#) and of the [resultant action plan](#) and work streams. They provide a tangible example of how we can all use digital tools to help us improve our health and self-manage our care needs.



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# Acknowledgements

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- ▶ **Dr Mohammad Al-Ubaydli** - Chief Executive, Patients Know Best
- ▶ **Ingrid Brindle** - Long-term patient, Chair of Haughton Thornley Medical Centres' Patient Group (Winner of the 2016 award for best Patient Group in the UK)
- ▶ **Adrian Byrne** - Director of Informatics, University Hospital Southampton NHS Foundation Trust
- ▶ **Peter Cambouropoulos** - ICT Programme Manager, Digital Transformation (South), NHS South, Central and West Commissioning Support Unit
- ▶ **Kevin Cross** - Digital Accessibility Lead, Texthelp Ltd
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- ▶ **Lorenzo Gordon** - Director, Maldaba Ltd
- ▶ **Declan Hadley** - Digital Health Lead, Lancashire & South Cumbria Change Programme
- ▶ **Dr Amir Hannan** - General Practitioner, Haughton Thornley Medical Centres; Director, Orbit Healthcare Ltd, local GP Federation; Co-Chair Greater Manchester NHS Values Group; Member of the Equality Diversity Council, NHS England; Chair West Pennine Local Medical Committee; Chair of the Association of Greater Manchester LMCs
- ▶ **Dr Lloyd Humphreys** - Vice President of Business Development, Patients Know Best
- ▶ **Dr Sarah Jefferies FRCP, FRCR PhD** - Consultant Clinical Oncologist, Addenbrooke's Hospital, Cambridge
- ▶ **Dr Phil Koczan** - GP and Digital Clinical Champion for Patient Online
- ▶ **Dr Howard Leicester** - DeafBlind professional in Health Informatics, recent Advisor to RCGP, RCP, NHS England and the Scottish 'Out of Hours' review
- ▶ **Charles Lowe** - Managing Director, Digital Health and Care Alliance (DHACA); Immediate Past President, Telemedicine and eHealth Section, Royal Society of Medicine



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- ▶ **Michael Seres** - Long-term patient, Founder/CEO 11Health
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All web links included in the references were accessed between April and October 2016.



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# 1: What types of PHRs are available?

During our research, almost everyone asked 'How are you defining a Personal Health Record?'. To get things started, we put forward a loose definition as follows:

## 'A personal digital space for health and care information that, ideally...

- ▶ brings together into one place information from all the records that health and care professionals create about you
- ▶ lets you add things yourself, including data from any health and fitness devices you use, and any information that helps you to understand and manage your health and care and live well
- ▶ allows you to do things such as make appointments, communicate with others or set goals for yourself and meet them
- ▶ enables you to share information from your PHR, if you wish, with people who are involved in your care - be they family members and friends, or health and care professionals.'

We also took a step back and considered whether 'Personal Health Record' is even the best term to use. Is it right to include the word 'health' but not the word 'care'? Should the name itself make it clear that we are talking about a 'digital' space and highlight opportunities for 'sharing' information between patient and healthcare professional? Is the term user friendly enough; should it be catchier?

In the end we decided that the term Personal Health Record, or PHR, itself doesn't necessarily have to say everything, and we stuck with it, because it seems to be the most recognised and widely used term for what we are discussing. But we do recognise that other descriptions are being used, and that 'PHR' is not necessarily the optimum terminology.

We've included definitions of PHRs used by other organisations in [Appendix A](#). You can find a more extensive checklist of possible features and functions to look out for in PHRs in [section 10](#).

We believe the following quote describes things really well from many perspectives:

'If you had a single, definitive PHR, it would give you, and everyone else who's involved in your care to whom you give access, a more holistic view of your health and care. You could see who's recorded what, make corrections and ask for clarifications about things you don't understand. You could look up any jargon you see, find peer support groups and use it as a means of communication with your health and care team. Your PHR would help you to manage your own care, explain who to consult about what and how to get help in a crisis...'

'If you're a carer, access to a record like this would help you to understand more fully what's going on with your loved one. It can be difficult to get all the information you need at the moment.'

'If you're a health or care professional, access to a single, definitive PHR would give you an holistic view of the whole person, with information on GP visits, consultant visits, test results and so on, as well as the role of people on the social care side, who the person's informal carers are, and what their personal preferences are.'

**Richard Pantlin (an expert on social care IT systems)**



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# 1: What types of PHRs are available?

## Fast facts

- ▶ **75% of the UK population go online for health information** and more than **50% use the internet to self-diagnose**, according to a report from 2015.<sup>2</sup>
- ▶ Latest data from NHS Digital shows **94.6% of GPs have enabled functionality** for patients to view detailed coded records results online, but only **0.4% of patients are registered** for this service.<sup>3</sup>
- ▶ Almost **nine in ten (86%) UK adults** have internet access at home.<sup>4</sup>
- ▶ Data from earlier this year in the UK showed that **87.9%** of adults had recently (in the last 3 months) used the internet.<sup>5</sup> Almost all younger adults (**99.2%**) aged 16-24 were recent internet users, compared with around four in ten (**38.7%**) adults aged 75 and over. **10.2%** of adults had never used the internet, and **25%** of disabled adults had never used the internet.
- ▶ **71% of all UK adults own a smartphone**, up from 66% in 2015.<sup>6</sup>
- ▶ There are more than **150,000 mHealth apps** in the Apple iTunes and Android apps stores.<sup>7</sup>
- ▶ The mobile health market – which already stands at **\$13.7 billion** globally – is forecast to grow by 34% annually.<sup>8</sup>
- ▶ Estimates predict **411 million smart wearable devices**, worth US\$34 billion, will be sold in 2020, with wrist-based devices – such as smartwatches and fitness trackers – continuing to dominate.<sup>9</sup>
- ▶ The global smart home market is expected to grow from **US \$46.97 billion in 2015 to US \$121.73 billion** by 2022, with home healthcare being one of six key classes of products in this market.<sup>10</sup>

'Digital health tools and information can help people to better manage their health and avoid unnecessary GP visits and hospital admissions.'<sup>11</sup>

NHS England

- <sup>2</sup> Healthcare UK, Department of Health and UK Trade & Investment. The UK. Your partner for healthcare solutions. Jan 2015 [www.gov.uk/government/publications/the-uk-your-partner-for-digital-health-solutions](http://www.gov.uk/government/publications/the-uk-your-partner-for-digital-health-solutions)
- <sup>3</sup> NHS Digital. NHS Digital Indicator Portal. Patient Online Services. POMI. [indicators.hscic.gov.uk/webview](http://indicators.hscic.gov.uk/webview)
- <sup>4</sup> Ofcom. The communications market report, 4 August 2016, [stakeholders.ofcom.org.uk/binaries/research/cmr/cmr16/uk/CMR\\_UK\\_2016.pdf](http://stakeholders.ofcom.org.uk/binaries/research/cmr/cmr16/uk/CMR_UK_2016.pdf)
- <sup>5</sup> Office for National Statistics. Statistical bulletin: Internet users in the UK: 2016 [www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016](http://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016)
- <sup>6</sup> Ofcom. The communications market report, 4 August 2016, [stakeholders.ofcom.org.uk/binaries/research/cmr/cmr16/uk/CMR\\_UK\\_2016.pdf](http://stakeholders.ofcom.org.uk/binaries/research/cmr/cmr16/uk/CMR_UK_2016.pdf)
- <sup>7</sup> Medscape Medical News. Number of Health Apps Soars, but Use Does Not Always Follow. Sept 2015. [www.medscape.com/viewarticle/851226](http://www.medscape.com/viewarticle/851226)
- <sup>8</sup> Reform. The future of public services: digital patients. May 2016. [www.reform.uk/publication/the-future-of-public-services-digital-patients](http://www.reform.uk/publication/the-future-of-public-services-digital-patients)
- <sup>9</sup> Forbes. Wearable Tech Market To Be Worth \$34 Billion By 2020. Feb 2016. [www.forbes.com/sites/paullamkin/2016/02/17/wearable-tech-market-to-be-worth-34-billion-by-2020/#5369809e3fe3](http://www.forbes.com/sites/paullamkin/2016/02/17/wearable-tech-market-to-be-worth-34-billion-by-2020/#5369809e3fe3)
- <sup>10</sup> Market and Markets. Smart Home Market by Product (Lighting Control (Timer, Daylight Sensor, Occupancy Sensor), Security & Access Control, HVAC, Entertainment, Home Healthcare and Smart Kitchen), Software & Service (Behavioral, Proactive), and Geography - Global Forecast to 2022. May 2016. [www.marketsandmarkets.com/Market-Reports/smart-homes-and-assisted-living-advanced-technologie-and-global-market-121.html?gclid=COu174Oqts0CFdIV0wodcTwDBg](http://www.marketsandmarkets.com/Market-Reports/smart-homes-and-assisted-living-advanced-technologie-and-global-market-121.html?gclid=COu174Oqts0CFdIV0wodcTwDBg)
- <sup>11</sup> NHS England. News. Martha Lane Fox sets out key digital proposals for the NHS. Dec 2015. [www.england.nhs.uk/2015/12/martha-lane-fox](http://www.england.nhs.uk/2015/12/martha-lane-fox)



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# 1: What types of PHRs are available?

## Your NHS records

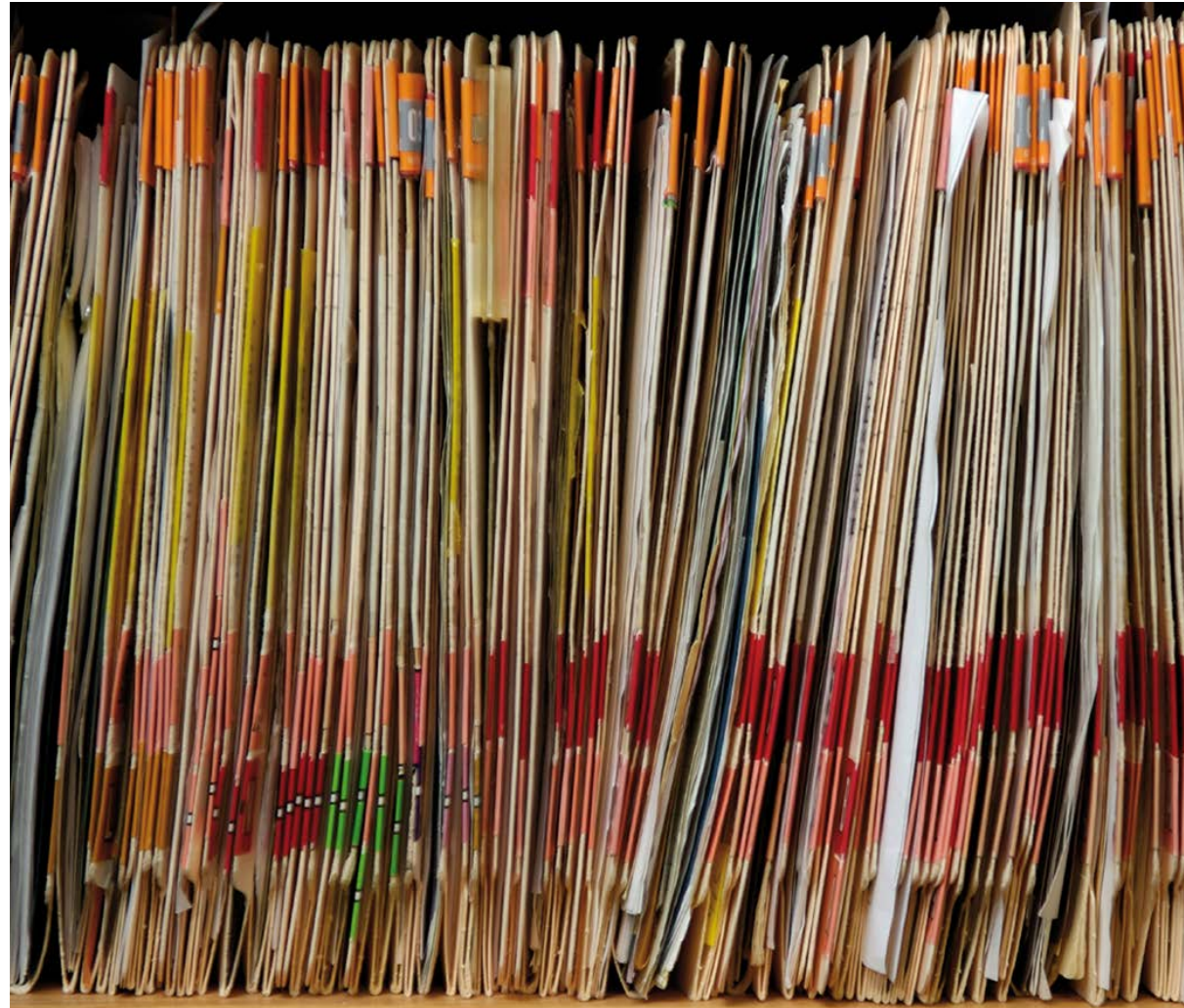
Each time you visit a health professional in the NHS, they make a record of that encounter. Records may be created by your GP, any hospital specialists you see, your dentist, physiotherapist, psychologist... the list goes on. Some of your records may still be on paper, others will be electronic.

These fragmented bits and pieces of information have often been kept separately. People tend to say they're in 'silos'. Which parts of your records you can see online, and how well those silos of information have been pulled together into one place, varies depending on where you live.

## GP records

Everyone in England should have access to free, online services from their GP practice, which are required by the GP contract. You should be able to do the following things online...

- ▶ order repeat prescriptions
- ▶ book appointments at your GP practice
- ▶ see your GP's electronic medical record about you.



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## 1: What types of PHRs are available?

### Ingrid Brindle explains how online access to GP records benefits her

#### Ingrid is a long-term patient and Chair of her GP Patient Participation Group in Tameside.

'Using my GP records gives me such a wonderful feeling of control over my stuff. It's so liberating being able to make appointments, order repeat prescriptions and see test results for myself. You can do all that through your record.

You can access your GP record 24/7, everywhere in the world. I've got an app on my mobile phone that enables me to do this. Once, when I was on holiday in France and I needed to go into hospital unexpectedly, I went in with all the info from my records, which my friend helped to translate.

When explaining record access to people, we should be asking, 'Would you like to be

more independent and not have to keep bothering the surgery to ask for things? Would you like to be able to check whether your referral letter's actually gone, so you can chase for your appointment if you've been waiting for a long time? Would you like to read your consultant's letter, so you can see whether you understand it and get more information if needed?'

We should also be asking, 'Would you like a reminder of what your doctor tells you during your consultations - about your medication, for example, so you can take it properly, or what's going to happen next?' People forget up to 80% of what doctors tell them during consultations and almost half of what they remember is incorrect.<sup>12</sup>

I can access lists of all my problems and the dates when things happened - when I had my last scan, when I had my operations,

when I started my medication... All the information is there and you can use it whenever you want, which can help in situations people might not even think about, such as filling in applications for insurance, benefits or care.

I see several consultants in different departments at my nearest hospital. I take my test results with me, so they don't have to repeat tests. I download letters and make sure they get to the people who should see them, so everyone's singing from the same sheet.'

Ordering repeat prescriptions is a doddle. I use my laptop, the practice sends it to the pharmacy and if necessary, the pharmacy will deliver! A lot of patient non-compliance with meds is because they run out.'



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<sup>12</sup> Personal Health Records: A guide for clinicians. Mohammad Al-Ubaydli, March 2011, Wiley-Blackwell ISBN: 978-1-4443-3252-0



# 1: What types of PHRs are available?

## What can you see in your GP record?

At the moment, GPs are not required to give patients access to everything in their electronic medical records. You should be able to see what's called your 'detailed coded data', which includes information on your medications, allergies, illnesses, immunisations and test results.

'Like all GPs in England, I'm contractually required to give patients free, online access to the detailed coded data in their records,' explains Dr Phil Koczan, a GP in London. 'GPs can share other things with patients if they choose to, such as free text and letters with attachments. Free text can include a considerable amount of information, such as notes that GPs type in on symptoms and their severity, observations they make during examinations, and thoughts on diagnoses that seem possible or they've ruled out.'

'GPs have historically used records as a way of writing down their own thoughts, to help them go about their job of providing the best

possible care for patients' adds Phil. 'Giving patients access to their records, particularly the free text, has implications for how we write our notes. It's worth considering that in the future GPs may be encouraged to make free text available to patients.'

The Medical Protection Society recommends that one should always assume that patients will read their clinical records at some stage.<sup>13</sup>

**'The Advisory Group endorses giving patients full access to their electronic data, including clinician notes.'**

**Making IT Work: Harnessing Information Technology to Improve Care in England<sup>14</sup>**

## Protecting from harm

'Giving patients access to their GP record has many potential benefits, but it might be harmful for people to see some of the information in their record,' says Dr Phil Koczan. 'GPs worry that some patients might

struggle to understand what's written in their notes, that some comments might be wrongly interpreted, be upsetting or annoying, or might raise patients' concerns and cause anxiety unnecessarily.'

'If it seems necessary to protect a patient's safety, GPs can hide certain things from the patient's view,' says Phil. 'We call this redacting information; the information isn't deleted from the record, it's just that the patient can't see it. GPs redact sensitive data that is likely to cause serious harm to the patient, their proxy or healthcare workers. This might include an entry about suspected abuse, or suspicions about a possible serious diagnosis that haven't been explained yet to the patient. GPs also redact confidential information that's been provided by, or is about, another person, to protect that person's privacy. This is known as third-party data.'

<sup>13</sup> Medical Protection Society. An essential guide to Medical Records. [www.medicalprotection.org/uk/advice-booklets/an-mps-essential-guide-to-medical-records](http://www.medicalprotection.org/uk/advice-booklets/an-mps-essential-guide-to-medical-records)

<sup>14</sup> Department of Health. Making IT Work: Harnessing Information Technology to Improve Care in England. Sept 2016 [www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs](http://www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs)



# 1: What types of PHRs are available?

## Patient portals - tethered records

The online services that GPs offer to patients were created by adding what tends to be called a 'patient portal' to the electronic medical records systems that GPs were already using. There are four main GP patient portals: Patient Access (from EMIS), Vision (from INPS), The Waiting Room 2 (from MICROTEST) and SystemOnline (from TPP).

Patient portals like this are known as tethered PHRs. They provide access to medical information that is held about you by a single healthcare provider.

### Giving patients the power to share their GP records

'The Patient Access patient portal has a 'Share My Record' function that enables patients to give other healthcare professionals 24-hour access to a view-only snapshot of their GP record,' says EMIS Health's Tim East.

'This can help, for example, if you're travelling and you need to go into A&E. It means you don't have to rely on your memory every time you see a new doctor. The patient controls what they want to share by ticking those elements of their data. Clinicians can access a patient's record by scanning a barcode on the patient's phone or via a time-limited website link, and there's a full audit trail showing who's seen what.

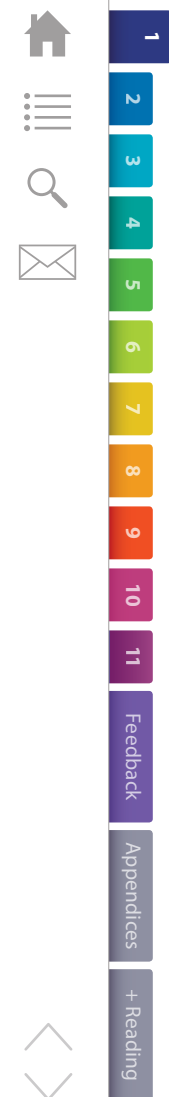
## Beyond primary care

Whether or not people have online access to NHS records outside of primary care varies. Some specialist departments within some hospitals offer patients access; some hospitals offer all patients access. Such hospitals at the moment are few and far between, but online access to hospital records is set to increase. For example, in England the government has committed that by April 2018 people will have access to online records that include information from all of their health and care interactions.<sup>15</sup>

PHRs that are already in use outside of primary care include bespoke systems created in-house by individual hospitals, such as myhealth@QEHB (a patient portal developed by University Hospitals Birmingham NHS Foundation Trust, with over 10,000 patients registered to use the system<sup>16</sup>), and commercially available systems such as Patients Know Best (a patient portal and health information exchange that's live in over 200 sites across 8 countries), Patient View

<sup>15</sup> House of Commons Library. Briefing paper Number 07572, 25 April 2016 A paperless NHS: electronic health records. [researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7572](https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7572)

<sup>16</sup> Royal College of Physicians. Personal health record (PHR) case study. Myhealth@QEHB June 2016. [www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-final-report](http://www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-final-report)





# 1: What types of PHRs are available?

(which began as a portal specifically for patients with kidney problems and now covers 90% of UK renal units, and is being used in other specialities too) and Get Real Health. Another example is the eRedbook ([see section 2](#)).

The functionality of these PHRs varies, as does the nature of the information patients have access to. You can find more information on each organisation's website and in The Royal College of Physicians' recent [Landscape Review](#).

## Seeing test results online

Access to NHS records can enable patients to see test results online. Sometimes those results might be upsetting, so it's important to ensure patients understand what they might see and when.

'At our surgery, we go through a consent process with people before giving them access to their GP records,' says Ingrid Brindle. 'You have to fill in a questionnaire, which has questions that help you to anticipate things that might happen when you're using your records and consider what you would do.'

'You can think through, for example, whether you'd look at test results during the evening or at a weekend, when you know you can't get reassurance or advice from your GP. I think people use their common sense when looking at test results online. If you are expecting particularly difficult news, or you're concerned and you think you might worry, you don't have to look. You can wait until you get support. Patients are not numpties.'

'We don't show all our results online straight away,' says Jim Williams, a health informatics specialist in Birmingham. 'We have some sense checking. So if a test shows it's possible someone might have prostate cancer, for example, or that they're HIV positive, we hold that back and don't post it online until we've got confirmation that the patient has attended an outpatient appointment.'

'For certain test results, such as those that say 'Query cancer', we commonly ask for a two-week delay before the result is added to the PHR,' says Dr Mohammad Al-Ubaydli, Chief Executive of Patients Know Best. 'If it's been more than two weeks and the patient still hasn't been told the result by their doctor, then we believe it's more dangerous to have that information hidden from you, so we release those results after a two-week delay. Patients are saying, 'I'm worried from the day the test is done,' whereas doctors tend to think patients are worried from the day the results come in.'



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# 1: What types of PHRs are available?

## Social care

As far as we can tell, people aren't generally offered access to digital PHRs by social services.

'When people have help at home, there should be a folder in the person's home containing a risk assessment, their care plan and care notes about what carers have done,' says Lisa Sullivan, a barrister in London. 'Care homes tend to use paper records too.'

'A care plan to a social worker is very different to a care plan to a GP,' explains Richard Pantlin. 'For a GP, it's about medicines and appointments. For a social worker, it's about whether someone needs help in the morning to get out of bed, get dressed and prepare breakfast. It's about the care and support people need to live independently, participate in society and have the best possible quality of life.'

'In social care, we're seeing a different kind of starting point with digital services to that seen in the NHS,' continues Richard. 'The local authorities who have moved ahead in this space have been focusing more on transactions than on sharing digital records. So people can do things online like self-referrals and self-assessments, to assess their eligibility to financial assistance with care. We are also starting to see e-market places that enable people to find and buy services that are offered in their local community using their personal budget.'

'It would be great if these online transactions were linked into PHRs along with care plans and other things,' adds Richard. 'Some people might have more than 20 people involved in their care, not even including friends and family. Just having all those contact details in one place in a PHR could offer tremendous benefit.'

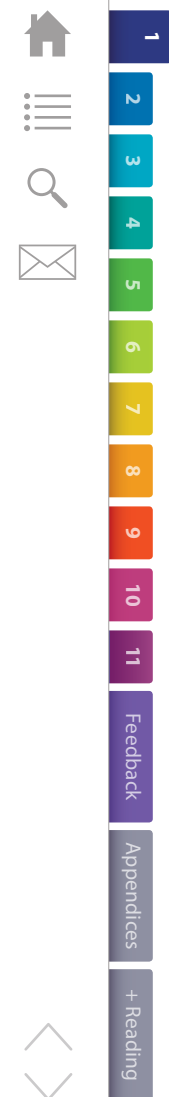
The businesses that provide care in the home or run care homes tend to be very different to the NHS, which is the world's 5th largest employer.<sup>17</sup> Many are small, family-run businesses, which puts them in a very different position to the NHS when it comes to procuring the technology needed for PHRs.

'The health and social care sector in England has a complex patchwork of different IT and technology systems in over 800 care organisations from acute trusts to social care.'<sup>18</sup>

Tech UK 2015

<sup>17</sup> Forbes. The World's Biggest Employers [Infographic] June 2015. [www.forbes.com/sites/niallmccarthy/2015/06/23/the-worlds-biggest-employers-infographic/#a87e80b51d09](http://www.forbes.com/sites/niallmccarthy/2015/06/23/the-worlds-biggest-employers-infographic/#a87e80b51d09)

<sup>18</sup> Tech UK. Personal Digital Care. Using technology enabled care to transform our nation's health and create UK wealth. Nov 2015. [www.techuk.org/insights/reports/item/6224-personal-digital-care-paper](http://www.techuk.org/insights/reports/item/6224-personal-digital-care-paper)



# 1: What types of PHRs are available?

## The consumer world

Of course, the NHS and social care providers aren't the only players when it comes to PHRs.

Major technology companies launched PHRs back in the noughties. Microsoft's HealthVault, for example, is designed to be controlled by patients, with patients generating the content. It also has the functionality to connect with data from NHS and social care providers.

There's a growing 'internet of healthy things', which enables us to track and document our behaviour, fitness, health and wellbeing in ways that have never been possible before. People are buying fitness trackers and other wearables, smart devices (such as pedometers, blood pressure monitors, heart rate monitors, peak flow meters, pulse oximeters, weight scales and blood glucose monitors) and, of course, smart phones.

Sensors in the home are helping people with dementia, for example, by monitoring whether an oven has been left on or bath taps have been left running, and smart home technology is becoming more sophisticated.

People are downloading apps that claim, for example, to help you stay motivated, track your mental health and wellbeing, analyse trends, and provide education and recommendations, to keep you at your best and help you achieve your health and fitness goals.

People are also getting their DNA tested to find out how their genetics might affect their chances of getting certain health problems and how they might respond to certain medicines. This could reveal important information to add to a PHR.

All of these things generate data that could be fed into PHRs and boost their functionality.

'Technology is enabling people to track and monitor things to do with their own health and wellbeing in more detail than ever before,' says Dr John Ainsworth, a professor of health informatics in Manchester.

'Feeding continuous diagnostic data from sensors into your PHR could help both you and your clinician by facilitating shared decision making, for example. However, the apps and

devices that are available at the moment don't all talk to each other, and if you get any, you may well find you can't connect them to your NHS records.'

'Cheap sensors that can monitor our wellness (for example our physical activity and sleep patterns) and our vital signs (such as our blood pressure, temperature, heart rate and respiration rate) are putting basic health measurement in the hands of anyone who's got a device such as a smartphone or a wearable. This could be hugely beneficial, particularly if combined with personal health records and good pattern-recognition software that can interpret the data. Evidence from the US demonstrates this could, for example, enable us to identify people with congestive heart failure who are likely to have a heart attack, so we can give them rescue medication. However, it's proving hard to get this sort of innovation into the NHS.'

**Charles Lowe (an expert in digital health)**



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## 1: What types of PHRs are available?

### Linking apps and devices with NHS records

'There's a growing ecosystem of smart devices and apps that enable patients to gather information on their own health, such as their blood pressure, blood sugar levels and weight,' says Tim East. 'At EMIS Health, we've integrated our GP patient portal, Patient Access, with Apple's HealthKit. This means patients can feed data seamlessly from any device that syncs with HealthKit into Patient Access. It's the patients' own data and they can offer to share it with their GP if they so wish. GPs can then copy this information to their own record if they choose to. So far, over 35,000 patients have sent data to their PHR this way. London is the highest area of take up with 4,814 patients, followed by Manchester with 651 patients and then Liverpool with 582 patients.'

Patients Know Best is another PHR that enables people to upload data from a range of devices. The Royal College of Physicians' [Landscape Review](#) includes information on which PHRs link to monitoring devices.



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## 2: Who might want PHRs?

The number of people who are using PHRs is still low.<sup>19</sup>

The Royal College of Physicians' Landscape Review identified that the most frequent users of PHRs tend to have a condition, illness or injury that requires regular medical treatment; people in poorer health access their records more than those reporting good health; greater deprivation is associated with a reduced probability of continuing to use a PHR after 6 months; and younger people (aged below 35 years) appear to be less likely to use a PHR than those aged 35 and over.

We asked people who they think could benefit from PHRs.

### People with long-term conditions

'It's probably people like me, who have multiple, long-term conditions, and need regular monitoring of their health, who need PHRs the most,' says Michael Seres, a long-term patient and founder of 11Health. 'I absolutely want access to my NHS records. I want to contribute to them and use them to

communicate with the healthcare professionals who support me, so we can work together as a team. What's my incentive? Improved self-management, better awareness? My incentive is to keep myself alive for longer and be part of the conversation, part of every decision. The more informed I am, the better I can manage and the better able I am to make decisions.'

Fifteen million people are living with a long-term condition just in England,<sup>20</sup> and 40% of the Scottish population have at least one long-term condition.<sup>21</sup>

### People who are keen to live a healthy lifestyle, and stay fit and well

People also emphasised the possible role of PHRs in helping people who are well to stay well, particularly if PHRs can be linked to motivational apps, fitness trackers and other smart devices.

'If you think you're well, it's not so easy to see that taking ownership of your health now will help you down the line,' says Michael Seres.

'I think we need a new model of care that puts more focus on prevention and not just treatment. Then you can argue that everyone needs PHRs. But there's got to be an incentive for people to want to do it. So we need more evidence on how PHRs can help and we need to tell people about it.'

'This is not about being patients, it's about being people.'

**Declan Hadley (a digital health lead in Lancashire)**

'It's important to remember, when we're considering who might benefit from PHRs, that the definition of health is not merely the absence of disease. The World Health Organisation defines health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' Healthcare has been focused on disease and the majority of funding streams reflect this.'

**Dr Amir Hannan (a GP in Tameside)**

<sup>19</sup> Royal College of Physicians. Personal health record (PHR) landscape review. Final report. May 2016 [www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-final-report](http://www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-final-report)

<sup>20</sup> The King's Fund. Long-term conditions and multi-morbidity. [www.kingsfund.org.uk/time-to-think-differently/trends/disease-and-disability/long-term-conditions-multi-morbidity](http://www.kingsfund.org.uk/time-to-think-differently/trends/disease-and-disability/long-term-conditions-multi-morbidity)

<sup>21</sup> Scottish Government. Long Term Conditions. [www.gov.scot/Topics/Health/Services/Long-Term-Conditions](http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions)



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## 2: Who might want PHRs?

### Relatives and friends of people who need help

'Proxy access to PHRs is potentially very helpful for carers and relatives of people with multiple long-term conditions, so they can see what's happening and find out how best to help,' says Dr Phil Koczan.

'My husband's got a long-term condition and has been in hospital quite a lot,' says Vicky Gardner, a long-term carer. 'We've found it's really useful for both of us to have access to my husband's hospital records. When my husband's in hospital, I can keep an eye on what's going on. At least then, you're not always trying to track down a doctor.'

'Wherever we are, we can see my husband's blood results and act on them if necessary,' says Vicky. 'If my husband says he's tired, for example, I'll look at his haemoglobin and if that's low, that helps us to understand why he's tired. And changes in your creatinine level can tell you that you need to drink more. The system explains test results to you. This does help. It makes it easier to sort things out for yourself and feel more in control of your own health.'

If you give someone else access to your GP record, you can ask your GP to hide from view (or redact) anything that you don't want your friend or relative to see.

'Proxy access to GP records helps family members, who might otherwise feel unsure or uninformed about how best to provide the support that their relatives may need, be it in just knowing that prescriptions are ready, viewing and understanding test results, or being able to check diagnoses or referrals.'

**Bruce Elliott (long-term patient, carer and NHS Digital employee)**

'Imagine the daughter of a man with dementia, for example, who loves her father and would like to help but can't take time off work to go to all of her father's appointments. Access to her father's PHR allows the daughter to arrange prescriptions, appointments... The daughter will do it. She can give a lot of help.'

**Dr Mohammad Al-Ubaydli**

### People in residential care homes and sheltered accommodation, and people who have care at home

'I believe PHRs could benefit people in residential care homes, sheltered accommodation and retirement villages, and people who need care in their own home,' says Richard Pantlin. 'If care homes had a fuller picture of each resident, and could liaise better with GPs and specialists, drawing on capabilities offered by telecommunication and telemedicine, we may see improvements in things like medicines management and perhaps avoid so many emergency hospital admissions from care homes.'

'People living in sheltered accommodation and retirement villages tend to have no more than a personal alarm at the moment, and perhaps a community hall, with events and the option of eating together. Those sorts of communities could get the technical infrastructure to allow telecare, perhaps in a room that's dedicated to this sort of thing. Devices like smart blood pressure monitors



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## 2: Who might want PHRs?

could feed data directly into PHRs and recordings of telecare consultations could be added in too.'

'There's also a lot of potential to use PHRs to help people to carry on living in their own homes,' continues Richard. 'Again, devices used in the home have traditionally been alarm systems – an alarm that people wear on their wrist or on a necklace so they can call for help in an emergency. Increasingly devices used in the home will enable monitoring of other things, and enable us to do things like send remote reminders to people with dementia. All these things could all link in to PHRs.'

'The effective delivery of telehealth can reduce mortality rates by 45%, A&E visits by 15%, emergency admissions by 20%, elective admissions by 14%, bed days by 14%, and tariff costs by 8%.'<sup>22</sup>

**Department of Trade and Industry, 2015**

### Parents of babies and young children

A PHR that's already being trialled is the eRedbook.

'The eRedbook is the digital version of the Personal Child Health Record, colloquially known as the Red Book,' says SiteKit's Dan Moulin. 'The paper record is given to all new parents to manage their child's health between birth and the age of five. It is updated by parents and health professionals.'

'The eRedbook allows health professionals and parents to enter and share information digitally,' adds Dan. 'Both the eRedbook and the Red Book contain the same data: immunisations, weight/height charts, upcoming appointments, developmental firsts and important contacts. In addition the eRedbook contains practical, personalised information for new parents, including links to relevant videos and information sources from NHS.uk and local information.'

'A perfect place to start with PHRs is with mums. Mums are motivated to care for their children. And most children are digital experts from a very early age, so it's good to involve them too.'

**Declan Hadley**

'I saw a digital service recently that you couldn't help but be bowled over by... the digital Red Book... the little red books that parents get when their baby is born... How wonderful to digitalise that. Keep the Red Book identity, but put those inputs online, on day one, help to make newborns digital pioneers, give their parents information... and use that to drive an arrowhead through the system, a generational cohort of youngsters who've got a fully digital electronic record from birth.'

**George Freeman, speaking at UK e-Health week, May 2016**

<sup>22</sup> Healthcare UK, Department of Health and UK Trade & Investment. The UK. Your partner for healthcare solutions. Jan 2015 [www.gov.uk/government/publications/the-uk-your-partner-for-digital-health-solutions](http://www.gov.uk/government/publications/the-uk-your-partner-for-digital-health-solutions)



### 3: Understanding your PHR

Many people we spoke to emphasised how important it is that people can understand their PHR – that their record has meaning.

The medical world is full of jargon that you won't find in a standard English dictionary – names for diagnostic tests, symptoms, conditions and even parts of the body that aren't part of everyday language. Do you have a 'femur' or a 'thigh bone', for example, 'erythrocytes' or 'red blood cells', a 'prognosis' or an 'outlook for the future'?

'It's all well and good having access to records, but people need to understand what's there, what their records mean,' says Shahid Muhammad, a long-term patient and scientist in Exeter. 'There has to be a knowledge base with it, links to further information, ways to find out more about things that confuse you.'

'If a patient doesn't know what a full blood count means, for example, there should be a way for them to gain that understanding, via links in the record to explanatory information and to forums where people can ask questions,' says Shahid. 'It's important for people to understand properly what their

care is going to entail, how it will be tailored. This gives them more control over how they will cope with everything and manage everything.'

'Our practice-based web portal [www.htmc.co.uk](http://www.htmc.co.uk), developed with patients and staff, has been essential in supporting patients to learn more about what is available and how they can understand their PHR, by signposting to trusted information developed by the practice as well as local, regional, national and international sources of information,' says Dr Amir Hannan 'Patients and carers have found information specific to them locally as being most beneficial and often hardest to find from alternative sources.'

'People need to know what the information in their records really means. They need to understand it and have access to additional support when needed.'

**Declan Hadley**

'When you're accessing a patient portal as a patient, it's you, on your own. We need patients to have all the appropriate support in place.'

**Dr Sarah Jefferies (a consultant clinical oncologist in Cambridge)**

'The combination of PHRs and apps, which provide a personalised way of writing to and reading from records, could start to be very powerful. A doctor's electronic health record, on its own, is a fairly incomprehensible dataset for patients. Understanding it requires a reasonable level of sophistication. Apps however can accept data in a form that suits people and write them to PHRs; likewise they can interpret and combine different data from PHRs for both patient and clinical users to maximise the benefit from the data. This essentially creates a common language between different clinicians, between social care and health, and between professionals and patients. Apps are therefore a way of breaking down barriers.'

**Charles Lowe**



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### 3: Understanding your PHR

#### Linking PHRs to online health information

An obvious way to build understanding is to include ready-made links in PHRs to high-quality, trusted sources of information that are available online. Some PHRs do that already.

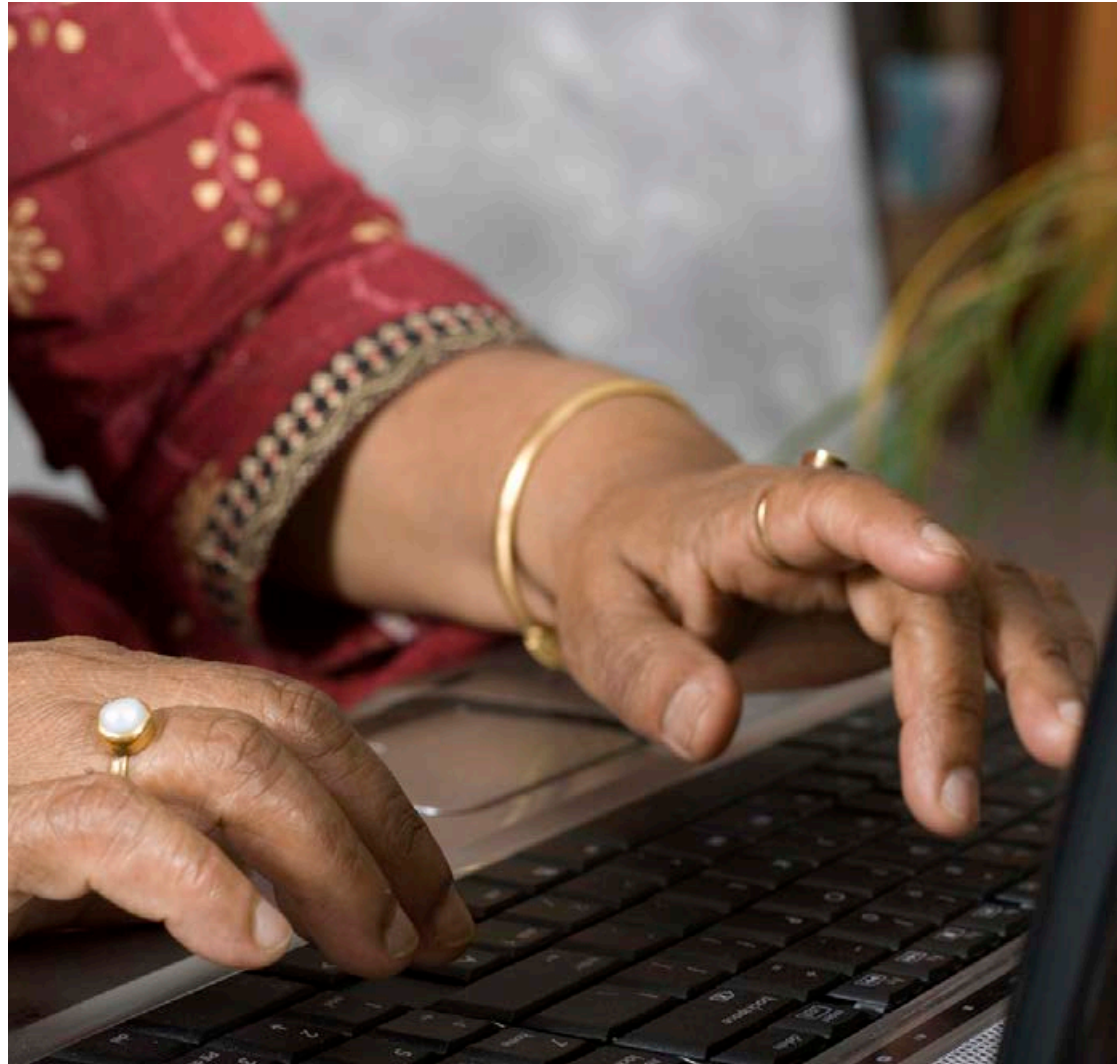
Some PHRs also allow people, and their health and care professionals, to add their own links to information that they find particularly helpful, so they can build their own personal library of useful information.

‘PHRs present an opportunity to reconsider how we integrate into the care pathway more robustly the provision of all of the information that people need to help them get on with life with a long-term condition.’

**Shahid Muhammad**

‘You could signpost to all sorts of useful information from PHRs – information on lifestyle and staying healthy, on health problems and how to cope with them, and on groups that might be able to help, such as peer support groups and charities.’

**Declan Hadley**





## 3: Understanding your PHR

### Laura Smith on a patient portal for people with cancer

#### Laura is a project officer at Cancer Research UK.

'Public Health England's National Cancer Registration and Analysis Service (NCRAS), Brainstrust and Cancer Research UK have been piloting a patient portal for people with cancer.

People can use the portal to see their tumour records, including their test results, summaries of imaging reports, what surgery they've had and when, and their other treatments. We included comprehensive supporting information, including a glossary and helpful links to information on cancer on the Brainstrust and Cancer Research UK websites.

There's space for people to add contact details and their own notes. There's also a quality of life tracking tool – a questionnaire – which people can use to monitor their wellbeing.

86% of patients who provided feedback said they'd recommend the PHR to others. Patients said that having access gave them a feeling of security, that it was good to be able to access and process information in their own time at their own pace, and that it helped them to think of questions to ask their doctors.

Patients liked using the quality of life survey to track their wellbeing over time and the fact that they could take the information along to consultations with their nurse.

Patients thought it would be useful to have information integrated with the records, for example, more information on their type of tumour, the glossary, and targeted resources. They come across lots of technical information so they wanted to be able to look up a term easily.

I think the portal enables patients to feel like they are making informed decisions

about what they want to find out and when. It isn't necessarily a good thing to bombard everyone with comprehensive information all in one go. We need to be providing the right information at the right time and patient portals can help us to do that.'

The pilot of this portal is coming to an end in December 2016. Cancer Research UK is continuing to work with existing portal providers as a way of providing supporting information and resources to cancer patients. They are also working with the NCRAS to develop an open standard application program interface (API) for any trusted PHR to link securely to NCRAS and enable its users to access their NCRAS records.



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## 3: Understanding your PHR

### Making sense of sensors

Sensors in smart devices such as fitness trackers and blood pressure monitors can automatically generate a continuous stream of vast quantities of data, which could all be fed into PHRs. It may well be that the best ways to display this information in a meaningful way, share it and act on it are yet to be determined.

‘We need better tools that enable us to make sense of all of the data streams from apps and devices, and customise how that information is fed back to people and presented so it suits the needs of different people – including patients and clinicians – and so they can make use of it, for example when making decisions,’ says Dr Pete Davies a **consultant** in diabetes and endocrinology in Sandwell. ‘For example, for Fitbit steps, I might be interested in the competitive aspect of how many steps I’ve done compared with my friends. Other people might prefer not to look at any of the data unless there’s an automatic alert that prompts them to do something, with clear instructions on what they need to do.’

‘If my 10,000 steps per day sits in my record, does my doctor care?’ asks Michael Seres. ‘No. But if my steps per day suddenly drop at the same time as my health gets worse, then that might be important. We could create intelligence around data so that the systems themselves can flag up warning signs. What we do with data and what the healthcare professional does is just as important as having access in the first place.’

‘We’re still in the process of working out what elements of information are most valuable. How can we distil down large amounts of data and make it meaningful for different people and different professionals? That’s where the real challenge lies.’

**Richard Pantlin**

### Defining systems and communicating them to patients

As well as being able to understand the content of PHRs, people should also be able to understand what to expect of them.

‘This is about two things,’ says Lisa Sullivan. ‘Firstly, it’s about systems, meaning ways of working. Doctors need to put systems in place and define them clearly, for example, whether patients can see test results before the doctor has reviewed them.’

‘Secondly, it’s about information that’s given to patients about those systems,’ adds Lisa. ‘Patients should be told what the system is, for example, whether or not they can see test results before the doctor.’

‘It’s all about managing the relationship and the expectations of the doctor and patient,’ continues Lisa. ‘The systems should be easy to understand, and patients should be told about them. Everything should be transparent.’



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## 4: Communicating with people who can help you

'The point of e-health is that it should be a tool for engagement, relationships and connectivity, not a substitute for it. Tech that removes the relationship is not good... Tech should create an environment where doctor can talk to patient, doctor can talk to doctor, doctor can talk to administrator, administrator can talk to patient... The challenge isn't in sophisticated tech, it's in the ability to provide and produce communities and relationships that matter, especially for those who need that the most.'

**Lord Victor Adebowale, speaking at UK e-Health Week in May 2016**

Some PHRs contain communication tools, which the people we spoke to value greatly. These tools may enable you to communicate with your health and care team, or with others, such as people who are experiencing the same sorts of things as you.

### Secure messaging

'I think secure messaging is a crucial element of PHRs,' says Dr Pete Davies. 'I'm strongly in favour of giving patients access to their records and at first I was thinking mostly about openness and transparency. But it quickly became clear that people want more than just access. They want to transact. They want to book appointments, order repeat prescriptions, and use secure messaging to communicate with people they trust about their care.'

'The messaging function in our PHR is so powerful... giving people a way of getting, in a timely manner, to the right person who can answer their questions,' says Pete. 'Messaging helps people with small decisions, as well as the obvious big ones, and those nuances can really help. As a doctor who works caring for people with long-term conditions, isn't that what it's all about? Trying to answer somebody's question in a way that they find works best for them?'

'We'd also like the ability to send out group messages so we can send surveys to patients, learn from them and send out targeted information,' adds Pete.

'Email is not the same as secure messaging, where patients log into a secure website and send a message that can only be seen by others who also log in, and who have a legitimate relationship with the patient, and include a full audit trail. Emails are not in the main secure, not encrypted and can be viewed by others. Appropriate explicit consent should be sought before email is sent as there are significant risks associated with email which could cause harm.'

**Dr Amir Hannan**



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## 4: Communicating with people who can help you

### Messaging and workload

'Patients can use our patient portal – myhealth@QEHB – to send secure messages to their clinicians,' says Jim Williams. 'At first, clinicians were worried about an influx of worried well and getting an overwhelming number of communications from people... receiving lots of emails from them. We've actually seen the complete opposite of that. We've got 12,500 users on the system and the volume of communications, such as people calling about results, has gone down quite rapidly, because the information is all there in the record.'

'We've found that using PHRs enables us to build closer and more meaningful relationships between patients and professionals.'

**Dr Pete Davies**

### Michael Seres on relationships and technology

'When I was 16, I saw a new doctor who said something that had a profound effect on me, and it's kind of how I manage my life to this point. My doctor said, 'Michael, this is the deal: I will only treat you if you take as much responsibility for your health as I do. I'm going to teach you about your condition. You're going to teach me what it's like to be in your shoes. And we are going to work together as a team.'

Healthcare is fundamentally just about a relationship – a relationship based around mutual respect, mutual trust, mutual empathy. Healthcare records are about jotting down that relationship.

How do I interact with my healthcare, how do I interact with my patient records now? Via What'sApp and Skype! A few weeks ago, for example, I had to go back to the clinic for a full review. I've had a bowel transplant and my doctor in Oxford wasn't sure whether there was borderline rejection. We needed a second opinion, so we Skyped in doctors in India and the US. We did all this from my hospital bed and together everyone discussed what might happen and what we should do. The Skype call was recorded and it's part and parcel of my record.'



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## 4: Communicating with people who can help you

### Opportunities for teleconsultations

'My appointments with my specialist consultants are 4-6 months apart,' says Shahid Muhammad. 'The only real reason for me to go to a clinic is to do the bloods. But I don't need to travel all the way to my specialist to do the bloods. The nurse at my GP surgery can take them.'

'Some people like to see their consultant face-to-face, but others might choose not to if they could use alternative forms of communication such as Skype and cut down travel time, time out of work, time out of busy daily lives. With Skype, WhatsApp, if texting or talking with a camera or using instant messaging, all of that information could be recorded and uploaded onto your PHR. Having the recording, or a transcript, ready and waiting in your PHR could help improve understanding.'

### Forums and peer support

'We wanted to include a support network in myhealth@QEHB,' says Jim Williams. 'You can use your PHR to find people with the same condition as you and create your own support networks of fellow patients who give you help, advice or friendship. Patients can converse with each other, start journals about their health, publish information to their support network, view other patients' news feeds and more.'



'Lots of patients would love to connect with other people like them. You only need to look at the success of Patients Like Me. Wouldn't it be great if we could connect people via PHRs so they can learn from each other and share experiences of managing their own condition? Patients are very much an untapped resource.'

**Dr Pete Davies**



## 4: Communicating with people who can help you

### Eliminating mistakes in records

'There's a concern that people will look for mistakes in records and shout,' says Ingrid Brindle. 'That hasn't happened in our experience. And it's best to find mistakes. People aren't going to jump all over their doctor just because they've found a mistake. We've found that people are just glad to have the chance to say they've found a mistake and to know it's going to be dealt with. We have had the right in law to see any of our personal medical information since the 1990s so the only change is the method of access.'

'On one occasion, the speech and voice recognition system I use had made a mistake, so there was a mistake in the record,' says Dr Pete Davies. 'The patient spotted this, pointed it out, and I corrected it. That's really powerful. That's how we get into co-production.'

'Doctors should make changes if a patient points out a mistake,' says Lisa Sullivan. 'If the doctor disagrees with what the patient is saying, for example if the doctor's recollection of what was said during a consultation is different to the patient's, then the doctor should note that disagreement in the record. The ability to spot and correct mistakes is a good thing for all. It could mean patient treatment is changed so as to avoid harm. With patients who are regularly reviewing their notes, it could mean fewer disputes arise over what happened in a consultation, meaning that fewer claims are brought and doctors are found negligent less often.'



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## 5: A more complete picture of you

Lots of the people we talked to suggested that the ideal PHR would provide an opportunity for you to gather together in one place a comprehensive set of information on your own health, needs and preferences, and that this may lead to greater continuity of care. Key things here include the option to add information yourself and the ability to join up all of the records that different health and care professionals create about you.



'When you go to see a new doctor in hospital, you typically have to give them all the information about you all over again. You have to do that each time you're referred to a new place to see a new doctor. Things are starting to change, but traditionally we haven't actively shared information about you across the healthcare system. Most supermarkets know more about you than your doctors do!'

**Declan Hadley**

'The more times you have to tell your story, the less you feel like a human being.'

**Lord Victor Adebawale, speaking at UK e-Health week, May 2016**

### Patients contributing information

Some PHRs allow patients, and their apps and devices, to contribute information.

'I want to have a way to give healthcare professionals access to my information in a way that lets them know about me properly,' says Shahid Muhammad. 'I've had renal problems for a long time, and I worry about work and other things in life. I want all that information to be somewhere where professionals can see it, so they can know that this is my whole life - my concerns, my difficulties, my ambitions and goals. Then we can weigh up all aspects of what to improve, not just the clinical.'

'Patients and carers want to talk to somebody who knows them as a person within a family and a community,' says Dr Amir Hannan. 'The social determinants of health are much more important in understanding what outcomes people get than simply looking at a test result or a disease category. The record rarely contains this information but over time a clinician working with the patient builds up this knowledge. Continuity of care and



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## 5: A more complete picture of you

enhancing the relationship between patient, carer and clinician is fundamental, and not just access to the PHR. We are more than our data.'

'With more and more gadgets becoming available, you'll be collecting most of the data for your PHR yourself, says Declan Hadley. 'There are devices, things you wear and things in the house that monitor your health and wellbeing. This is becoming more about the consumer. It will be more about stuff you can buy in PC World and Boots, and it might mean you might know more about your condition and how it is effecting you than your doctor.'

### Dr Pete Davies on sharing information using apps

'We've started recommending a glucose tracking tool called 'Diasend', which a few patients are trying out.

It allows people to upload information from glucose meters, insulin pumps, continuous glucose monitors and mobile apps. It puts all that information into the cloud and onto your phone in an app and allows patients to share their information with their doctor.

Before using Diasend, we had to wait for patients to attend their appointment, then ask for their device and download information from it in the consulting room. Now we can access that information before we see patients. That helps with the consultation. It's a more meaningful way to use information than spending our valuable time together getting the info off a device.'

## Joining up records - eliminating silos

It's not possible yet for most people to access PHRs that bring together into one place all of the records that different health and care professionals create about them, but this is an important goal that could benefit patients and professionals alike.

'Access to GP records is very much a starting point in the NHS and social care, providing access to records from a single care setting,' says Dr Phil Koczan. 'But this is only the starting point. People are also looking at patients accessing a wider set of data that's brought together from multiple care settings.'

'Across the UK, there are several large-scale record-sharing programmes, for example in Leeds, Bristol, Hampshire and North West London, although they don't all feature patient access yet and the extent to which they integrate information from health and social care varies,' says Declan Hadley.

'The Care Information Exchange in North West London shows the scale and scope of what you can achieve,' says Patients Know Best's Dr Lloyd Humphreys. 'It aims to give a population



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## 5: A more complete picture of you

of 2.3 million people access to PHRs that bring together information from CCGs, social care, trusts that provide acute care, mental health services, community services, and others.'

'Having all your records in different silos, for example with your GP and different hospitals, makes it very difficult to manage as a patient. You don't want to have lots of different logins for a range of different systems. People need to have all of their information in one place.'

**Laura Smith**

'When somebody arrives at hospital after being referred by a GP, they want the hospital to know who they are, why they are there, what the referral was for and what the treatment is.'<sup>23</sup>

**George Freeman, House of Commons, April 2016**

### Connected communities

PHRs could also be a key part of a future where communities are far more digitally connected.

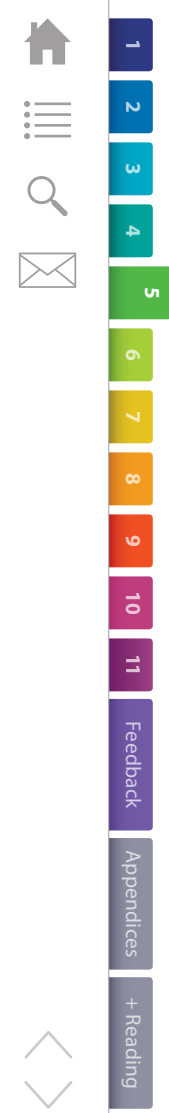
'In the future, we may bring together different sectors via PHRs,' says Dr Pete Davies. 'At the moment, each sector is at a different level of development, but we may one day have connected communities, with a form of information exchange between, for example, GPs, hospitals, ambulance services, pharmacies, social care... This could do an awful lot of good.'

'There are loads of things that health professionals can't give, because they don't have enough time, and that's unlikely to change,' says Shahid Muhammad. 'We need to find ways to reduce the pressures on front-line NHS staff. There is a growing need to work in partnership across communities to increase awareness of local services. PHRs and social media can play an important role in this.'

'Rally Round Me' gives you some idea of the possible benefits of connecting people using digital tools. It's about creating a community around you, so people can, for example, cut the grass for you if you're in hospital. You as a citizen can share bits of your data to help coordinate people to help you.'

**Declan Hadley**

<sup>23</sup> Commons Select Committee. Debate on the use of digital patient records in the NHS. 21 April 2016 [www.parliament.uk/business/committees/committees-a-z/commons-select/backbench-business-committee/news-parliament-2015/debate-on-the-use-of-digital-patient-records-in-the-nhs](http://www.parliament.uk/business/committees/committees-a-z/commons-select/backbench-business-committee/news-parliament-2015/debate-on-the-use-of-digital-patient-records-in-the-nhs)



## 5: A more complete picture of you

### Dr Mohammad Al-Ubaydli on the approach of Patients Know Best

'Patient portals add a viewing layer to an institution's own electronic record system, which lets the patient see what's going on. This locks the patient to that institution, rather than locking the institution to the patient, and replicates institution-based fragmentation. It's an approach that does not scale.'

'What we're seeing now is that governments all over the world want data to be integrated – they want an integrated digital health and care record for each patient, because apart from the patient, the party that pays the biggest price for fragmented care is the government. But all too often, everyone is allowed access to that integrated care record except the patient. Access for patients is an afterthought.'

'At Patients Know Best, we suggest the PHR should be centred on the patient, and that health or care professionals should all give

copies of the information they create to the patient to hold in one place. Not only is that the right thing to do morally, but it's scalable if we enable full data portability across every institution's medical records system. Each patient ends up with a single digital record across all of health and social care.'

'We divide the record into general health, for the majority of the information, but also sexual health, mental health and social care. That granularity reduces the problems surrounding what patients do and don't want to share, because it's patients' consent that drives the sharing of the information, so patients and professionals can work together.'

The Patients Know Best PHR is an example of an '**untethered PHR**', which is controlled by the individual rather than an institution. Typically, untethered PHRs are 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. This requires the patient and the healthcare institutions' permission and relevant interoperability protocols to be in place.



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## 6: Privacy, security and consent to share

Unsurprisingly, issues surrounding privacy, security and patients' ability to control who can see and use information in PHRs are top of everyone's minds.

'Having a PHR raises issues about what is shared, how, with whom and why,' says Dr Amir Hannan. 'As a clinician, we cannot do anything to a patient without getting explicit consent (except in a few very rare cases). This requires us to explain what we are doing and why, and the pros and cons of different options in a meaningful way. We have to engage patients and carers in a conversation and decide together what we will do. This is true if I am about to examine a patient, do a blood test, or refer patients to a hospital, where consent is gained before personal information is shared.'

Why should access to your personal record be any different? Simply asking a patient if a clinician can see their record, when the patient or carer has not seen it themselves, is no longer appropriate, may not be safe and is not a great experience. Patients (and with

appropriate consent carers) should be able to see what is recorded about them, check for accuracy, ensure nothing is missing or mistakenly added and when they last viewed their record. They should then be in a position to consent for others to see information pertaining to them. This builds confidence and trust. It safeguards privacy, helps to maintain security and enables appropriate sharing of records.'

'Getting consent to share records from the patient – and giving patients control over who's seeing their records and which bits each person sees – is absolutely critical. Identity management is another big issue, as is security.'

**Dr Phil Koczan**

### Existing and proposed safeguards

Healthcare professionals have an ethical and legal duty to safeguard the confidentiality of information they hold about their patients and must seek patients' consent before sharing their data (with some exceptions). Laws and regulations that already safeguard health records include the Data Protection Act, the Human Rights Act, the NHS Constitution and the NHS Care Records Guarantee (see Appendix 3).

Dame Fiona Caldicott, the National Data Guardian for health and social care, has made proposals<sup>24</sup>, which were put out for public consultation in July 2016, on:

- ▶ new data security standards
- ▶ a method of testing compliance with the new standards
- ▶ a new consent/opt-out model for data sharing in health and social care, to enable patients to make an informed decision about how their data will be shared.

<sup>24</sup> Department of Health. George Freeman MP. Written statement to Parliament. Review of health and care data security and consent. July 2016. [www.gov.uk/government/speeches/review-of-health-and-care-data-security-and-consent](http://www.gov.uk/government/speeches/review-of-health-and-care-data-security-and-consent)



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## 6: Privacy, security and consent to share

'We have to keep the security of PHRs as tight as possible to prevent unauthorised intruders from gaining access and to defend against cyberattacks. Many people care more about the security of their health records than almost anything else, including their bank details. We use ethical hackers to test our security and this is monitored on a 24-hour basis by these hackers.'

**Jim Williams**

### Data as a commodity

It's important to be aware of privacy and security issues when using apps and devices available commercially too.

'A wide range of apps and devices enable people to collect health data,' says Dr John Ainsworth. 'Some of the organisations that provide these products see data collection as part of their business model. They see data in the same way as Facebook. There's no requirement to make policy on data handling highly visible in the terms and conditions. It could be buried somewhere in all the small print.'

In the US, a Model Privacy Notice for PHRs - a voluntary, openly available resource - has been designed to help developers clearly convey information about their privacy and security policies to users of their products.<sup>25</sup> The Model Privacy Notice, which is currently being updated, is designed to encourage transparency and help consumers make informed choices.

'Information governance' is the term used to refer to the processes used to ensure personal information is collected, managed, transmitted and used in a secure and confidential way.<sup>26</sup>

The National Data Guardian defines information governance as 'how organisations manage the way information and data are handled within the health and social care system in England. It covers the collection, use, access and decommissioning as well as requirements and standards organisations and their suppliers need to achieve to fulfil the obligations that information is handled legally, securely, efficiently, effectively and in a manner which maintains public trust.'<sup>27</sup>

'Data is the new oil.'

**Lord Victor Adebawale, UK e-Health week, May 2016**

<sup>25</sup> HealthIT.gov Model Privacy Notice (MPN) [www.healthit.gov/policy-researchers-implementers/model-privacy-notice-mpn](http://www.healthit.gov/policy-researchers-implementers/model-privacy-notice-mpn)

<sup>26</sup> Royal Pharmaceutical Society. Electronic Health Records: Guidance for Community Pharmacists and Pharmacy Technicians March 2016 [www.rpharms.com/pressreleases/pr\\_show.asp?id=3952](http://www.rpharms.com/pressreleases/pr_show.asp?id=3952)

<sup>27</sup> National Data Guardian. Information: To Share or Not to Share? The Information Governance Review [www.gov.uk/government/publications/the-information-governance-review](http://www.gov.uk/government/publications/the-information-governance-review)



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## 7: Doing more for ourselves

'Health is what people do. Not what they say. Not what they see. Not what they hear. Not what others are doing. Not what is discussed in conferences or written in papers or policy documents or strategies. It is what people do which counts. When this is community led and supported by healthcare, it becomes vibrant and sustainable.'

**Dr Amir Hannan**

'80% of health is what you and your friends, relatives, relationships achieve together at home, work, away from home and in your life. It is not available in a bottle from the GP or hospital. We don't have a National Health Service so much as a National Disease and Death Management Service. Citizens are the biggest creators of health and ill health and need assistance, tools, training and encouragement to do better!'

**Dr Richard Fitton (a retired GP)**

Many of the people we spoke to said they thought PHRs could help people to look after their own health and wellbeing – that PHRs may help promote self-management, or self-care, and relieve growing pressures on NHS and social care services.

'Let's think about something simple, like recording weight,' says Dr Mohammad Al-Ubaydli. 'If you have to send a nurse round to someone's home to do that, a single visit might be more expensive to the system than providing someone with a digital scale so they can do it themselves and feed the data into their PHR.'

'There's a lot of compelling evidence that patients who are active participants in their own health and care have better outcomes,' adds Shahid Muhammad.

'The average person with diabetes spends 6 hours a year face-to-face with a health professional. It is the decisions that they make in the other 8,754 hours that will determine the quality and length of their lives. Only by helping them to make good choices, and by supporting them in making those decisions, can we really improve their outcomes.'<sup>28</sup>

**Self Care Forum**

'With 60 to 70 per cent of premature deaths caused by detrimental health behaviours, it is vital that people engage more with improving their own health... What people do in their everyday lives - what they eat, how much they exercise and how far they follow medical advice - largely determines their health and their need for health care.'

**The King's Fund, 2014<sup>29</sup>**

<sup>28</sup> How to Implement a Self Care Aware Approach to Demand Management. A Guide from the Self Care Forum [www.selfcareforum.org/getting-started/how-to-guide](http://www.selfcareforum.org/getting-started/how-to-guide)

<sup>29</sup> The King's Fund. Supporting people to manage their health. An introduction to patient activation. May 2014 [www.kingsfund.org.uk/publications/supporting-people-manage-their-health](http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health)



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## 7: Doing more for ourselves

Perhaps PHRs can help us to build the knowledge, skills, motivation and confidence we need to look after ourselves better? Perhaps they could make it easier for us to do some of the things that professionals have traditionally done, thereby relieving some of the pressures on health and care professionals?

Perhaps they could also prompt and support us to live as healthily as we can, analysing data in the record to work out what actually helps us to get into good habits, or make it easier for us to volunteer to take part in medical research?

This may be more speculative than evidence-based thinking at the moment, but here we describe two approaches that people told us about that have already proved successful.

### Example 1: Uploading home videos to PHRs is improving diagnosis of epilepsy

‘Doctors in Peterborough invited parents to take videos of their children at home during seizures and upload the video to their PHR,’ says Dr Mohammad Al-Ubaydli. ‘The clinical team discovered that the quality of the information they see in those videos is higher than what they see if children go into hospital for two days for monitoring. This made it easier for doctors to tell whether or not the children had epilepsy and, if they did, it improved the doctor’s ability to treat the children’s epilepsy. It saved bed days, and meant parents and children didn’t have to go to hospital, so improving patient experience.’

### Example 2: Helping people with inflammatory bowel disease to direct their own care

‘Experience at Luton and Dunstable Hospital shows PHRs can help people with stable inflammatory bowel disease to manage their condition from the comfort of their own home,’ says Dr Lloyd Humphreys. ‘This approach is expected to reduce the number of outpatient appointments. Patients take responsibility for some routine monitoring, for example of their blood pressure and their weight, and assess their own symptoms, feeding all the information into their Personal Health Record. They receive tailored advice sheets, which help them with self-management and help them to decide when they need to go to hospital and what they could do to avoid another visit. The system also notifies nurses if patients are scoring low. It saves patients from having to come into hospital for routine check-ups and means that, if symptoms flare up, patients can be seen within 48 hours.’



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## 7: Doing more for ourselves

### Prompting positive changes in our lifestyles

A key question is whether PHRs could help us to change our behaviour in ways that improve our health or stop us becoming ill in the first place. Unhealthy lifestyles are a major cause of non-communicable, chronic diseases (such as cardiovascular disease, cancer, respiratory diseases and diabetes), which kill 38 million people around the world each year.<sup>30</sup>

The findings of a recent review, although not specifically into PHRs, show promise.<sup>31</sup> The review concluded that people are more likely to adopt heart-healthy behaviours when guided and encouraged via the internet, their mobile phones or other devices, including personal sensors.

People can become more physically active, eat better, lose a little weight and reduce tobacco and alcohol use.

Programs that feature goal-setting, self-monitoring and multiple modes of communication with tailored messages tend to be more effective, as are programs that include some interactions with healthcare providers.

The researchers reviewed 224 studies, involving generally healthy adults, published between 1990 and 2013. Most of the studies lasted less than six months, so it's unclear whether people carry on living more healthily over the longer term.

'Telehealth and other self-monitoring solutions are also providing a means to identify patients whose condition is deteriorating and where early intervention could mean that a hospital admission is avoided. For example, the US Department of Veterans Affairs' telehealth programme has reduced resource utilisation as a result of its proactive approach to condition monitoring at home, ranging from 20% to over 55% for some chronic conditions.'

**Nuffield Trust 2016<sup>32</sup>**

'Personal Health Records, if appropriately accessible by apps, could help make self-care work. You've got to give people micro-goals. If your doctor tells you you've got to lose 30% of your body weight, you may well just give up. If you set up a programme, with a weight-loss goal per week, and say 'Let's see how you get on,' then people can respond. You can eat a bit less and you can reduce your weight and it all works. The best way to do that is to have a personal health and care record at the centre.'

**Charles Lowe**

<sup>30</sup> World Health Organization. Media Centre. Noncommunicable diseases. Fact sheet. Jan 2016.

[www.who.int/mediacentre/factsheets/fs355/en](http://www.who.int/mediacentre/factsheets/fs355/en)

<sup>31</sup> American Heart Association. Internet and mobile devices prompt positive lifestyle changes. Aug 2016.

[newsroom.heart.org/news/internet-and-mobile-devices-prompt-positive-lifestyle-changes](http://newsroom.heart.org/news/internet-and-mobile-devices-prompt-positive-lifestyle-changes)

Afshin A et al. Information Technology and Lifestyle: A Systematic Evaluation of Internet and Mobile Interventions for Improving Diet, Physical Activity, Obesity, Tobacco, and Alcohol Use. Journal of the American Heart Association 2016; 5: e003058. [jaha.ahajournals.org/content/5/9/e003058.full](http://jaha.ahajournals.org/content/5/9/e003058.full)

<sup>32</sup> The Nuffield Trust. Delivering the benefits of digital health care. Feb 2016.

[www.nuffieldtrust.org.uk/publications/delivering-benefits-digital-health-care](http://www.nuffieldtrust.org.uk/publications/delivering-benefits-digital-health-care)



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## 7: Doing more for ourselves

### How doctors respond to patient-generated data

If levels of self-care and self-management do grow, and we play a greater role in monitoring our own health using tools such as apps that prompt us to record our own symptoms, and devices that monitor our vital signs and physical activity levels, then it's important to consider how this patient-generated information should be communicated to health and care professionals and how they should respond to it.

'If patients are monitoring their own health remotely and feeding in data into their records in real time from devices, that raises important questions about how we handle that information,' says Dr Phil Koczan. 'If a patient is checking their blood pressure, for example, they might have a spike in their blood pressure in the night. If that goes into their record, who is responsible for checking that and responding to it? Does this mean GPs will have to be monitoring that data? We could have intelligent systems that generate automatic alerts when something is wrong.

Then what do you do with those alerts? If GPs are getting lots of information like that on top of their existing workload, they're going to need people to help. We need to have discussions about these things.'

'There should be guidelines – perhaps from professional bodies such as the Royal Colleges – on how to deal with information from apps and devices. The guidelines should define which data doctors need to look at, when they should look at it, what they should do about it etc. Perhaps we could have clever systems that alert doctors when there's something they need to look at?'

**Lisa Sullivan**



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## 8: Ease of use

People we spoke to emphasised how PHRs will need to be easy to set up and easy to use if they are to be used widely and regularly.

*'Ease of use makes the difference between successful and unsuccessful products.'*

**Peter Cambouropoulos (an ICT programme manager in Hampshire)**

*'You've got five to 10 seconds... if your app doesn't work within five to 10 seconds, people lose interest. People want things to work straightaway.'*

**Tim East**

### The importance of co-design

People recommended consulting the views of users at all stages in the lifecycle of a PHR.

'We got 12 or 13 patients to come in from a very early stage in the design process for myhealth@QEHB to look at things with us and we've involved patients all the way along,' says Jim Williams. 'Patients help us to work out whether something is a good idea or a bad idea. We send out surveys too. People have come back, for example, and said, 'We don't use that section, we don't find it adds any value,' and so one or two sections we've turned off.'

*'IT systems must be designed with the input of end users, employing basic principles of user-centered design. Poorly designed and implemented systems can create opportunities for errors, and can result in frustrated healthcare professionals and patients.'*

**Making IT Work: Harnessing Information Technology to Improve Care in England<sup>33</sup>**

<sup>33</sup> Department of Health. Making IT Work: Harnessing Information Technology to Improve Care in England. Sept 2016  
[www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs](http://www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs)



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## 8: Ease of use

### Pick and mix software

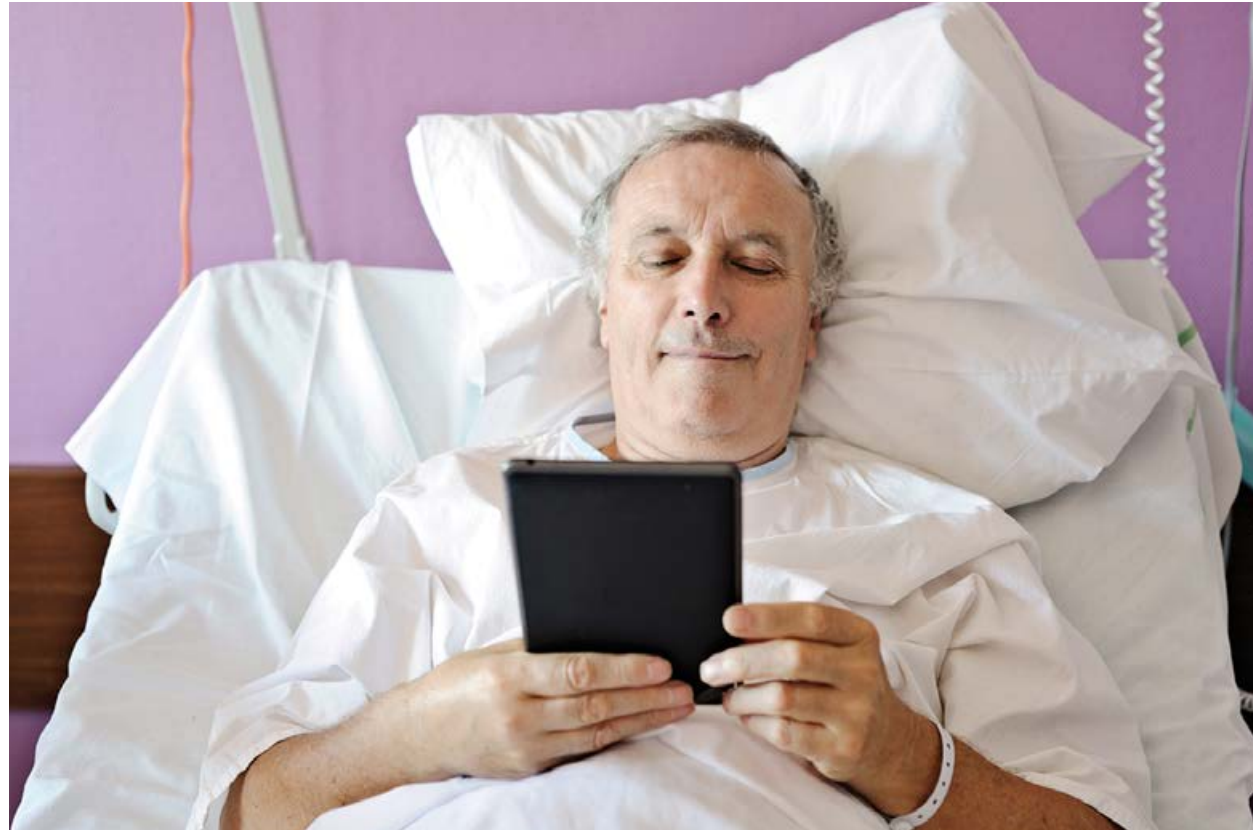
Some people suggested we should work towards a situation where people can use the software of their own choice to access their PHR.

'I feel strongly that we need lots of choice for patients,' says Declan Hadley. 'We need to consider how people want to interact with their data. We need to create a framework that means you can access your data where you want, when you want and how you want, using the device and app of your choice. We need to create a system like BACS... you can go to any bank, any cash machine, and get your money.'

'I think that the infrastructure needs to be open,' says Adrian Byrne, a director of health informatics in Southampton. 'We could separate the platform from the integrated digital care record so that patients can use a selection of their own apps and devices to log into their record.'

'People shouldn't be pressured to use a particular product. Just like some people choose to drive a Fiat or a Ford. What matters is what's best for each individual. Interoperability is important so people can use what they like the most.'

**Dr Pete Davies**



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## 8: Ease of use

### Helping people to get to grips with the tech

People also emphasised the importance of offering support to people who are using PHRs, for example via online tutorials, telephone helplines and, if needed, face-to-face help.

‘We’ve found fewer people need help using their PHR than you expect,’ says Dr Mohammad Al-Ubaydli. ‘But then when people do need help, they can need more help than you would expect. For people who do struggle, you can bring in a patient’s support network. People’s relatives, carers... they want to help, but of course you need a consent infrastructure to let a relative help.’

‘[Principle no 8:] ‘Going Live With a Health IT System is the Beginning, Not the End.’ The ‘Go Live’ period in a large hospital or trust is always difficult, but is nonetheless just the start. Health IT systems need to evolve and mature, and the workforce and leadership must be appropriate for this task. While patient safety is non-negotiable, regulators and commissioners need to have a degree of tolerance for short-term slow downs and unanticipated consequences in the period following EHR implementation.’

**Making IT Work: Harnessing Information Technology to Improve Care in England<sup>34</sup>**

<sup>34</sup> Department of Health. Making IT Work: Harnessing Information Technology to Improve Care in England. Sept 2016  
[www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs](http://www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs)



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## 8: Ease of use

### Accessibility

As with any digital technology, some people may be unable, or find it more difficult, to access PHRs. For example, around 12 million adults in the UK don't have basic internet skills and 14% of households lack internet access.<sup>35</sup> 25% of disabled adults have never used the internet, compared to 10.2% of all adults. Less than a third of women over 75 were recent internet users.<sup>36</sup>

*'While three quarters of UK adults now own a smartphone, those most likely to gain from health interventions - low income earners and older people - are least likely to own a device.'*<sup>37</sup>

**Reform, 2016**

'The accessibility of PHRs is a concern,' says Professor Jeremy Wyatt, a professor of digital healthcare in Southampton. 'The Royal College of Physicians is addressing this in new work around user journeys. We're using a wide definition of accessibility, taking into account physical things like eyesight and dexterity, and memory, cognitive and motivational problems. The definition of accessibility needs to be explored and potentially widened.'

In December 2015, Martha Lane Fox, the former UK Digital Champion, recommended four key ways to increase digital inclusion in health and social care, including making sure those with the most health and social care needs, who are often the least likely to be online, are included first in any new digital tools being used across the NHS.<sup>38</sup>

<sup>35</sup> Ipsos MORI. Basic Digital Skills. UK Report 2015. [s3-eu-west-1.amazonaws.com/digitalbirmingham/resources/Basic-Digital-Skills\\_UK-Report-2015\\_131015\\_FINAL.pdf](https://s3-eu-west-1.amazonaws.com/digitalbirmingham/resources/Basic-Digital-Skills_UK-Report-2015_131015_FINAL.pdf)

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[www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2015-08-06](http://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2015-08-06)  
NHS England. News.

Ofcom. The communications market report, Aug 2016, [stakeholders.ofcom.org.uk/binaries/research/cmr/cmr16/uk/CMR\\_UK\\_2016.pdf](https://stakeholders.ofcom.org.uk/binaries/research/cmr/cmr16/uk/CMR_UK_2016.pdf)

<sup>36</sup> Office for National Statistics, Internet Users in the UK 2016, [www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016](http://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016)

<sup>37</sup> Reform. The future of public services: digital patients [www.reform.uk/publication/the-future-of-public-services-digital-patients](http://www.reform.uk/publication/the-future-of-public-services-digital-patients)

<sup>38</sup> NHS England. News. Martha Lane Fox sets out key digital proposals for the NHS. Dec 2015. [www.england.nhs.uk/2015/12/martha-lane-fox](http://www.england.nhs.uk/2015/12/martha-lane-fox)



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### The Accessible Information Standard (AIS)

The AIS aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they **can easily read or understand**, so they can communicate effectively with health and social care services. By law, all organisations that provide NHS care or adult social care must follow the AIS.



The AIS includes some specific requirements around Personal Health Records, including:

- ▶ The individual patient, service user, carer or parent should be aware of the exact information recorded about their information and communication support needs, including to verify accuracy.
- ▶ Where online systems enable patients or service users to access their own records, and subject to Data Protection Act 1998 safeguards, such systems: must enable an individual to review the data recorded about their communication and information needs and request changes if necessary; and, where necessary functionality exists, should enable an individual to record their own communication and information needs using this system where appropriate.

These requirements are explained in the AIS [Specification](#), which details what providers of NHS care and/or adult social care must do in order to comply with the Standard.

Further information on the AIS is available in the [Implementation Guidance, Summer 2016 Update](#) and [two free e-learning modules](#).

The AIS doesn't specifically include website accessibility, unless a health or care professional has referred a patient or service user to a website for information. 5.6.4 'explanatory note about health and social care websites' in the [Specification](#) and [Implementation Guidance](#), Appendix E, explains how and why this is relevant.



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## 8: Ease of use

### Using digital technology to break down barriers

Many of the people we spoke to were enthusiastic about the opportunities digital technologies provide to increase the accessibility of health records and health information.

*'The digital revolution provides all sorts of opportunities. There are lots of things you can do with digital that you can't do with paper to improve accessibility. There are screen readers, for example, for people with no vision.'*

**Declan Hadley**

*'If you don't speak English as a first language, viewing your records gives you more time to build your understanding of what's been said during consultations and you can seek help from friends and family who do speak English.'*

**Ingrid Brindle**

'We develop software that improves the accessibility of online information,' says Texthelp's Kevin Cross. 'I genuinely believe our software changes lives. Low income earners, older people, those with low literacy, or English language challenges are often the biggest users of health services, but the most likely to be excluded online. A person with dyslexia, for example, might be happy to ask for help when using a travel site to book a holiday. But they may be less keen to ask for help when accessing personal health information, because health is a very private matter. It's very important for them to have that accessibility to their health information.'

'Our software sits on websites, such as NHS England's website, and it turns text into speech,' adds Kevin. 'It reads text out loud. There's also a text magnifier, which helps the visually impaired. The software will translate into 99 languages. There's a screen mask and a simplifier, which block on-screen clutter and remove distracting content for easier reading for people with cognitive disorders. There's also an MP3 file creator, which generates an MP3 file so you can listen offline at your own pace and your own leisure.'

'Technology is really a bridge, not a barrier,' says Dr Mohammad Al-Ubaydli. 'Personal Health Records help people to overcome physical and cognitive disabilities. If a patient doesn't understand something, let them go home and see it on their PHR with someone who can help. If you use a wheelchair and it's not necessarily that easy to travel to see your doctor, or you have cystic fibrosis and you can't sit in a waiting room with other patients because of infection risks, you could have a video consultation instead using your PHR. Screen readers don't work with paper, but you can use them to read your PHR. Patients Know Best works in 19 different languages. Where are you going to get things on paper in 19 different languages?'



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### Lorenzo Gordon on a PHR for people with learning disabilities

'Part of the problem we're involved in solving is allowing better communication between everyone involved in an individual's care via My Health Guide, including the individuals themselves. We've taken a different approach, putting the person at the heart of their information, and giving them, not the health or care professional, control.'

'Paper records do not transition well between different social care and health providers. That's why something like My Health Guide works, because the person carries it around with them on their tablet. Wherever they are, the information is.'

'My Health Guide speaks text to people, and lets them record voice messages (that can also be converted into text) to help with

literacy problems. It also handles video and audio, all of which can be shared with authenticated remote users in a web browser.'

'Our experience has been that this approach empowers a vulnerable demographic (people with learning disabilities) and enables them to better engage with their healthcare. Initial reports from our trial data suggest a decrease in the number of engagement episodes when people use My Health Guide compared to 6 months prior.'

However, the reality for many people living with a disability or accessibility challenges is that there remain significant barriers to using digital tools to manage and communicate about their health.

'Digital by default' but not yet 'Accessible by design' – digital healthcare still has some way to go,' says Dr Howard Leicester, a DeafBlind professional in health informatics. 'Records are still largely organised for clinicians; content remains full of jargon; while navigation, for those like me, depends on mostly expensive and difficult 'assistive technologies' like screen-readers.'

'A PhD became possible for me 20 years ago. Reports and data were available in electronic form, for the first time, because the Department of Health went online. A thesis in .doc format was the automatic consequence of loading properly labelled webpages into Microsoft Word.'

'Although engaging with digital healthcare is, for me, still a case of 'improvisation', I remain positive for the future. As this report proves, there's much going on to be positive about.'



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## 8: Ease of use

Doctors and nurses using speech and gesture controlled systems will realise these are the same 'Assistive Technologies' used by some with 'special needs'.

'Above all, digital healthcare will become an accessibility exemplar. Nearly everyone is using mobiles and tablets, making accessibility considerations the 'default' position. We all depend on health to do other things in life, making 'accessible' the design approach across all sectors, and with health as the necessary foundation.'



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## 9: Evidence of impact

PHRs are essentially tools. They are tools that provide enormous opportunities to change the way we approach our health and care. How well we can seize those opportunities is, to a large degree, yet to be revealed.

One thing that concerns some people is a scarcity of evidence on the impact of PHRs in the UK. In its recent Landscape Review, The Royal College of Physicians (RCP) has concluded that 'evidence in the UK is based on small studies that obtained views on how patients feel about PHRs, rather than on well-designed quantitative studies that objectively assessed their impact on health processes or outcomes'. The RCP also highlighted a 'lack of a viable business case'.

The CEO of the American Medical Association, James Madara, has gone as far as likening some digital health products to 'digital snake oil', while saying others are 'potentially magnificent'.<sup>39</sup>

'Digitising effectively is not simply about the technology, it is mostly about the people... Return on investment from digitisation is not just financial... short-term return on investment is more likely to come in the form of improvements in safety and quality than in raw financial terms. Cost savings may take 10 years or more to emerge (the so-called 'productivity paradox' of IT), since the keys to these gains are improvements in the technology, reconfiguration of the workforce, local adaptation to digital technologies, and a re-imagining of the work.'

**Making IT Work: Harnessing Information Technology to Improve Care in England**<sup>40</sup>

<sup>39</sup> James L Madara. Digital Dystopia. June 2016.

[www.ama-assn.org/ama/pub/news/speeches/2016-06-11-madara-annual-address.page](http://www.ama-assn.org/ama/pub/news/speeches/2016-06-11-madara-annual-address.page)

<sup>40</sup> Department of Health. Making IT Work: Harnessing Information Technology to Improve Care in England. Sept 2016

[www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs](http://www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs)



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### Changes to workflow

Giving patients access to GP records has inevitably involved changes to workflow for healthcare professionals in GP practices, as explained below. One of the things we'd like to find out more about, as highlighted in [section 11](#), is how PHRs affect overall workload.

'Giving people access to their records initially generates increased workload for GP practices just as newly diagnosed patients with diabetes, heart disease, mental health or cancer. GP practices are funded to deliver care which recognises the work needed to get the job done. The Quality and Outcomes Framework rewarded practices for achieving certain targets which were quality markers and encouraged rewarding good work,' says Dr Amir Hannan.

'Patients are invited to get records access and understanding. We ask them to fill out a questionnaire. The practice staff spend some time processing requests, reading questionnaires to check people understand what they are signing up for and reading through records to check whether they contain any information that may cause them harm.'

'General practice is in a crisis and is having to prioritise the workload. Anything that increases workload is going to be scary and prevent practices from doing it. We need to urgently look at what activities practices are doing which do not add any extra value to the patient or the practice or which could legitimately be done by others. Patients who can better manage their care can reduce workload, improve health outcomes for themselves and make the jobs for practice staff easier and more enjoyable.'

'There can also be work associated with helping people to use their record,' adds Amir. 'What are people going to do if they can't work out how to use the record system? They are going to ring the GP surgery. It's a service we're providing, not just a record. It's only in the last year that patients have been able to reset passwords for themselves. Before that, people from the GP practice had to always reset the passwords for them.'

*'It's obvious what the costs of records access are to GP practices, but it's not so obvious what the benefits are. It's hard to quantify how many times I don't ring the practice if I have access to my records. It's hard to quantify what you don't do, what you stop doing because you've got access. Not a lot of research has been done.'*

**Ingrid Brindle**



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## 9: Evidence of impact

'The greatest barrier to PHR implementation was perceived to be physician resistance due to concerns about the impact on their workload and on their patients. This was coupled with uniform agreement that the single most effective strategy for promoting patient PHR uptake and use was if their trusted health professional encouraged them to do so... Salient advice was that implementing a PHR is not an IT project. Instead it should be viewed as an operational and culture change project with an IT component.'

**Susan Wells et al, writing in the Journal of the American Medical Informatics Association 2015<sup>41</sup>**

'Surveys show that while three-quarters of adults think they should have full access to their health records, only one-third of doctors share this view.'

**Parliamentary Office of Science and Technology, 2016<sup>42</sup>**

'Becoming a digitally enabled health care provider is not about replacing analogue or paper processes with digital ones. It is about rethinking what work is done, re-engineering how it is done and capitalising on opportunities afforded by data to learn and adapt. Where technological interventions have failed, technology has simply been layered on top of existing structures and work patterns, creating additional workload for health care professionals... Indeed, without careful implementation they can create inefficiencies and staff frustration and even threaten the quality of care.'

**Nuffield Trust, February 2016<sup>43</sup>**

<sup>41</sup> Wells S et al. Organizational strategies for promoting patient and provider uptake of Personal Health Records. J Am Med Inform Assoc 2015;22:213–222. [www.ncbi.nlm.nih.gov/pubmed/25326601](http://www.ncbi.nlm.nih.gov/pubmed/25326601)

<sup>42</sup> Houses of Parliament. Parliamentary Office of Science and Technology. Postnote 519 February 2016. Electronic Health Records [researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-0519](http://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-0519)

<sup>43</sup> Nuffield Trust. Delivering the benefits of digital health care [www.nuffieldtrust.org.uk/publications/delivering-benefits-digital-health-care](http://www.nuffieldtrust.org.uk/publications/delivering-benefits-digital-health-care)



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## 9: Evidence of impact

### Can using PHRs help bring about efficiencies?

'We've been investigating whether using technology like PHRs can help to eliminate waste in healthcare and add value,' says Dr Pete Davies. 'If a patient tries to get through to me on the phone, they might get an answerphone, or a secretary might say they'll pass on a message. I may get a message in my inbox saying, 'Can you ring Vera?' So I ring Vera and she's not in. That's a wasteful, non-value-added trail of activities all to answer a very simple question. The alternative, a secure message sent direct via a PHR, is perfect. It cuts out all the waste in the process. It lets you get straight to the activity where you add value. Everyone gets maximum value from less effort.'

Pete conducted an analysis of his data to find out to what extent use of the PHR might avoid the need for hospital appointment attendance: 'My findings were that for nearly half of patients there was clear evidence that at least one face-to-face attendance had been avoided (median use period for patients was 5 months, the longest use-period was 11 months at the time of the analysis). The flipside was that for the patients who avoided hospital attendance, my team and I had exchanged twice as many messages with them, which highlights an important issue about how changing practice can impact on work flows and be conceived as extra work for healthcare professionals.'



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### Evidence of benefits

We hope the quotes that we've included in this guide give you a good idea of people's views on the benefits and impact of PHRs. Below we highlight further information that we came across while working on this guide. We are keen to find out more, and believe a comprehensive review of potential benefits would support increased take up of PHRs.

<sup>44</sup> Patient Online Support and Resources Guide 2nd Edition. March 2016.

[www.england.nhs.uk/ourwork/pe/patient-online](http://www.england.nhs.uk/ourwork/pe/patient-online)

<sup>45</sup> de Lusignan S et al. Patients' online access to their electronic health records and linked online services: a systematic interpretative review. *BMJ Open* 2014;4:e006021 doi:10.1136/bmjopen-2014-006021. [bmjopen.bmj.com/content/4/9/e006021.full](http://bmjopen.bmj.com/content/4/9/e006021.full)

Mold F et al. Patients' online access to their electronic health records and linked online services: a systematic review in primary care. *Br J Gen Pract*. 2015 Mar;65(632):e141-51. doi: 10.3399/bjgp15X683941. [bjgp.org/content/65/632/e141.long](http://bjgp.org/content/65/632/e141.long)

#### Patient Online highlights the following benefits of giving people access to their GP records:<sup>44</sup>

- ▶ Improved access to care services
- ▶ Expanded health knowledge for patients
- ▶ Increased information sharing
- ▶ Reduced administrative workload for practice staff
- ▶ Increased patient satisfaction
- ▶ Improved communication between patients and practices
- ▶ Increased operational efficiencies for practices
- ▶ Reduced travel for patients
- ▶ Reduction of DNAs [people who do not attend their appointments] for practices
- ▶ Increased ability of patients to make more informed decisions

Further benefits highlighted in two systematic reviews<sup>45</sup> include patients reporting increased convenience and improved self-care, and patient-led safety improvements through identifying medication errors and facilitating use of preventative services.

These reviews report a moderate increase of email or online messaging, no change in telephone contact and variable effects on face-to-face contacts. However, other tasks were necessary to sustain these services, which impacted on physician time. There were no reports of harm or breaches of privacy. The reviews also report a lack of evidence about whether online access translates into better health outcomes.

**'Fully integrated, patient-centred PHRs would form a unique research resource in the UK - because of the fact that we've got the NHS - for organised research into health conditions, preventing them and treating them.'**

**Richard Pantlin**



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### Accelerated Access Review

The Accelerated Access Review aims to speed up access to innovative drugs, devices and diagnostics for NHS patients. Potential areas of reform include regulation, reimbursement and uptake. John Jeans<sup>46</sup> has pinpointed six key issues that innovators should be able to answer at a very early stage, if their product is to have any chance of being widely adopted in the NHS, which could help developers of PHRs as well as the health and care organisations who are using them:

- 1 How will this innovation significantly change the patient's clinical pathway and establish a new standard of care?
- 2 What will be the positive clinical, social and economic impacts from this changed pathway and new standard of care?
- 3 How will these impacts be measured with sufficient precision to provide compelling evidence for the adoption of the innovation?
- 4 What changes in workflow will be required to maximise the benefit of these impacts in a defined health and care system?
- 5 How will the re-engineering of this workflow be resourced?
- 6 How can these benefits be spread by disseminating the changes across and between healthcare systems?

<sup>46</sup> Accelerated Access Review and John Jeans. Six questions every health innovator should ask. Nov 2015. [www.gov.uk/government/speeches/six-questions-every-innovator-should-ask](http://www.gov.uk/government/speeches/six-questions-every-innovator-should-ask)  
Accelerated Access Review. About us. What we do. [www.gov.uk/government/organisations/accelerated-access-review/about](http://www.gov.uk/government/organisations/accelerated-access-review/about)



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# 10: Checklist of key things to consider with PHRs

The world of PHRs is growing, but fragmented. What's on offer from the NHS, social care and the consumer world varies and, on the whole, it tends to be available in silos.

At the moment you should be able to access your GP records via the patient portal that's added to the GPs' own electronic medical records systems. You might be able to access your hospital records in a similar way. Care plans from social care tend to be on paper.

It's starting to be possible to integrate data from commercially available apps, wearables and other smart devices with NHS records, but few people have done that so far. Most people will find it hard, if not impossible, to pull digital copies of all of their health and care records together into one place without putting in the work themselves. Healthcare teams often cannot do that either, although there are several schemes across the country that aim to create more integrated health records.

In the previous sections of this guide, we've summarised issues, opportunities, challenges and benefits of PHRs, drawing on voices of experience. We conclude by bringing together a list of things for you to consider when thinking about how and whether a PHR may help you in your personal or professional life, or help the people your organisation serves or cares for.

We've listed features that people highlighted during our discussions as being particularly important things to look out for. We've included features and functions that seem desirable, whether they exist already or whether they do not. We hope this will help everyone to push the boundaries, make a success of PHRs and explore how best to seize the many opportunities they offer.



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## 10: Checklist of key things to consider with PHRs

### The information content

- ✓ **1. How comprehensive is the information in the PHR? For example:**
  - a Does the PHR enable people to bring together into one place all the records that health and care professionals make about them, people like their GP, any hospital specialists they see, and any carers who help them at home?
  - b Can people see the entire content of health and care professionals' records about them or just certain parts?
  - c How far back in time does the record go?
- d Can people add their own information, so the PHR provides a more complete picture of what matters to them? Can they...
  - i comment on information that health and care professionals contribute
  - ii add in their own notes
  - iii collate a personal library of favoured health information and sources of support
  - iv feed in data automatically from apps, wearables such as fitness trackers and smart devices, such as blood pressure monitors
  - v input information using structured tools such as quality of life questionnaires and other patient reported outcome measures?
- e Can people delete information that they've added?

- ✓ **2. Is there a clear audit trail, showing who's contributed what, when and how, as well as who's accessed what and when?**
- ✓ **3. Is the content up to date?**



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## 10: Checklist of key things to consider with PHRs

### Providing training and managing expectations

- ✓ 4. Is training available for everyone who will use the PHR (including patients, carers and health and care professionals)?
  - a Does the provider supply ready-made promotional material so you can easily tell different users about it?
  - b Can people access technical support if they need it?
    - i Are there online tutorials, an online or telephone helpdesk, and the option of face-to-face, hands-on support?
  
- ✓ 5. Does everyone know what to expect?
  - a Is the vision clear? Does everyone know why they are using the PHR? What are the incentives for using the PHR?
  - b Do individual users understand their own rights and responsibilities? Are the terms of use clear?
  - c Do you have access to questionnaires and other documents that help people to think through how they will use their PHR, and the possible consequences of doing so?
  - d Is it clear, and do all users understand, who is expected to do what and when, how using the PHR fits with workflows and with life? For example, is it clear how and when test results will be released for view by patients? How quickly are health and care professionals expected to respond to messages? What should people do if there are mistakes in the record? And how should people respond to data from apps and devices?
  - e If the PHR is new and only just being introduced, will the full functionality be introduced at once, or will it be introduced in an incremental way, starting with the more basic functionalities and extending the range over time?



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## 10: Checklist of key things to consider with PHRs

### Usability

✓ 6. Is the PHR easy to set up, use and understand? Is it appealing or even invisible (meaning it operates in the background without the user needing to do anything once it's set up)?

- a Is the system easy enough to use without any training? Is it intuitive?
- b Does the PHR provide an intelligent gateway to online health information in a way that boosts understanding? For example, does it include links to information on:
  - i illnesses people are diagnosed with, diagnostic tests they have, medications they are prescribed and ways to find treatment and support
  - ii services and community groups in their area, and support offered by health charities
  - iii peer support groupsAnd where does that information come from?
- c Can you customise the way information is displayed to suit different users' needs in different circumstances, so each person sees the right bits of the PHR in the right ways?
- d Is the information (including data from apps, wearables and devices) meaningful and can people act upon it?
- e Have users (including patients, carers and health and care professionals) been involved during development, implementation and appraisal of the PHR? Is there an opportunity for ongoing improvement of the PHR system, for example via iterative modifications that take into account feedback from all types of users?

✓ 7. How accessible is the PHR?

- a What features does it have to enable accessibility for all? For example, does it work with screen readers or screen simplifiers?
- b Is the PHR available in different languages?



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## 10: Checklist of key things to consider with PHRs

### Communicating

#### ✓ 8. Can people use their PHR to communicate?

Can patients communicate with everyone who helps out with their health and care, is the communication secure?

Can patients communicate with people who are facing the same challenges as them, both privately and through forums?

What sort of communication options are included, for example email-style secure messages, instant messages, video consultations, speech to text, social networks.

Can messages be recorded and added to the record so patients can check back later on what people have told them?

### Doing other things

#### ✓ 9. What other things can people do with the PHR?

Can patients book appointments, order repeat prescriptions and have a say in referrals?

Is there a diary function, with reminders and alerts?

Is there a contact list, with explanations of different people's roles?

Can people use their PHR to rate the services of care providers?



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## 10: Checklist of key things to consider with PHRs

### Seizing opportunities for new models of care

- ✓ 10. Does the PHR enable people to take more responsibility for their own health and care, and work together with health and care professionals, and others, in new ways?
- a. Does the PHR enable you to take advantage of new models of care that use, for example, remote monitoring (which can enable more proactive and targeted early interventions if vital signs and/or symptoms fall outside the set parameters), telehealth (which can improve access to specialist expertise via video consultations) and telecare (a system of sensors used to monitor a person's environment and behaviour in the home or community and identify when they might need help or support so appropriate action can be taken)?<sup>47</sup>
  - b. Does the PHR link to decision aids?
  - c. Can people use the PHR to contribute to and follow their own care plan, record their personal treatment priorities and preferences and share information about what matters most to them and the challenges they face in daily life?
  - d. Does the PHR enable people to set goals for themselves and monitor their progress towards those goals? Does it provide instructions on what to do or motivational feedback – either automatically or with input from health and care professionals?
  - e. Does the PHR enable people to capture real-time information about their symptoms, feelings or behaviour (using self-report, questionnaires, and apps, wearables and devices) and share that information with others?
  - f. Does the PHR have an analytics function to help people to recognise patterns in their symptoms, feelings or behaviour?
  - g. Does the PHR link to a wide range of services offered by NHS, social care, community and voluntary sector organisations to help coordinate the physical, mental and social elements of health?
  - h. Does the PHR notify people about clinical trials that are relevant to them or market products to them?

<sup>47</sup> Tech UK. Personal Digital Care. Using technology enabled care to transform our nation's health and create UK wealth. Nov 2015. [www.techuk.org/insights/reports/item/6224-personal-digital-care-paperaccelerated-access-review/about](http://www.techuk.org/insights/reports/item/6224-personal-digital-care-paperaccelerated-access-review/about)



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## 10: Checklist of key things to consider with PHRs

### Privacy, security and sharing information

- ✓ 11. Can patients download information from their PHR? Can they share information in their PHR with other people?
- 12. Is the PHR private and secure? Are effective information governance processes in place?
  - a. Is there a reliable way to verify the identity of everyone who logs-in?
  - b. Who owns the data, who controls how it is used and who benefits from it?
    - i. Is it clear when, how, why and with whom data is shared?
    - ii. Does the person who the PHR is about control who sees what, and can they change privacy settings easily?
    - iii. Is the data used for the person's own direct care and is it used for any wider purposes, e.g. big data analyses that aim to determine how well a particular hospital or specialist unit is performing, track the spread of, or risk factors for, a particular disease, or assess how safe and effective different treatments are.
  - c. Where is the data stored and how is it moved around?
  - d. Is the system secure enough to prevent unauthorised users from breaking in?
  - e. Is it easy for users to find out how their data is used, stored, passed on or sold to third parties, or what would happen if the company involved goes into administration?



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## 10: Checklist of key things to consider with PHRs

### Impact

- ✓ 13. Is there clear evidence on the impact of using the PHR?
  - a. Can you tell how the PHR will impact clinical processes, workflows of health and care professionals and demand for services, and what the implications are for staffing needs, training needs and payment models?
  - b. Is there a clear business case for the PHR? Who pays what for it?
  - c. Is there evidence on the benefits and harms of using the PHR?
    - i. For example, does the PHR improve the quality and coordination of care, support shared decision making, promote healthy lifestyles, and help improve people's health, fitness and wellbeing (both by preventing illness and helping people manage any conditions they have got)?

### Flexibility and standards

- ✓ 14. Does the PHR work on different devices and with different browsers and front ends?
  - a. What devices can you use the PHR with?
  - b. Can you use a single device to access more than one PHR?
  - c. Can people choose a front end or software of their own choice to interact with the data in their PHR? (This is unlikely to be possible now, but may be in the future.)
- ✓ 15. What standards does the PHR use and do they enable full interoperability with other systems?

'This is in the expectations of millennials... young people. They have expectations of health and social care. They expect to be citizens not patients. They expect to have things that stop them getting ill in the first place. They expect tech that's used and designed with them. They want to know the value of the information they are giving you and want to know what you're doing with it. It's about prevention. It's about communication. It's about relationships.'

Lord Victor Adebawale, at UK e-Health Week, May 2016



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# 11: Where to next?

As is probably inevitable in the early days of a new technology, our conversations with people about PHRs have raised as many questions as they have answers.

Here are some of the things we'd like to find out more about:

- 1 How many people are using PHRs, how often are they using them and what are they using them for?
- 2 What sort of people are using PHRs and how does usage vary with things like age and whether or not people have a long-term condition?
- 3 What do people think of PHRs? What do people want from PHRs? What do they find appealing, what worries them, what would they like to do that they can't do?
- 4 How many patients and how many health and care professionals have access to untethered PHRs that join up records created in different places by different people?
- 5 Which companies are developing and supplying tech for PHRs (including to the NHS, social care and direct to patients and the public)? What recommendations do they have to help everyone to seize the opportunities offered by PHRs?
- 6 What sort of research is being conducted into how best to make sense of and respond to the vast streams of data that can be generated by mobile apps, the sensors in wearables, smartphones and other devices, and the wider internet of things?
- 7 How do PHRs affect the working lives of health and care professionals? For example, if people use secure messages to communicate with their health or care professional, how much time do professionals spend on those messages and what are the knock on effects on other forms of communication, including telephone calls and face-to-face consultations? What are the implications regarding who does what and when?
- 8 How can PHRs impact the lives, health, fitness and wellbeing of people who use them? What are the potential benefits and harms?
- 9 Are PHRs supporting patients to do more themselves, are they facilitating self-care and are they, ultimately, improving health outcomes?
- 10 How can we use PHRs to enable people to contribute to research, either actively in trials or by giving access to their data?



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## 11: Where to next?

- 11 What features do existing PHRs have to boost accessibility and what features should they have?
- 12 How are people using PHRs to explore possible new models of care?
- 13 What are the business models for PHRs? How do they affect spending?
- 14 How do PHRs fit within the wider digital health world (including mobile apps, telecare, telehealth, teleconsultations and wearable technology), who's doing what to ensure good interoperability between different PHRs and between PHRs and other digital health technologies, and what more can be done here?
- 15 What can we do to help people to tell which PHRs, apps and devices to use and how to use them?
- 16 Do people think PHRs are easy to understand and easy to use, and what do we need to do to improve things?

If you have any experience, evidence or research to share on any of these points, or PHRs more widely, we'd be really interested to hear from you.



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# Invitation to provide feedback

## We welcome your comments and suggestions about this publication

By giving us constructive feedback, and sharing any related research or projects you are aware of, you can help us to produce higher quality and more relevant information in the future.

If you would like to give your feedback contact us at [admin@pifonline.org.uk](mailto:admin@pifonline.org.uk).



# Appendix A: Some definitions of Personal Health Records

## Royal College Physicians<sup>48</sup>

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

## Markle Foundation<sup>49</sup>

'An Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.'

## HealthIT.gov (USA)<sup>50</sup>

'A personal health record (PHR) is an electronic application used by patients to maintain and manage their health information in a private, secure, and confidential environment.

PHRs:

- ▶ Are managed by patients
- ▶ Can include information from a variety of sources, including health care providers and patients themselves
- ▶ Can help patients securely and confidentially store and monitor health information, such as diet plans or data from home monitoring systems, as well as patient contact information, diagnosis lists, medication lists, allergy lists, immunization histories, and much more
- ▶ Are separate from, and do not replace, the legal record of any health care provider

- ▶ Are distinct from portals that simply allow patients to view provider information or communicate with providers
- ▶ Properly designed and implemented, PHRs can help patients manage their health information and become full partners in the quest for good health.'

<sup>48</sup> Royal College of Physicians. Personal health record (PHR) landscape review. Final report May 2016. [www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-final-report](http://www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-final-report)

<sup>49</sup> 2020health.org. Personal Health Records Putting patients in control? September 2012. [www.2020health.org/2020health/Publications/publications-2012/Public-Health-Records.html](http://www.2020health.org/2020health/Publications/publications-2012/Public-Health-Records.html)

<sup>50</sup> HealthIT.gov. What is a personal health record? [www.healthit.gov/providers-professionals/faqs/what-personal-health-record](http://www.healthit.gov/providers-professionals/faqs/what-personal-health-record)



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### Knock knock, who's there? Verifying identity

It's important to have a way to verify your identity – to confirm that you are who you say you are – if you are to access health records that NHS and social care staff create about you.

To gain access to your GP records, your practice will normally ask you to fill in a short form and take two forms of ID into the surgery, one containing a photo. Your GP practice will then give you login details and a password, which you need to keep secret.

Procedures used to access hospital records vary. For patients to have access to a wider set of joined-up records, gathered together from multiple service providers, may require an approach more along the lines of [GOV.UK Verify](#).

The identity of health and care professionals, and anyone else who accesses information in PHRs, must be verified too. Any member of staff who is given access to national systems

'One of the most important things we need, if people are to have PHRs that bring together information on all of their interactions with health and care services, is a national identity service. We need a way to be sure that Jane Smith from the High Street is actually Jane Smith, and that she can access the right Jane Smith's records and no-one else's.'

**Peter Cambouropoulos**

'It is critical to have, at some point, an identity service that will allow a patient to connect their on line identity with health and care services. One patient, one identity, one set of login credentials. This may be a user name and password for now, but soon this will be biometric of some sort.'

**Adrian Byrne**

that hold health information needs a smartcard, along with a username and password. Procedures used to access local systems vary, but many are starting to use smartcards.

### Locating records

If your different health and care records are going to be pulled together into one place, then there needs to be a way to locate all of your records and connect them together. The saving grace is that we all have an NHS number. If your NHS number is used as a unique and common identifier, then every interaction you have with the NHS should ideally be recorded against your NHS number.



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### Interoperability

Your records don't have to be stored in one place for you to see them all in one place, but if we are to transfer and share data between systems, those systems need to be able to talk to each other - therefore interoperability is vital.<sup>51</sup>

The Professional Records Standards Body (PPRSB) is working with the public and professionals to define standards needed for good care records, to help to create a consistent, coherent shared electronic record system across health and social care that provides a comprehensive picture about each person when and where that's needed.

#### Recommendation on interoperability from 'Making IT Work: Harnessing Information Technology to Improve Care in England'<sup>52</sup>

'9. Ensure Interoperability as a Core Characteristic of the NHS Digital Ecosystem – to Promote Clinical Care, Innovation, and Research'

'The new effort to digitise the NHS should guarantee widespread interoperability. The goals of interoperability are to enable seamless care delivery across traditional organisational boundaries, and to ensure that patients can access all parts of their clinical record and, over time, import information into it. Widespread interoperability will require the development and enforcement of standards, along with penalties for suppliers, trusts, GPs, and others who stand in the way of appropriate data sharing. The system, standards, and interfaces should enable a mixed ecosystem of IT system providers to

flourish, with the goal of promoting innovation and avoiding having any one vendor dominate the market. Plans for interoperability should be harmonised with other ongoing efforts to join up elements of the health and social care systems, such as those represented by the Sustainability and Transformation Plans (STPs).'

'Interoperability should be built in from the start. Local and regional efforts to promote interoperability and data sharing, which are beginning to bear fruit, should be built upon. National standards for interoperability should be developed and enforced, with an expectation of widespread interoperability of core data elements by 2020.'

<sup>51</sup> INTEROPen are an open collaborative and action group, made up of organisations and individuals, aiming to accelerate the development of open standards for interoperability in the health and care sector. [www.interopen.org](http://www.interopen.org)

<sup>52</sup> Department of Health. Making IT Work: Harnessing Information Technology to Improve Care in England. Sept 2016 [www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs](http://www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs)



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### A secure network

To transfer and share data, we also need a secure network. There's already a system called N3, which is a secure encrypted network for transferring data. It's the roads and rails, the infrastructure we need to securely and safely deliver sensitive healthcare data. The Health and Social Care Network programme will provide a successor to N3, a standards-based network that will enable multiple suppliers to provide interoperable network services to health and social care organisations, to enable the integration of health and social care services, flexible and remote working patterns as well as access to national, regional and locally hosted applications.<sup>53</sup>

'From a technical point of view, one question surrounds where you hold the data. Is it more desirable, and feasible, to hold the data in different places and exchange it, or to bring it all together and hold it all in one place? It seems far easier, both from a technical point of view as regards interoperability and security, and for consent, if each system holds its data and that data can't be updated by other systems. You can still see a bigger set of data that gives a fuller picture by viewing different sets of data together even if they're actually held separately. People might want to comment on content that's held elsewhere though, of course.'

**Richard Pantlin**

<sup>53</sup> NHS Digital. About HSCN. [systems.hscic.gov.uk/hscn/about](https://systems.hscic.gov.uk/hscn/about)



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## Wales

### National progress on records access

Patients can use the My Health Online (MHOL) service to book GP appointments or request repeat prescriptions. This service has been rolled out to all GPs in Wales.

Wales is committed to providing citizens with online access to their information held in the GP practice electronic system by April 2017. The service will be further developed to include online access for people to their GP-held health records with clinical information from their hospital appointments or admissions, including discharge advice and information. Further details on this can be found in [Welsh Government \(2015\) Our plan for a primary care service for Wales up to March 2018](#).

[Informed Health and Care - A Digital Health and Social Care Strategy for Wales](#), published in December 2015, outlines technology and greater access to information will help improve the health and well-being of the people of Wales.

### Summary records for emergency care

#### Welsh GP Record (previously known as the Individual Health Record - IHR)

Since 2009, out-of-hours doctors in Wales have been able to view a summary of a patient's medical record held by their GP.

Plans are in place to extend access to the GP record to:

- ▶ All clinical teams involved in the direct care of the patient
- ▶ Secondary care pharmacists and pharmacy technicians involved in the direct care of the patient
- ▶ Doctors and nurses involved in the direct care of a patient in an outpatient setting



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### Scotland

Pieter van de Graaf, Clinical Strategy Lead, SG eHealth Division, explains what's happening in Scotland in a blog about [The-digital-way-to-patient-empowerment](#):

'To ensure we make substantial progress with patient-facing health IT developments, we're currently taking a multi-track strategic approach in Scotland:

- ▶ We're aiming to make personalised health information (including a summarised electronic patient record) and baseline services available to each citizen by 2020. In the meantime, the [NHS24](#) and [NHS Inform](#) websites will soon be refreshed to improve the on-line self-care guides and information we're already providing. This is happening in close cooperation with patient organisations.
- ▶ We're consolidating and extending our portfolio of comprehensive patient platforms for chronic conditions such as [PatientView](#) and [MyDiabetesMyWay](#). These provide digital tools for patients with conditions which best lend themselves to effective self-management and co-production with clinicians.

- ▶ We're promoting the development of [Primary Care Digital Services](#) for patients by investing into a Digital Services Development Fund over the next three years.

Eventually, we are hoping to bring these strands together through a patient portal. You can find out more about the above in my presentation on ['The future of patient access to Electronic Health Records and Services in Scotland'](#) given at the BCS Health Informatics Conference...

Realising this approach means bringing people together. Scotland has 14 territorial health boards, 7 special health boards, 32 local authorities and 996 general practices. These all have a role to play in implementing our national strategy on a regional or local basis together with, and for the benefit of, our 5.3 million citizens. If you have any views on how this can be done better, please make sure you join the [National Conversation on 'Creating a Healthier Scotland'](#).

### Northern Ireland

In October 2016 the Department of Health for Northern Ireland published [Health and Wellbeing 2016: delivering together](#), a report setting out a future vision of healthcare in Northern Ireland.

The report discusses eHealth and care, and ambitions to make better use of technology and data to deliver a healthcare model focused on service users, on improving the health and wellbeing of the population, and on getting beyond organisational and professional silos.

The report commits to 'expand the range of information and interaction available to citizens, service users and those providing services both online and through apps. This will include building a new patient portal which will allow secure online access to their own health and care information where service users want this. This new patient portal will be in place for dementia patients next year and rolled out across the North by 2021.'



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# Appendix D: Policy drivers and government initiatives in England

The [GP contract](#) defines the online services that GPs are required to provide to patients.

The [Five Year Forward View](#) makes a commitment that, by 2020, there will be ‘fully interoperable electronic health records so that patient’s records are paperless’.

The government committed in [Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens: A Framework for Action](#) that ‘all patient and care records will be digital, interoperable and real-time by 2020’. The framework states:

‘In 2015, all citizens will have online access to their GP records and will be able to view copies of that data through apps and digital platforms of their choice. But it is essential that citizens have access to all their data in health and care, and the ability to ‘write’ into it so that their own preferences and data from other relevant sources, like wearable devices, can be included. Patients won’t have the ability

to edit the entries their clinician has made but their comments will be visible. This framework prioritises comprehensive access – with the ability for individuals to add to their own records – by 2018.

[...]

All patient and care records will be digital, real-time and interoperable by 2020. By 2018 clinicians in primary, urgent and emergency care and other key transitions of care contexts will be operating without needing to use paper records. This will be achieved by alignment of national technical and professional data standards with regulatory and commissioning requirements. By April 2015, building on the existing interoperability programme, the NIB, in partnership with users and industry bodies, including the Foundation Trust Network and the NHS Confederation, will coordinate agreement on these standards and how they should be ‘hard-wired’ into commissioning and regulatory oversight.’

There will be a staged approach to electronic health records - by 2016 all patients should be able to access their own GP electronic record online in full, seeing not just a summary of their allergies and medication but blood test results, appointment records and medical histories. By 2018 this record will include information from all their health and care interactions. By 2020, the NHS has committed to be ‘paper-free at the point of care’.<sup>54</sup>

The National Information Board’s [Workstream Roadmaps](#) set out plans to make it easier for the public to access health and care information by improving digital services.

The Department of Health (DH) Information Strategy [‘The Power of Information’](#) stated that by 2015:

- ▶ all general practices will be expected to make available electronic booking and cancelling of appointments, requesting of repeat prescriptions, viewing of test results, communication with the practice and access to records
- ▶ all NHS patients will have secure online access, if they want it, to their personal GP records.

<sup>54</sup> House of Commons Library. Briefing paper Number 07572, 25 April 2016 A paperless NHS: electronic health records. [researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7572](http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7572)



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## Appendix D: Policy drivers and government initiatives in England

Local health and care systems have been organised into what are called '[LDR footprints](#)', which include local commissioners, providers and social care partners. Each has already completed a '[Digital Maturity Self-assessment](#)' and '[Local Digital Roadmaps \(LDRs\)](#)', due by 30 June 2016, setting out how they will achieve the ambition of 'paper-free at the point of care' by 2020. This work falls within the broader context of what are called '[Sustainability and Transformation Plans](#)'.

The first wave of seven [Test Beds](#) was announced by NHS England Chief Executive Simon Stevens in January 2016. Frontline health and care workers in seven areas will pioneer and evaluate the use of novel combinations of interconnected devices such as wearable monitors, data analysis and ways of working, which will help patients stay well and monitor their conditions themselves at home. Successful innovations will then be available for other parts of the country to adopt and adapt to the particular needs of their local populations.

Also of relevance are [Vanguard sites](#), which are exploring new care models, and [integrated care pioneers](#), and the [GP Connect programme](#), which aims to support better clinical care by opening up information and data held within GP Practice IT systems for use across health and social care.



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### Latest developments – the Wachter review

A recent independent review, chaired by Robert Wachter ([Making IT work: Harnessing information technology to improve care in England](#)), suggests that a more realistic expectation, if sufficient funds are made available, is that the entire NHS should be digitised by 2023 rather than 2020.<sup>55</sup>

Responding to the Wachter review, the Health Secretary Jeremy Hunt [announced plans](#) to achieve 'NHS digital excellence' that include 12 new 'global exemplars' (NHS organisations that pioneer best practice), training NHS staff in digital skills and new digital services for patients, outlined as follows:

- ▶ 'The expansion of the existing NHS 111 non-emergency phone line service to include a new online 'triage' service for less serious health problems – this will enable patients to enter their symptoms

online and get tailored advice or a call-back from a healthcare professional according to their needs. The service is being developed with leading clinicians and then piloted to ensure the best patient outcomes.

- ▶ NHS-approved health apps to guide patient choice – NHS England will launch a library of NHS assessed apps, as well as advising on other wearable devices, to ensure people can select reputable and effective products to monitor and improve their health.
- ▶ A relaunch of the NHS Choices website to improve the range of services - it will be relaunched as NHS.UK with a fuller range of online patient services, including the ability to register with a GP, see and book appointments, and order and track prescriptions.

- ▶ Instant access to personal health records online - inspired by the 'blue button'\* - app in the US, the new NHS. UK site will also enable patients to securely download their personal health records, giving them instant access to important healthcare information, such as prescriptions and test results.
- ▶ More interactive, local information about the performance of health services – from today, the MyNHS website will give better data on how NHS services are performing across dementia, diabetes and learning disability services. Maternity, cancer and mental health data will follow later this year. In future, the revamped site will also include maps, graphs and tools so that patients can see how the performance of their local services has changed over time.'

\* In the US, the 'blue button' symbol signifies that a site has functionality for customers to go online and download health records.<sup>56</sup>

<sup>55</sup> Department of Health. Making IT Work: Harnessing Information Technology to Improve Care in England. Sept 2016

<sup>56</sup> HealthIT.gov. Your health records. About blue button. [www.healthit.gov/patients-families/blue-button/about-blue-button](http://www.healthit.gov/patients-families/blue-button/about-blue-button)



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## Appendix E: Summary Care Records

If you're registered with a GP practice in England, you should have what's called a 'Summary Care Record (SCR)', unless you've chosen to opt out of having one. Your SCR contains key information from your GP practice on your name, address, date of birth, NHS number, medicines you're taking, allergies you've got and bad reactions you've had to certain medicines.

Your SCR provides healthcare professionals with information they wouldn't otherwise have if, for example, you visit Accident and Emergency or you are admitted for urgent care in hospital.

You can't access your SCR online yourself, but you can ask your GP to add additional information to your SCR if you think that will help improve your care, such as information on any long-term health conditions, personal preferences about your care and communication needs.



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## Further reading

NHS England's Patient Online programme is designed to support GP practices to offer and promote online services to patients. They've produced guidance for the public [www.england.nhs.uk/ourwork/pe/patient-online/about-the-prog/po-public](http://www.england.nhs.uk/ourwork/pe/patient-online/about-the-prog/po-public) and for professionals [www.england.nhs.uk/ourwork/pe/patient-online](http://www.england.nhs.uk/ourwork/pe/patient-online).

The Patient Online team has also worked with the Royal College of General Practitioners to develop further training materials: [elearning.rcgp.org.uk/mod/page/view.php?id=4709](http://elearning.rcgp.org.uk/mod/page/view.php?id=4709).

The Local Government Association (LGA), the Association of Directors of Adult Social Services (ADASS) and the Society of IT Management (Socitm) has produced 'Engaging Citizens Online: briefings to support digital adoption' for senior managers with responsibility for public engagement as well as social care informatics leads and web managers [www.local.gov.uk/chip/-/journal\\_content/56/10180/7618132/ARTICLE](http://www.local.gov.uk/chip/-/journal_content/56/10180/7618132/ARTICLE)

The IGA provides advice, guidance and support on information governance in health and care [systems.hscic.gov.uk/infogov/iga](http://systems.hscic.gov.uk/infogov/iga).

2020health.org, '[Personal Health Records: Putting patients in control?](#)', 2012

Nuffield Trust, '[Delivering the benefits of digital health care](#)', 2016

Office of the National Coordinator for Health Information Technology, '[Patient Engagement Playbook](#)'

Patient Information Forum, '[Guide to Health Records Access](#)', 2013

Royal College of Physicians, '[Personal Health Record \(PHR\) Landscape Review](#)', 2016

National Advisory Group on Health Information Technology in England, chaired by Robert Wachter, '[Making IT Work: Harnessing Information Technology to Improve Care in England](#)', 2016

NHS England, '[Children's Digital Health Strategy](#)', 2016.



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