

# Personal Health Records

Putting patients in control?

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## Foreword

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Ill health is full of uncertainty. Patients are frequently in the dark: about their condition, about their options; about what will happen to them. And even for the well informed, the NHS is full of complexity and difficulty – many patients and families report the frustrations of being passed from pillar to post, of being made to tell their story over and over again, of hospitals losing their notes.

Technology is now at a point where it can help us overcome these problems. People can go online to access their GP-held record, see test results, obtain tailored health information and book appointments. The digital functions enjoyed by patients at the Haughton Thornley Medical Centre and other practices offer greater control and convenience, just as digital technologies have transformed other aspects of everyday life. They also contribute to shaping a different, more grown-up relationship between patients and clinicians. In other contexts, patients are holding Personal Health Records so that they can share across organisational boundaries in the interests of their seamless care.

As this perceptive study shows, the barriers to further progress are not so much technical as cultural. So far the movement to open access to patient records has been led by a handful of visionary doctors. The clinical community needs to do more to make this movement mainstream, not maverick. To date it has garnered little interest – though there are plenty of benefits for clinicians.

Patients strongly feel the benefits of access when they have it. Dr Amir Hannan of Haughton Thornley Medical Centre tells a moving story of a patient, due to transfer to a different practice, who was in tears at the prospect of no longer having access to her record. It had become part of her life. But patients are not taking to the streets to demand access to their records: we don't know what we don't know. The clear message of this report is that in seeking to generate 'patient pull', advocates of record access must emphasise the transactional benefits, rather than access per se. The attraction of online banking is the convenience of transacting, not reading your bank statement. Perhaps it is similar in health.

'It's my record' is still a counter-cultural notion in the NHS. (And legally your health record is still the property of the Secretary of State.) Ensuring that patients' access to their record is the norm will be part of a larger process of democratising health, promoting self care and supporting people to manage their long term conditions. We shouldn't make a fetish of it – as some Government policy documents are in danger of doing. It's not the be all and end all of good care, and we should never forget that a large portion of the population is still not 'digital'. But record access and Personal Health Records will help. We should quietly and efficiently get on with it. The best way of doing that is by very clearly realising and demonstrating the benefits. These are well set out in this excellent report.

**Jeremy Taylor**

Chief Executive, National Voices

## About the authors

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### **John Cruickshank**

John is a Consultant Director at 2020health and an independent expert in NHS IT and telehealth, operating at the complex interface between government, NHS and industry. Since 2010, he has authored a series of influential and authoritative reports published by 2020health on how the NHS must make better use of technology: ‘Fixing NHS IT: A plan of action for a new government’; ‘Healthcare without walls – a framework for delivering telehealth at scale’; and ‘Telehealth – what can the NHS learn from experience at the US Veterans Health Administration?’.

His 30-year career has included leadership roles in the healthcare practices of major systems integrators and consultancies. In addition to his work with 2020health, he advises public and private sector organisations committed to the strategic use of information and telehealth technologies in healthcare. John is a graduate in economics and management science from St John’s College, Cambridge.

### **Carl Packman**

Carl undertook some research for 2020health during 2012. In 2009 he undertook research in children’s policy for various organisations, after which he became a researcher for the Westminster Health Forum.

He has previously written for the Guardian, the New Statesman, The Huffington Post and The Philosopher’s Magazine on issues ranging from health and social care, organ donation, to personal finance and crime. He is also a regular blogger and book reviewer for the LSE blog and other websites. Recently he completed a book-length study of the payday lending industry, to be released by finance publisher Searching Finance later in 2012.

### **Jon Paxman**

Jon joined 2020health as a copy-editor and senior fellow in late 2011, transferring his writing, editing and research skills from the worlds of film, television and classical music. Jon is currently partnering health IT expert John Cruickshank in 2020health’s independent evaluation of the ‘Yorkshire and the Humber Regional Telehealth Hub’, and is Project Lead on 2020health’s report into Personal Health Budgets.

## About this publication

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‘Personal Health Records: putting patients in control?’ is our fourth report in two years examining how the NHS can best exploit some of the latest developments in IT. The timing of this report is significant, with the Coalition Government’s stated objective to give all NHS patients online access to their GP health records before the end of this parliament. Despite the turmoil in recent years surrounding the roll-out of care records by the National Programme for IT in the NHS, the ethical rights and potential long-term benefits of allowing patients access to, and ultimately more control over, their personal health records are simply too important to ignore. The new initiative is called ‘Record Access’, which in time may well evolve into the more dynamic Personal Health Record (PHR), the likes of which are currently available to several million consumers in the USA, though only to a limited few in England.

Our report examines the scope and potential benefits of both Record Access and the PHR. It appraises current patient attitudes toward online health record access, both in theory and in practice, and identifies fundamental prerequisites for the mass uptake of such services. The evidence-base is admittedly limited at this present time, so we take into account developments from abroad, as well as findings from our own surveys of patients and potential users in England. Indications overall are that where we find increased patient involvement in personal healthcare, so we expect to find better health outcomes alongside lower service costs.

During this project we benefitted from interviews and discussions with charities, academic institutions, government, NHS stakeholders and industry. 2020health would like to thank all those who shared with us their data, knowledge and expertise, together with members of the public who participated in either online or face-to-face surveys.

This report was funded by an unrestricted educational grant from Microsoft, giving us the freedom to draw our own conclusions. We are greatly indebted to our sponsor. As well as driving our on-going work, involving frontline professionals in policy development, sponsorship enables us to communicate with and engage officials and policymakers in the work that we do. Involvement in the work of 2020health.org is never conditional on being a sponsor.

**Julia Manning**

Chief Executive, 2020health.org  
September 2012

# 1 Executive Summary

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The Government recently announced that by 2015 all NHS patients will have online access to their personal GP records. So-called 'Record Access' is a key objective for enabling the individual greater involvement in the management of their health. In some cases, individuals are already managing their own 'Personal Health Record' (PHR) – an online record owned by the patient, allowing them to add and organise personal health information, as well as to integrate health records from different providers, and share this with other individuals and institutions at will.

This report explores the desire of patients to adopt and use PHRs in England and is based on face-to-face and online surveys (totalling over 250 respondents). Our work also included a separate comprehensive review of the literary and evidence base around relevant developments both in the UK and internationally.

Our work generally confirmed that where already provided, Record Access facilities are well liked by patients. The evidence review points towards improved levels of patient self-management, knowledge, communication, satisfaction and trust through Record Access. People overwhelmingly value the transactional support that Record Access offers, particularly in terms of appointment booking and ordering repeat prescriptions. However, less than 1% of GP practices currently provide the facility, and significant work is needed to reach even the 5% levels of uptake the Department of Health (DH) has projected for 2015, let alone access for all NHS patients.

The barriers to uptake have more to do with culture and change than technology. While security appears to be a concern for those not using the technology, it becomes much less so for those who do use it, if the end gains are worthwhile. Record Access requires behavioural change, with patients becoming more involved and informed as equal partners in their care, making positive healthy choices to improve or maintain their health.

On a wider international level, governments, healthcare providers and medical insurers promote uptake of PHRs with broadly the same message; namely, that patients who engage with their own healthcare secure better health outcomes and incur lower costs. Mass uptake is perhaps some way off, but evidence points to mounting interest in PHRs around the world. The benefits are most palpable for those living with chronic conditions or disability, or those living in remote areas without easy access to primary care services. The main leaders are Denmark and (parts of) the USA; in both countries, approximately 10% of the

population are believed to use PHRs. Uptake has been most rapid where there is an underlying, longitudinal electronic health record to which patients have access, as evidenced by Kaiser Permanente.

Turning to the future of PHRs in England, PHR usage is most likely to take off amongst patients committed to self-management. Those with complex, chronic conditions, often with more than one long term condition, are most likely to find a PHR useful and have the most to gain in the first instance.

Our work also highlighted ideal uses of PHRs amongst the healthy population, where people's shared care arrangements demand continuity of information, particularly where care crosses organisational boundaries. Maternity and child health represent two good examples and work is underway.

Beyond this, uptake of PHRs remains at an early stage. Interest will only be captured where PHRs are demonstrably useful, fitting well into people's daily lives, particularly if they are remote to health services. Other prerequisite features are that the PHR must be secure, reliable and easy to use. The use of apps could be key in driving PHR uptake, especially where they integrate well with NHS health record systems.

Most importantly, the impact and uptake of PHRs rests on a change in culture and mind-set around shared care and self-management. There is a developing evidence base that can stimulate public interest, as well as guide and encourage stakeholders to invest in the set-up of PHRs.

A Stakeholder Group led by the Royal College of GPs was recently formed to coordinate the delivery of Record Access. In our view, the Group should oversee both the delivery of the Government commitment on Record Access and encourage the more widespread adoption of PHRs. It needs to create an overall vision for what can be achieved and devise practical activities to generate impetus.

# 1 Executive Summary

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In particular, we recommend that the Group oversees the following activities:

- Policy – ensuring the adoption of Record Access and Personal Health Records reflects NHS-wide initiatives to improve self-care.
- Evidence base – learning and disseminating lessons around practical usage and the outcomes achieved.
- Levers – to ensure adequate incentives are provided to drive uptake, for example through the NHS Commissioning Board’s new mandate.
- Stakeholder engagement – across clinical and patient groups nationally and locally; providing relevant support and incentives to IT suppliers to develop systems geared to patient needs.
- Communications – improving awareness to create patient demand, especially where a practice does not already offer Record Access; publishing guidance for clinicians, practice staff and patients.
- Processes – enabling simplicity of use and sign-up; clarity and consistency of access and security; and ensuring equitable access through a variety of internet-ready media.

As consumer awareness grows, alongside reassurances over consent and security provision, so we believe uptake of Personal Health Records can increase dramatically. In this way people can become more actively involved in their own healthcare, being better equipped with resources for self-management and in turn securing improved health outcomes.

## 2 Introduction

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### 2.1 Background

On 29 November 2011, in his Autumn Spending Review, the Chancellor of the Exchequer announced: ‘The Government will ensure all NHS patients can access their personal GP records online by the end of this Parliament.’

Patients having access to their own records online (referred to as ‘Record Access’) is recognised as an early step towards patients managing their own ‘Personal Health Record’ (PHR). For the purposes of this report, we use the Markle Foundation’s definition of a PHR, as follows:

*‘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.’*

(During our research, we found many varied definitions of Personal Health Records, summarised in Appendix A, which also includes a glossary of terms.)

The barriers to bringing about online patient access to their health records are significant. For instance, public understanding of the social as well as clinical benefits of Record Access needs promoting if demand is to be stimulated by patients.

We have written this report so that policy makers, clinicians, patients and those in health informatics may gain greater insight to the debate about the benefits of Record Access and PHRs. We first explore the background and policy drive towards Record Access, and then consider further steps to ensure patients get the most from the system. We also explore the desire of patients to adopt and use PHRs and what kinds of patients would be most motivated to use them.

This report is based on our own surveys, supplemented by a comprehensive review of the evidence around relevant developments both in the UK and abroad, and with consideration of people’s online usage with other sectors and services. We also draw on case studies and examples to illustrate progress and issues.

In focusing on the perspective of the patient, the report does not address wider but crucial issues arising from increased patient use of PHRs, such as: the impact on clinical practice and culture; the organisation of care; the business case; security and consent mechanisms; or the implementation issues associated with bringing PHRs into use. Moreover, we do not comment on particular PHR

products but draw on case studies from a variety of suppliers to illustrate their use.

2020health’s work was undertaken during the spring of 2012. It was made possible by an unrestricted educational grant from Microsoft, who also supported the Patient Information Forum’s ‘Guide to Health Records Access’, published earlier in the summer.

### 2.2 Process adopted

To establish the questions and concerns that patients have about Record Access and PHRs, we undertook a study between March and May 2012, involving the following activities:

- Interviews with key individuals working at the national policy level as well as those involved in implementing projects, ranging from GPs through to professionals in health informatics (see Appendix B)
- Evidence review from relevant health publications, both in the UK and internationally, as well as a more broad consideration of general online usage and record handling in the UK. This evidence review is available as a separate PDF document.
- Three dedicated focus group sessions, at an Open Age centre, Sure Start centre and with gym users (Appendix C summarises the results)
- Online polling through surveys to ascertain online activity, what consumers foresee a PHR being used for, advantages and disadvantages of a PHR, and issues around access (Appendix D)

The rest of the report is structured as follows:

- **Chapter 3** – policy context and Record Access
- **Chapter 4** – PHRs: an international perspective
- **Chapter 5** – PHRs: the UK perspective

In addition to the appendices mentioned above, we have also prepared a Frequently Asked Questions document (FAQ; see separate pull-out) for prospective patients. This could be tailored or developed according to different contexts and intended PHR usages.



## 3 Policy Context and Record Access

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In this chapter, we consider the policy context towards improved self-care and the value that Record Access can provide in this regard. We also consider the benefits and concerns that patients and others have expressed in relation to Record Access.

### 3.1 Policy and historical context – the journey towards Record Access

In 2002, Sir Derek Wanless delivered an evidence-based assessment of the long-term resource requirements for the NHS in his major report ‘Securing our Future Health: Taking a Long-Term View’.<sup>1</sup> This report has proved instrumental in driving the health policy of governing parties ever since.

Sir Derek concluded that in order to meet people’s expectations and deliver the highest quality care over the next 20 years, the UK would need to devote more resources to healthcare while at the same introducing reform to maximise efficiency. In particular, he identified the need to work towards a ‘Fully Engaged Scenario’, with high levels of public engagement in relation to their health, based around much improved levels of self-care, healthcare ICT and public access to health information.

The NHS itself was already considering increased public engagement. The NHS Plan<sup>2</sup> (2000) had dedicated a chapter to ways and means of building a patient’s knowledge, including plans to allow patients electronic access to their health records by 2004.

Following on from the NHS Plan, the NHS Electronic Record Development and Implementation Project (ERDIP) created a series of exemplar projects to explore the development and application of shared electronic health records (EHR). The intent was to ‘lay the foundation for the development of a full cradle to grave EHR’, and in so doing some of the issues about patient participation in the EHR were explored. These included informing the patient of all the actions taken on their behalf by healthcare professionals; e.g. in the case of maternity and child health: midwives, obstetricians, health visitor or GP.

In 2002, and in part responding to the Wanless review, the Government created the National Programme for IT in the NHS (NPfIT), an ambitious programme to use IT to modernise the health service. Our report ‘Fixing NHS IT’<sup>3</sup> in March 2010 described the progress achieved with NPfIT and set out a pragmatic plan for action for the new Government. In particular, the report reviewed progress on one key aspect: to provide patient access to the nationally-held Summary Care Records (SCR) through a facility called HealthSpace.

Case Study 2.1 describes the policy drivers behind HealthSpace and its progress. It also summarises the results achieved, based on a significant evaluation project<sup>4</sup> led by Prof Trish Greenhalgh of University College London (UCL), which reported in June 2010. She commented, ‘personal electronic health records, managed by patients and interfacing with clinician held records, are seen as having a key role in the new care model, by facilitating storage and exchange of information, promoting engagement with self-management, and supporting continuity of care’.

Elsewhere in this report we draw on the experience with HealthSpace to highlight key patient priorities and concerns around PHRs.

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1. Wanless D ‘Securing Our Future Health: Taking a Long-Term View’, HM Treasury 2002.  
2. Department of Health, ‘NHS Plan July 2000’  
3. Cruickshank J ‘Fixing NHS IT – a plan for a action for a new government’ 2020health March 2010  
4. Greenhalgh T et al ‘The Devil’s in the detail’ University College London May 2010

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## 3 Policy Context and Record Access

### Case Study 3.1 – NHS HealthSpace

In specifying the HealthSpace concept in 2003, the Government indicated that the system was intended to address the following policy objectives:

- Personalisation of care, allowing NHS care to be adapted to individual needs
- Patient empowerment, with patients better able to manage their illnesses
- Accountability, quality improvement and safety
- Reduced NHS costs through more self-management of long-term conditions
- Improved health literacy, improving people's ability to understand and manage their illness

HealthSpace consisted of two levels: a basic account, a depository for an individual's health information which individuals must complete themselves; and an advanced account, through which patients could access their Summary Care Record, book appointments and communicate remotely with practitioners.

The usefulness and roll-out of HealthSpace was affected by issues around the Summary Care Record that it accessed. As well as

significant public concerns over confidentiality, the SCR suffered from controversy as to its primary purpose and the depth of information to be held on the record. On advice from an expert group in autumn 2010, the Coalition Government scaled down the scope of the SCR and confirmed its use was primarily for urgent care purposes.

HealthSpace was also hampered by the fact that it was considered difficult to use. As a result, the evaluators Greenhalgh et al found that uptake from basic account to advanced account was 0.13% rather than the 5–10% expected. In short, the system failed to engage patients.

In May 2012, Dr Charles Gutteridge, the national clinical director for informatics at the Department of Health, confirmed that HealthSpace would cease to exist 'in the next 12 months'. He said, 'It is too difficult to make an account. It is too difficult to log on. It is just too difficult... the DH need to create a new portal through which patients [can] view their Summary Care Records.' The subsequent NHS Information Strategy announced that 'a comprehensive online portal would bring together the best of the relevant information and online services currently provided by the existing national web services: NHS Choices, NHS Direct online, NHS 111 online content and HealthSpace. This will act as a 'front door' to the best information on health and care available on the internet'.

### 3 Policy Context and Record Access

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Following the General Election in May 2010, as part of its drive towards transparency, the Coalition Government announced in its Programme for Action: ‘we will put patients in charge of making decisions about their own care, including control of their health records’. This would feed into the Quality, Innovation, Productivity and Prevention (QIPP) initiative.

Established by the previous Government, the QIPP initiative is a large scale transformational programme for the NHS, designed to improve the quality of care the NHS delivers whilst making significant efficiency savings. Central to QIPP is addressing the issue of the treatment of patients with long term conditions. The NHS already spends 70% of its budget on the 15m people who have one or more of these conditions. With our ageing population, patient numbers are expected to grow by 23% over the next 20 years. The QIPP LTC programme aims to improve self-care and the role of health information is central to this, including the ability for patients to access their record and track key results and other information.

The White Paper ‘Equity and Excellence: Liberating the NHS’ published in July 2010 announced the key principle of ‘no decision about me without me’, the intent being for patients to be much more in control of their own care, supported by greater access and use of health information, including access to the information held about them in their own care records.

The White Paper stated (paras 2.6 and 2.10):

*‘The Government intends to bring about an NHS information revolution, to correct the imbalance in who knows what...[It]is also about new ways of delivering care, such as enabling patients to communicate with their clinicians about their health status online. We will provide a range of online services which will mean services being provided much more efficiently at a time and place that is convenient for patients and carers, and will also enable greater efficiency.*

*‘We will enable patients to have control of their health records. This will start with access to the records held by their GP and over time this will extend to health records held by all providers. The patient will determine who else can access their records and will easily be able to see changes when they are made to their records... Our aim is that people should be able to share their records with third parties, such as support groups for patients, who can help patients understand their records and manage their condition better. We will make it simple for a patient to download their record and pass it on to any organisation of their choice.’*

In preparing for such an ‘information revolution’, the Government also announced that it would issue an NHS Information Strategy (eventually published 21 May 2012), which would articulate more specific aims around health record control and access. A key issue to consider was the delivery practicalities of Record Access.

## 3 Policy Context and Record Access

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### Online Britain – an overview of uptake and security concerns

As relevant background to the promotion of online health record access, it is worth appraising the uptake of more general online services, for example around banking and social networking, and individual concerns about privacy. Here we summarise our key research findings in this area, with more detail available in the separate evidence review.

According to the Office for National Statistics, in the first quarter of 2012 there were 42.2m users of the internet in the UK, accounting for 83.7% of the adult population. The 16–24 age group had the highest proportion of users (98.6%), compared to 27.4% of over-75s.

According to the Oxford Internet Institute, 44.4% of all internet users can be defined as ‘next generation internet users’, who are those accessing the internet through platforms such as social networking. With internet access increasingly available through mobile devices rather than PCs, and often with data and applications held remotely in the ‘cloud’, digital inclusion is changing rapidly.

In Britain as a whole, 17% of young people did not have access to the Internet in 2009: these people Grant Black of Oxford University calls ‘non-users’. More young people (about 83%) were online than older people (about 70%) and 64% of young non-users (aged 16–24) were not employed.

In 2007, academics Carina Paine, Ulf-Dietrich Reips, Stefan Stieger, Adam Joinson and Tom Buchanan approached the subject of internet users’ perceptions of privacy concerns. Their main findings were that users of the internet generally do worry about their privacy. Out of the 399 respondents to their survey, common causes for concern were: viruses 16.1%; spam 10.5%; spyware 9.9%; hackers 8%; access to personal information 6.8%; security 5.6%; Id theft 3.7%; Trojan 3.1%; deception/dishonesty 1.2%.

The common reasons for not having concerns were stated to include: IT experience 23.1%; not caring 17.4%; nothing to hide 15.7%; not knowing 11.6%; asking ‘Why should I?’ 4.1%; had no problems before 3.3%.

### 3 Policy Context and Record Access

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Measuring the use of Social Networking sites between 2007 and 2009, researchers at Oxford University found that of the 1,578 people who responded, 66% claimed to use social networking sites.

In terms of privacy on social networking sites, which does not necessarily fit with earlier concerns mentioned about online privacy, it has been suggested that the average individual is linked to approximately 290 people on Facebook.

This perhaps demonstrates little general concern over internet security among people comfortable with the online medium.

When related to transactions like internet banking, concern over privacy is highlighted again. However, a 2012 study on the role of trust in internet banking adoption by Cardiff University found that while a majority of customers were initially reluctant to adopt online banking on the grounds of privacy and trust, they subsequently became active users after a period.

The report notes that even if online security in every transaction was measurable objectively, it would never be enough to settle our subjective fears about online security, that is to say 'it is unclear whether this measurement would readily correspond to the consumers' perceptions of security.'

A study featured in the same report by Cardiff University of 441 Halifax online banking users, demonstrated that uncertainty reduction and knowledge about 'intention' are key components of trust in internet banking. Such trust, they argue, is based on three things: reliability of the bank; perceived security in safeguards such as firewalls and encrypted pages; and perceived privacy and assurance that the information given will not be sold to third parties without consent.

Internet users are generally worried about privacy, even if this is not always reflected in their online behaviour. But there is an increasingly confident group of mixed age users accessing the internet through various mediums, for which control and access outweigh the concerns about online safety.

## 3 Policy Context and Record Access

### 3.2 Record Access announcement

Following further consideration of the practicalities involved, as mentioned in Section 2, the Government announced in November 2011 the aim for all patients to have read-only electronic access to their GP medical records ('Record Access'), if they so wish.

This possibility was first described in our 'Fixing NHS IT report', which stated:

*'Software already exists to enable the patient to have access to their primary care record with some of the major solutions. Many patients already benefit from booking GP appointments and ordering repeat medications in this way. Some 50 or so GP practices have provided full patient access to view their record and the capability exists for it to be activated on a much more widespread basis.'*

*'Understandably, there are concerns among some GPs about the impact of opening up their records, particularly at the practical level of managing access, but also at the wider level of how it will change the relationship with the patient and how they use the service. Such fears may or may not be groundless. Thoughtful management of the process may be able to minimise any such risks.'*

A commitment to Record Access was reaffirmed by the NHS Future Forum<sup>6</sup> in their recommendations released in January 2012, when they stated that:

*'...patient access to records will be a vital underpinning of a developing culture of self-care and self-management.'*

In particular, they commented:

*'Almost all GP practices hold electronic health records, and there are no serious technical barriers to opening them to patients. People have a right of access to their records as part of the NHS Constitution, yet such access is still the exception to the rule. Where records have been made available to patients, we have heard that this has resulted in clear benefits for patients and for practices, with patients becoming more engaged and their demands on their GP practices declining. Though patient demand for access to their health records is currently low, it is growing, in line with wider trends in society. Access to records will in future be an important contributor to maintaining and building enduring trust in an evolving NHS and, conversely, a lack of access could be harmful to trust.'*

*'Patient organisations want patient access to records opened up, but they also want the right protections and support for patients to go alongside. Patients with access to their electronic health records value it highly and use it as a platform to improve their health literacy, self-management, and engagement with their health, and to transact more conveniently with services. It has been put to the NHS Future Forum that patient access to records will be a vital underpinning of a developing culture of self-care and self-management.'*

To date, many of the initiatives have been driven by a small band of GP pioneers – case study 3.2 cites one such example. Indeed, according to the NHS Information Strategy document 'The Power of Information', less than 1% of practices currently provide Record Access, although over 50% have the systems capability to offer it (through the PAERS capability as a front end to the EMIS practice system, which has the largest market share).

In contrast, around 30% of practices support transactional services such as online appointment booking and the ability to request repeat prescriptions, although once again many more practices have the systems capability (over 70%). As other GP systems suppliers develop and offer this capability (potentially enabling 90% coverage), there is a direction of travel that can make Record Access a fundamental part of care, especially for those patients with long term conditions. Increasingly the barriers to uptake are cultural and change issues, not technology.

6. NHS Future Forum 'Information' Department of Health, Jan 2012

### 3 Policy Context and Record Access

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#### Patient feedback to Record Access commitment

The commitment to Record Access was broadly welcomed by patient organisations; indeed research conducted by the DH revealed a frustration among patients that it was not available already:

*'I am fed up with debate, action is long overdue; I have every right and need to know about my health, accept and intend to manage my health along with the medical staff, to help me lead my life, let us get on with this!'*

*'It is plainly silly that patients can't see and use their records just like they would access their bank accounts. E.g. I am planning a trip overseas and need to look at when I last had certain vaccinations etc., or want a copy of my blood tests to take to a hospital appointment.'*

*'I am concerned GPs and other health professionals can write what they like and we don't know and only years later find out they wrote things incorrectly and we (the patient) have been affected 'badly/wrongly' by such mistakes! GPs/health professionals will be more careful in writing patient records when they know we have full access to them and can review them; our records should be written 'in cooperation' with us 'the patient' and not 'away' from us!'*

The reaction we received through our survey work from potential service users was mixed, perhaps illustrating a general lack of patient pull. For example, when we spoke to ten attendees of a coffee session at an Open Age centre in Westminster, London, responses included:

*'If you had an accident in Wales or something, they would take those electronic records so they'd know how to treat you – to see what you were allergic to, or medication that you are already on, and they'd have access to have to that ... if you've had an accident then you're not in a fit state to talk about it'*

*'It's good that we're able to see our records at any time without fuss ... when I was working in a maternity ward you used to have to pay £10 to see your record ... but to actually be in charge of them is a very bad idea'*

**But some expressed concerns or apathy:**

*'What is the point?'*

*'Someone could lose it'*

*'Doctors are getting more money for doing less and less and less'*

*'Majority of people don't even care about what's on their records'*

## 3 Policy Context and Record Access

### Case Study 3.2 – Haughton Thornley Medical Centre

Dr Amir Hannan is a full-time general practitioner at Haughton Thornley Medical Centre in East Cheshire. From his early days in General Practice, Dr Hannan sought to build a 'partnership of trust' between patient and clinician. He enabled his practice to offer patients online access to their electronic medical notes and gain a much better understanding of their health via access to trusted health information, maintained on the surgery's website or practice web portal ([www.htmc.co.uk](http://www.htmc.co.uk)). The portal was developed in conjunction with patients in the practice and Glen Griffiths, an e-Health and Digital healthcare specialist experienced in this area.

Dr Hannan encourages patients to use the portal so that together they work as a team to improve the patient's health. In the context of managing a long term condition – as well as minor ailments and acute problems – this enables patients to better understand the treatment and other choices available, supporting shared decision making. The patient therefore becomes empowered.

The practice web portal is loaded with tools and resources, allowing patients of the surgery to book appointments, order repeat prescriptions and access health records. It also provides health tips on diet and smoking, tailored information for teenagers and carers, evidence-based care pathways and even provides information to explain what to do when someone dies. The portal makes extensive use of national information available from NHS Choices, amongst others, but has a local focus at all times.

Also featured on the website are internal and external links to self-care features, which patients are encouraged to consult first before booking an appointment. Other cost and time saving features include video demonstrations for patients suffering with asthma and diabetes. The average patient with diabetes spends approximately 3 hours with clinicians a year only, so learning to self-manage is crucial. Online resources managed by the practice can provide valuable support.

The uptake at Haughton Thornley Medical Centre has been successful, and continues to build. As of March 2012, from a total list of 11,845 patients, 1,917 (16%) now have online access to their GP electronic health records. By patient type, the breakdown is as follows:

- 157 from a total of 709 diabetic patients (22%)
- 59 cancer sufferers out of a possible 219 (27%)
- 30 out of 30 from a nursing home (100%)
- 73 out of 418 pregnant Mothers (17%)
- 148 Bengali patients from a possible 1,560 (9%)

On the website there is a video of a patient representative, Margaret Rickson, who requests to access her record electronically. One aim of this video is to break the myth that only young people are interested in health technology facilities – something clearly demonstrated not to be the case in East Cheshire.

When patients ask the same questions, the Practice writes a response and posts it on the website for others to learn from, preventing unnecessary patient visits and saving precious GP time. These subjects include heart disease, asthma, cancer, fibromyalgia and self-care.



## 3 Policy Context and Record Access

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A research team led by Claudia Pagliari of the University of Edinburgh recently reviewed stakeholder experience<sup>7</sup> at 32 of the 57 general practices offering Records Access. Published in May 2012, their key findings included:

- *‘The generally favourable attitudes revealed by all three stakeholder groups in this survey reflect a common finding in the research literature on Record Access and Personal Health Records; namely that where these are available such systems are well liked by patients and accepted by most professionals.*
- *‘Both patients and clinicians’ believed that Record Access had facilitated shared decision making, health knowledge and self-management, suggesting greater patient empowerment.*
- *‘Most patients (92.3%) had found it easy or very easy to set up Record Access at home (one found it somewhat difficult) and all found the system easy or very easy to use. All were comfortable with the way in which their consent was requested, and most (92.3%) had no concerns about creating an online account.*
- *‘All but one patient had been using Record Access for 10 or more months. Most (84.6%) had viewed their record 6 or more times since registering, and 30.8% more than 10 times. Most (84.6%) had used the system once or more within the preceding fortnight.*
- *‘Most clinicians (80%) believed that Record Access had been well received by patients; the remainder believing it had made no difference.*
- *‘Most reported had shared their record with a spouse, partner or other family member (76.9%).*
- *‘All patients found Record Access “somewhat useful” (38.5%) or “very useful” (61.5%).’*

Further findings from the study are reported below. The authors do emphasise ‘the need for further research to explore patient characteristics associated with the use of Record Access, as would studies examining the mediating influence of clinician characteristics’.

### 3.3 NHS Information Strategy

Published in May 2012, the Strategy (‘The Power of Information’)<sup>8</sup> devotes a whole chapter to the ambition for it to become routine for patients to be able to access their health records online.

The document outlines how the Government will – in partnership with the RCGP – work with patient groups and other professional organisations to develop a plan to support people in accessing services and their records online. From 2013, the NHS Commissioning Board will be responsible for promoting this work with the RCGP and other groups. Particular consideration will be given to matters such as what identity and authentication mean, together with the standards and processes for access and sharing of the record.

The document also outlines how ‘we should be able to access more and more of our health and care records online. An early priority is to be able to access maternity records and the “Red Book” online, since the evidence shows that parents and parents-to-be find these immensely useful.’ In this way, the Government intends for wider use of patient portals, providing an individualised window into one or more organisations’ health records. This is considered further in Section 5.

### 3.4 Other reactions

While some patient groups have been enthusiastic, other parties have cited concerns over patient access, notably the British Medical Association (BMA) around data protection and privacy. The box below summarises their main concerns, and provides a response in terms of the validity of the concerns or how best they should be addressed.

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7. Pagliari C, Shand T, Fisher B ‘Embedding online patient record access: a survey of stakeholder experiences’ JRSM 2012  
8. Department of Health ‘The power of information’ May 2012

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### 3 Policy Context and Record Access

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#### Online Britain – an overview of uptake and security concerns

On 25 January 2012, Dr Laurence Buckman, Chairman of the General Practitioners Committee, BMA, wrote to Peter Short, National Clinical Lead for GPs, NHS Connecting for Health, submitting the BMA's views on the support needed to gain genuine benefit from patient access to GP records.

Dr Buckman raised a number of concerns about Record Access, including the following of specific relevance to the patient viewpoint:

- The patient understanding the record
- Security and confidentiality
- Patients being exploited by companies
- Patient recorded entries

Dr Buckman noted that historically the record has not been written by medical professionals for general lay readership and so will require substantial support, and potentially extend, rather than reduce, consultation time. In one published research, 33% of patients surveyed reported difficulty in understanding their medical record: for instance abbreviations, terminology and test results. On the other hand, recent unpublished research suggests that 75% patients say they understand the record, particularly when linked to Patient Information Leaflets.

Not only is Dr Buckman generally concerned about security and protection, he worries that individuals could be coerced into disclosing personal information, for example if that person finds themselves in an abusive relationship. It is expected that in these circumstances, guidance should be given to patients to contact the surgery so that their access can be turned off.

Another of Dr Buckman's concerns is that with patient-edited information, contributions could be subject to what he calls 'gross manipulation', noting that any change in patient input of this nature must be approached with caution. In response, it is felt that it would be best to start with structured entries by patients.

Citing the evaluation of HealthSpace by the University College London, Dr Buckman notes that there is little evidence that there are cost-benefits to a change in levels of patient record access. Recent unpublished research however suggests that Record Access offers substantial savings in telephone calls and appointments with clinicians. This confirms similar conclusions from the US.

### 3 Policy Context and Record Access

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In May 2012, Dame Fiona Caldicott, the NHS information governance champion, was also quoted as stating that it was ‘quite a tall order for hard pressed GPs and their teams to manage this within the next two to three years’, due to the challenges facing GP practices. She pointed to the

*‘potential for GPs to face additional workload to make records available; the handling of patients’ reaction when records are found to be inaccurate, or are otherwise concerned by their contents; and whether patients should be allowed to see their test results before their GP.’*

Others have echoed concerns around the difficulties patients may find in deciphering their record. As Professor Jeremy Wyatt of Warwick University commented in the British Medical Journal in June 2012:

*‘Most patient records now are an informal aide memoire, full of quirky individualism and undefined local practice governing how words, phrases, and codes are used. So that the record can be understood by all, it must change into a document written for others to read, using language and codes predictably organised under standard headings agreed on by the professions.’*

Equally, patients need advice on how to look after their electronic health and social care records. In this regard, the BCS, the Chartered Institute of IT and DH recently co-announced a plan ‘to develop clear and easy-to-follow guidance for patients and the public on the subject of electronic health and social care records... The guidance is intended to support the increasing number of patients and the public accessing their records online, and those making use of the growing number of electronic services to store and share personal health and care data.’ This work is to be welcomed.

From our own survey work, the importance of security mechanisms is borne out. 67 (78.8%) out of the 90 people (without long term conditions) surveyed about record access and record ownership raised the issue of security – and the risk of unauthorised access to one’s record – as a key concern around the potential usage and accuracy of the electronic health record.

Of the 172 people we surveyed who self-identified as having one or more long term condition, 130 (78.3%) responded with concerns about security. Of those, 63 (48.8%) were very concerned that information available on their PHR will be accessible to health professionals for whom it is not relevant. However, 22 (17.1%) of those who raised security fears were, regardless, frequent users of online health management resources and 56 (43.4%) were fairly regular users.

Taken with other research around the uptake of online banking, and the international experience with PHRs (see next chapter), one can readily form the view that while security appears as a concern for those not using the technology, it becomes much less so for those who do use it, if the end gains are worthwhile. As one patient explained it to us,

*‘Using smart cards to access online banking may be a real hassle, but it is much less than having to go in person to a branch to action things, so people persevere!’*

Perhaps the same analogy will be made in the future as patients increasingly engage with Record Access and PHRs?

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### 3.5 Key features

We now turn to the question of what features patients would find most useful as part of Record Access.

The Pagliari 2012 paper, reporting on active Record Access users, ranked the most frequently used features as follows:

1	84.6%	Accessing test results
2	53.8%	Accessing clinician letters
3	53.8%	Checking condition
4	53.8%	Encounter

Our own survey work with over 260 participants provided slightly different findings on what patients felt to be most important, albeit that most respondents had not used Record Access in practice. For example, amongst the 172 people polled who classified themselves as having a long term condition, the following functions were felt to be most useful:

1	78.7%	Ordering repeat prescriptions
2	77.3%	Secure messaging to your GP
3	76%	Appointment booking
4	60%	Tailored health information
5	40%	Monitoring health trends
6	37.3%	Access to support groups

Equally, for the 90 participants who did not disclose a long term condition, the following functions were prioritised:

1	87.1%	Appointment booking
2	75.6%	Ordering repeat prescriptions
3	67.1%	Secure messaging to your GP
4	62.2%	Tailored health information

While there are understandable anomalies between the different rankings, the overall message is clear: people overwhelmingly value the transactional support that Record Access brings.

On a wider basis, from our literature review, we have also found patients highlighting the following functions and benefits:

- Facility to view my data and note if it is accurate or not
- Ability to comment on my record without others editing what I say
- Ability to choose and manage how my records are shared with other trusted parties
- Accurate recording of my special needs so the services become truly ‘personalised’
- Access to my own health data for other purposes e.g. completing forms for benefit claims or insurance
- Ability to keep track of my healthcare from home without a need to visit the surgery
- Better understanding of my condition through access to the complete medical record
- Ability to print out a copy of the record, which helps when I move house or see clinicians outside the practice
- Enabling my carer to help me track and manage my health condition better

## 3 Policy Context and Record Access

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### 3.6 Perceived benefits

While Records Access can facilitate better care it is not an end in itself. Rather it needs to bring about behaviour change, where patients become more involved, informed, equal partners in their care and make positive healthy choices to improve or maintain their health. If we allow people access without providing further information, support and interpretation, Record Access will achieve nothing.

So what has been the experience to date in terms of benefits and impact to patients?

The 2012 Pagliari study reported the following:

- *‘Impacts on patient self-management – while most clinicians (66.7%) did not perceive that Record Access had changed the way patients manage their health, 26.7% did.*
- *‘Impacts on knowledge and self-care – most patients believed it had improved their knowledge of their condition (92.3%) or their understanding of clinical management (76.9). 76.9% believed it had helped them to manage their health, through encouraging them to take medication on time (23.1%), follow lifestyle advice (46.2%) or become aware of how their behaviour is influencing their health (46.2%).*
- *‘Impacts on satisfaction – 46.2% of patients indicated that Record Access had improved their satisfaction with the health centre and 46.2% that it had made no difference. One reported a negative influence.*
- *‘Impacts on communication and trust – 38.5% of patients indicated that Record Access had improved their trust in the health centre and their confidence in sharing information or decisions with their doctor, while 61.5% indicated that it had not affected these factors. Just over half clinicians (53.3%) thought it had facilitated shared decision making and trust during consultations and 20% felt more confident in communicating with patients as a result.’*

An earlier study<sup>9</sup> (reported 2009), conducted by Brian Fisher et al, explored the perceptions of 43 users of Record Access, aged between 20 and 71 years. Of these, nine were in the healthy group, eight had long-term health conditions, 10 were in the mental health group and 16 were pregnant. One of the themes that emerged from the report is that full access was used to prepare patients for consultations and compensate for poor or complex communication. It had little effect on behaviour but acted to reassure patients’ confidence in doctors.

Other studies have reported that Record Access has led to one or more of the following benefits to patients:

- A better understanding of how their doctors think
- Correcting the record, by validating against patient recall and thus improving safety and avoiding possible treatment errors
- Convenience without need for face-to-face professional ‘re-assurance’
- Reduced anxiety and stress associated with diagnosis and treatment
- Greater engagement with condition and chosen pathway
- More in charge of their illnesses and their lives

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9. Fisher B ‘How patients use access to their full health records: a qualitative study of patients in general practice’ JRSM 2009

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## 3 Policy Context and Record Access

### 3.7 Prerequisites for effective roll-out

The supporting Evidence Base document to the ‘Power of Information’ makes certain projections about the degree of uptake of Record Access: 5% by May 2015 and 30% by 2021. Based on international experience, these are ambitious targets.

To enable delivery, the DH and RCGP have established a stakeholder group to drive the Record Access forward. 2020health believes it will need to look at a number of areas of action, including:

Category	Prerequisites
Stakeholder Engagement	<ul style="list-style-type: none"> <li>National clinical leadership from the RCGP (and other Royal Colleges) to champion it with GPs and other clinicians, achieving a common understanding of what is meant by Records Access</li> <li>Encouraging intermediaries such as patient organisations to help patients better understand what their record means</li> <li>Support and incentives for suppliers; gearing systems to patient needs as well as those of practices</li> </ul>
Communications	<ul style="list-style-type: none"> <li>Improving awareness through producing relevant, engaging information and case studies, social networking and support from patient groups that look at Records Access from a patient’s perspective</li> <li>Publication of peer-reviewed evidence and examples of benefits for patients and GPs</li> <li>Creating patient demand in GP practices where Record Access functionality is not available</li> <li>Guidance to help patients become aware of the benefits of access; and understanding the content of their records (The BCS – DH work on providing advice to patients on how to look after their electronic health records – will be key here)</li> </ul>
Policy and process	<ul style="list-style-type: none"> <li>Simplicity of sign up and use (current processes can be somewhat time consuming for both practices and patients)</li> <li>Effective channels for patients to ask questions and get transparent responses</li> <li>Clarity and assurance around access, consent, security and governance provisions</li> <li>Clarity around dealing with patient requests to change data held on their records, together with a clear audit trail</li> <li>Ensuring equitable access through a variety of internet-ready media, with particular effort to reach the digitally excluded (older and disabled people being the most likely not to have access, as well as those in lower socio-economic groups, including traveller communities and the homeless)</li> </ul>

## 3 Policy Context and Record Access

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### 3.8 Conclusions

In this chapter we have charted the policy journey towards the Government's objective of Record Access.

In particular, we have highlighted the increasing shift in policy towards encouraging improved levels of self-care, primarily around the management of long term conditions. The 2010 White Paper announced the key principle of 'no decision about me without me', the intent being for patients to be much more in control of their own care, supported by greater access and use of health information, including access to the information held about them in their own care records. This commitment to Record Access was reaffirmed by the NHS Future Forum, with the statement that 'patient access to records will be a vital underpinning of a developing culture of self-care and self-management.'

To date, many of the Record Access initiatives have been driven by a small band of GP pioneers and less than 1% of practices currently provide the facility. As GP systems suppliers develop and offer this capability (enabling a potential 90% coverage), there is a direction of travel that can make Record Access a fundamental part of care, especially for those patients with long term conditions. Most people value highly the transactional support that Record Access brings, particularly in terms of appointment booking and ordering repeat prescriptions. The evidence review points towards improved levels of patient self-management, knowledge, communication, satisfaction and trust through Record Access. The barriers to uptake are rapidly becoming cultural and change issues, not technology. Record Access must lead to behaviour change, where patients become more involved, informed, equal partners in their care, making positive healthy choices to improve or maintain their health.

We have identified a programme of activity needed to deliver on the commitment of Record Access. The recently formed DH/RCGP stakeholder group will need to look at a series of actions around stakeholder engagement, communications, policy and processes to achieve the ambitious levels of uptake that DH has targeted.

## 4 PHRs – an international perspective

The world comprises diverse cultures and belief systems, but it would seem that we largely share common attitudes towards the electronic PHR. Based on our research, consumers generally support the concept of remote 24/7 access and ‘patient control’, but they fear the spectre of invaded privacy and unwanted disclosure.

We have found that governments, healthcare providers and medical insurers promote uptake of PHRs with broadly the same message; namely, that patients who engage with their own healthcare secure better health outcomes and incur lower costs. A PHR centralises important medical information, ensures against data loss and medical errors, facilitates user convenience (such as ordering repeat prescriptions), and enables patients to make better lifestyle choices. The benefits are most palpable for those living with chronic conditions or disability, or those living in remote areas without easy access to primary care services.

In this chapter, we paint a picture of the development and use of PHRs around the world, in turn looking at Europe, the USA and elsewhere.

### 4.1 Europe

The need for improved levels of self-care and the role that PHRs may take in this have been consistent themes for some time as policy makers consider the future of healthcare across Europe. For example, the May 2012 report<sup>10</sup> by the eHealth Task Force to the European Commission called ‘Redesigning health in Europe for 2020’ noted a number of levers for change, the first being ‘My data, my decisions’ with the following attributes:

- Individuals being the owners of their own data
- Data being liberated (i.e. ‘open’ and shared on the condition that it is subject to rigorous safeguards)
- Connected datasets (personal datasets all woven into one single datastream) to reap benefits such as support for a continuous health treatment rather than isolated interventions
- Total inclusion, including hard-to-reach individuals

The report calls for the creation of a legal framework and space to manage the explosion of health data. This needs to put in place the safeguards that will allow citizens to use health apps with confidence that their data is handled appropriately. Subsequently it will create the conditions for the integration of user-generated data with official medical data so that care can be more integrated, personalised and useful for patients.

At the country level, the relationship between state and individual, and the development of an eCitizen culture, has an important bearing around uptake. Denmark,<sup>11</sup> with a population of 5.5m, leads the way in European eHealth and patient-controlled health records. It boasts a universal Electronic Health Record system and a national PHR service available to any Danish citizen. Launched in 2003, the country’s government-run PHR portal is Sundhed.dk, a website where ‘the citizen can...view treatments and diagnoses from his own hospital patient record, book appointments with his GP, renew prescription drugs, monitor own drug compliance, survey shortest waiting lists for operations and quality ratings of hospitals, register as organ donor, and get access to local disease management systems in out-patient clinics.’ The uptake amongst patients of the PHR facility is approximately 10%.

Denmark’s strong eHealth ranking is assisted by the fact that more than 95% of the population has internet access. Around 90% claim to use the internet to search out health information; by contrast, the figure for the USA is 67%. Elsewhere in Europe, patient-held smartcards are now widely used. In France, Germany and Austria for example, they are primarily used for health insurance purposes, and there have been recent investigations to see whether they could be broadened to incorporate PHR capabilities.

### 4.2 USA

In the USA, public attitude towards the PHR is somewhat unclear. While a 2006 survey<sup>12</sup> for the Markle Foundation found that almost two-thirds of the US public (65%) was interested in electronic access to their own personal health information, a similar majority four years later claimed that they saw little value in possessing a PHR. This statistical anomaly may simply come down to the context and wording of the question; so what about user adoption trends?

10. EHealth Task Force ‘Redesigning health in Europe for 2020’ European Union May 2012

11. Grey BH et al ‘Electronic Health Records: An International Perspective on “Meaningful Use”’ Commonwealth Health Fund November 2011

12. Lake Research Partners ‘2006 US survey on ePHRs’ Markle Foundation November 2006



## 4 PHRs – an international perspective

According to a Deloitte survey in 2010, in 2008 just 3% of US adults were using some sort of PHR; by 2010 this had risen to 10%. The same research quoted findings<sup>14</sup> from the California Healthcare Foundation, that ‘while privacy is still a concern, consumer sentiment is slowly changing. Once consumers start using a PHR, fears about privacy and confidentiality noticeably diminish.’

Nevertheless, some apathy towards the PHR even among users has been recorded, with comparatively few exploiting the potential on offer. The success of the PHR clearly depends on significant cultural change.

The range of PHR products is vast. In 2009 a study published by the Journal of the Medical Library Association identified 91 distinct types of PHRs in the US alone. At the basic end of the spectrum it is a stand-alone product, with all medical information entered by the consumer. This information may be held online, or electronically stored on a smartcard or some other mobile

device (such as a flash drive) to provide important emergency data. The most comprehensive PHRs are tethered to the user’s official medical health records (some linked to an EHR), with information entered by both clinician and patient. These products offer many conveniences to the user, such as prescription refills, access to lab test results, and secure messaging with a clinical team.

Illustrating the difficulties in the market, one of the major players, Google Health, decided to close down its PHR capability in 2011, commenting ‘It is not having the broad impact we’d hoped...there has been adoption among certain groups of users like tech-savvy patients and their caregivers, and more recently fitness and wellness enthusiasts’.

Among the most advanced and widely used PHR systems are those of Kaiser Permanente, the Veterans Health Administration (VHA) and Aetna. Case study 4.1 considers Kaiser Permanente’s PHR service and uptake, while case study 4.2 highlights patient attitudes towards information sharing within the context of the VHA.

### Case Study 4.1 – Kaiser Permanente

The US healthcare provider Kaiser Permanente (KP) operates in nine states and the District of Columbia, serving 8.7m members with 36 hospitals and medical centres, and 533 medical offices.

By 2011, KP claimed a 58% adoption rate among eligible members for ‘My Health Manager’, the company’s electronic PHR. Linked to the EHR, My Health Manager became fully operational in 2007, allowing members to:

- View past visit information, latest test results, immunizations, allergies and healthcare reminders
- Exchange secure e-mail with their doctor’s office
- Schedule appointments and manage prescriptions (such as ordering refills)
- Learn about specific medications in KP’s health encyclopaedia

- View health information and use features on behalf of a family member
- View follow-up instructions for past visits
- Take or review a Total Health Assessment

The rapid adoption<sup>15</sup> of KP’s PHR testifies to the trustworthiness, usability and convenience of the service. Among its most frequently used components are prescription refill, online appointment transactions, test results viewing, and consultation of the health encyclopaedia and medical facility directory. Time and cost saving benefits have also been noted: between 2007 and 2010, secure messaging between members and doctors’ offices increased from 12% to 28%, while members’ visits to doctors’ surgeries fell from 72% to 58%.

Membership demographics reveal wide breadth, across age and income especially. KP is concerned about the lack of Hispanic members, although they are planning more pages in Spanish on the My Health Manager site.

14. California Healthcare Foundation ‘New National Survey Finds Personal Health Records Motivate Consumers to Improve Their Health’ April 2010

15. Glen C et al ‘The Kaiser Permanente Electronic Health Record: Transforming And Streamlining Modalities Of Care’ Health Affairs 2009

## 4 PHRs – an international perspective

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### Case study 4.2 – US Veterans Health Administration

As a large integrated healthcare system, the VA provides healthcare services for a population of about 23 million eligible veterans, with 225,000 employees operating from 153 hospitals and many other centres (2009 figures). The VHA's information system is built around a comprehensive, integrated, open source electronic health record (EHR) known as VistA (Veterans health information systems and technology Architecture).

The VA's 'My HealtheVet' is one of the world's most sophisticated online PHR systems, providing secure patient access to the EHR. As our previous report on the use of telehealth in the VA demonstrated, the VA has a major commitment to delivering remote care at scale with over 50,000 telehealth users.

As of June 2011, My HealtheVet had over 1.3m registered users, predominantly male (88%) and with a median age of 61. In a recent My HealtheVet survey, 79% of participants expressed interest in sharing some or all of their PHR with a family member, caregiver, or non-VA healthcare provider.

Well over half of respondents (62%) indicated that they would share information with a spouse or partner. Two thirds of these were willing to share all components of their PHR, with equal or greater interest in sharing the single components of medication lists, schedule appointments and lab/study results.

A quarter of respondents expressed interest in sharing their PHR with an outside healthcare provider. Nearly half (49%) of these would want share all components of the PHR, while 57% would share the specifics of medication lists and/or laboratory (or study) results.

Most respondents registered interest in delegating specific PHR responsibilities, such as requesting prescription refills, scheduling appointments, entering health information and communicating with the care provider.

Users expressed less interest in sharing personally-entered health information, while the majority of respondents wanted their personal correspondence with the provider to remain confidential.

Patients also indicated that they thought it important that information they uploaded into their PHR, such as blood sugar or blood pressure levels over time, be downloadable as graphs that they could print and bring to a future doctor's visit.

Satisfaction with the My HealtheVet system has been rated as high, with the overwhelming majority of users happy to recommend the service to other veterans.

## 4 PHRs – an international perspective

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The US government has encouraged providers to create a ‘Blue Button’ service, which allows users to instantly download a copy of their PHR to any computer, in order to store it electronically or to print out. The service further assists information sharing with family or carers, or with any other clinician or medical provider.

The challenge for the USA is to establish national standards that will ensure PHR security, interoperability and transportability.

### 4.3 Rest of World

New Zealand ranks close to Denmark in terms of the EHR, with every general practice in the country hooked up to the system. However, it is only just beginning to explore PHR options.

Australia is ahead in this respect, with a national PHR system due to launch in July 2012.<sup>16</sup> Its aims are: increased consumer involvement in the management of their health by giving them access to their own health records; better quality of care through communication and sharing of health information between consumers and health professionals.

The Australian ‘Person-controlled Electronic Health Record’ (PCEHR) will initially have limited flexibility. The essentials of 24/7 access, user governance, and clinician/user information input are in place; importantly, ‘the first release delivers the core functionality required to establish a PCEHR System that can grow over time.’ In the 2012–13 financial year, the Australian Government projects approximately 500,000 citizens to take up the PCEHR service, with 1.5 million in the following year, 2.2 million in the year after and 2.6 million in three years’ time.

In Canada, Toronto’s Sunnybrook Health Sciences Centre offers PHRs to its patients, and the Canadian Medical Association have launched a (physician-driven) electronic patient health record platform, allowing patients direct link with their physicians. Those considered more likely to adopt PHRs are people with serious chronic conditions or disabilities, parents with small children, people with a strong interest in maintaining healthy life styles, and the elderly or their caregivers.

Various other countries around the world are considering or countenancing PHRs, either through national or regional programmes, or through private healthcare initiatives. Countries with published reports on PHRs include Japan, India, South Korea, Iran and Mexico.

### 4.4 Conclusion

Mass uptake is perhaps some way off, but evidence points to mounting interest in PHRs around the world.

While consumer uptake is linked to cultural trends, particularly general internet activity among the population and education surrounding self-care, a key driving factor seems to be the presence of a comprehensive, integrated EHR.

Among the frontrunners in the field, Kaiser Permanente, the Veteran Health Affairs and Denmark each delivered the full, longitudinal health record before making the PHR available to patients. In these cases the uptake has been relatively high, with Kaiser leading the way at 58% among eligible members.

In other cases, demand has been stimulated directly by patients. In the US, for instance, individuals with commercial health insurance may choose to hold the record themselves if they are concerned about continuity of care. In this way, if they switch from one health insurer to another (by changing jobs, for example), they have the assurance of taking with them their health information.

In the next chapter, we explore the development of PHRs in the NHS and patient attitudes towards them.

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16. ‘Australian PHR Mandate Demonstrates Significance of MMRGlobal’ Bloomberg May 2012

## 5 PHRs – the UK perspective

### 5.1 What distinguishes PHRs from Record Access?

As demonstrated in Chapter 4, the international evidence points to mounting interest in PHRs around the world. In this chapter, we explore the development of PHRs in the NHS and patient attitudes towards them, in particular addressing:

- The distinction between PHRs and Record Access
- The uptake of PHRs amongst the healthy
- PHRs for complex/chronic care users

Recognising that PHRs act as a means to enable better care and coordination, Table 5.1 summarises the types of capabilities that typical PHRs provide, and shows which of those elements are distinct from the Record Access capability (and general patient portals) explored in Chapter 3.

PHR Characteristic	Record Access?
Allow patients to access personalised care plans	✓
Allow patients to download, store and organise letters and scans, information about inoculations/injections	✓
Track the progress and results of tests	✓
Book GP visits, order prescriptions	✓
Secure messaging with the GP and practice colleagues	✓
Integration/linkage with NHS-hosted electronic health records	✓
Patient-entered data; enable patients with complex and chronic conditions to track and monitor their conditions through recording of data at home, keeping a symptoms diary	✗
Allow data to be transferred from telehealth devices at home and monitored by a clinician	✗
Provide use of specifically focused apps to help lose weight, give up smoking, etc.	✗
Provide use of apps to motivate general wellbeing and fitness goals	✗

## 5 PHRs – the UK perspective

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The PHR utility is wide-ranging and offers potential solutions to age-old problems. For example, when consulting a GP, patients often have to recall parts of their medical history from memory (not always successfully), taking up valuable time in clinic. As noted in the table, part of the PHR's function is to support patient-entered data. This can include subjective data such as symptom scores, qualitative descriptions of symptoms or medical problems. It may also be possible for patients to complete questionnaires and to write their history before arriving for a consultation. The current RCGP advice is that 'health professionals should use this to supplement, not replace, their clinical assessment'.

Furthermore, through direct patient entry or via interoperable devices, patients' self-monitoring data from telehealth devices could be added into their PHR. This could include blood pressure, peak flow, blood sugars and oxygen saturation measurements, and lifestyle information such as diet and exercise charts.

### 5.2 Uptake of PHRs amongst the healthy

Our research in terms of evidence review, surveys and case studies suggests that the uptake of PHRs amongst the predominantly healthy, general population will only happen where it is demonstrably useful, fitting well into people's daily lives, particularly if they are remote to available services. Other prerequisite features are that the PHR must be secure, reliable and easy to use. Without this, PHRs will only ever be for enthusiasts.

As the 2010 UCL evaluation of HealthSpace noted, PHRs need to align well with patient attitudes, self-management practices and with their care plan, otherwise the PHR will not capture the public's imagination. The experience with HealthSpace found that the information in the Summary Care Record was too brief and restricted, and, as described in Chapter 3, the hurdles to its access prevented uptake.

As a proxy for understanding the views of actively healthy people within the general population, we surveyed ten regular gym users (between 2 to 4 times per week) to ascertain the desire to own and control a PHR. While there was desire to monitor weight, calorie intake, pedometer usage and communicate with others about progress via social networking tools, there seemed little overt desire to use a PHR for this purpose. However, all but one said using a PHR would appeal to them.

From our online survey of people who did not classify themselves as having a long term condition, 33 (49.3%) of the 67 respondents believed that a PHR would help them be more organised and keep track of their healthcare records; just 13 (19.4%) did not believe this would be the case at all.

The predominant concern raised was around security and who else would have access to the record, especially if these were employers and insurance companies. Another issue raised was the 'internet-savvyness' of younger people compared to that of the older generation. Though some mentioned concerns that they would not have time to check their records, others felt that the self-policing of the record was a good thing, drawing analogies to checking one's online banking records.

Where a PHR can integrate into other digital tools that enable us to live easier lives, then uptake amongst the largely healthy may well occur. For instance, one user we spoke to gave the following scenario:

*'When I have an international business trip coming up, I record it in the Trip-It app. If this could check back to my PHR to ascertain whether my inoculations are up to date for that country, and then highlight that I need a tetanus jab, and go ahead and book me an appointment by checking my on-line calendar, that would be enormously helpful.'*

In this way, the use of apps could be key in driving uptake around PHRs for the healthy population, especially where they can integrate with NHS health record systems. The box below summarises the Government's recent efforts to encourage the development of health apps, and some relevant developments in their use.

## 5 PHRs – the UK perspective

### Maps and Apps in the NHS

In the autumn of 2011, the Department of Health invited people to contribute to a conversation<sup>17</sup> about innovation, information and apps for health and care – the Maps and Apps project. In a six week period, almost 500 entries were received.

Commenting on the culture shift taking place in health and technology, the Secretary of State for Health Rt Hon Andrew Lansley MP commented that:

*‘So many people use apps every day to keep up with their friends, with the news, find out when the next bus will turn up or which train to catch. I want to make using apps to track blood pressure, to find the nearest source of support when you need it and to get practical help in staying healthy, the norm.’*

To capture this move, Cambridge Healthcare are currently developing and promoting an e-health portal for patients which will, with the NHS IT infrastructure, provide a platform for an unlimited amount of healthcare applications on secure personal health records platforms. They have now created [howareyou.com](http://howareyou.com), which has been briefed to the Secretary of State as the ‘Facebook of healthcare’.

Another initiative has been launched by NHS Local,<sup>18</sup> offering a range of digital services for NHS staff and the public in the West Midlands. One of its essential aims is to increase awareness amongst the public about what a care plan means and how they themselves can be part of their care planning. Through providing apps to the public, and with intent to offer a PHR integrated with the clinical record in the future, so patients and their carers will naturally start to interact with their clinicians.

Our research work also highlighted an ideal use of PHRs amongst the healthy population, where shared care arrangements demand continuity of information around that held by the patient.

As Fiona Godlee, editor of the BMJ, commented in the June 2012 BMJ,

*‘As for designing better pathways of care, it turns out that the only people who know how the whole system works are the patients. Their input transformed the North West London scheme and became, like integrated care itself, obvious. 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.’*

For example, during pregnancy, the mother holds the paper record and will see a range of clinicians, including her midwife. A similar shared care scenario exists around child health, where the mother already holds the paper record known colloquially known as the ‘Red Book’. A major pilot project is underway for an electronic version of this, described in Case Study 5.1.

17. ‘Read all about your favourite health apps and ideas’ Department of Health October 2011

18. <http://nhslocal.nhs.uk/>

## 5 PHRs – the UK perspective

### Case Study 5.1 – ERedBook (Personal Child Health Record Online)

The UK's first electronic Personal Child Health Record (ePCHR), or 'eRedbook' is currently in development and testing, with the aim to get greater parental engagement, to improve data sharing and hence improve outcomes for children.

Building upon the success of the paper version of the PCHR (Redbook), which has been in development over the last 20 years and is used nationally, the ePCHR will provide parents and clinicians with the additional digital tools they need to effectively manage a child's healthcare.

Healthcare organisations involved in the testing and evaluation include NHS Rotherham Foundation Trust, Liverpool Community NHS, NHS South Warwickshire, NHS Moray, Portsmouth Hospitals NHS Trust and One to One Midwives.

The eRedbook, developed by Sitekit Health Ltd, will spearhead the shift from clinician to citizen management of healthcare data, as highlighted in the 'Power of Information'.

Dr David Low, National Clinical Lead for Paediatrics and Child Health, Department of Health Informatics Directorate, cited the eRedbook as a fundamental part of this paradigm shift, highlighting the key challenges and benefits the move from paper-based to online patient records would bring.

Other devices which will access the record include mobile phones, digital pens, and tablets like the iPad. The eRedbook will be designed to interoperate with GP systems, commissioning systems, child health systems, Secondary Use Systems and the National Screening Programme.

In May 2012, the Government announced a £37m national programme to transform the lives of nearly 170,000 older people across the UK, named DALLAS (delivering assisted living lifestyles at scale). The programme intends to explore way of using innovative products, systems and services to create more independent lifestyles. Four schemes have been chosen to work with local communities. One of the DALLAS schemes ('Year Zero') intends to use a version of the eRedBook, as part of a wider initiative to empower individuals to actively manage their health information from cradle to grave.

## 5 PHRs – the UK perspective

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Other example areas are being piloted at South Devon Healthcare Foundation Trust (see Case study 5.2), using a patient-controlled medical records system that integrates into the NHS secure network. This offers safe tools for patients to work online with clinicians, and is designed to enable patients to better organise, manage and control their own healthcare provision.

### Case Study 5.2 – South Devon Healthcare NHS Foundation Trust

South Devon Healthcare NHS Foundation Trust uses the PHR application as part of the Trust's IT strategy for joining up primary, secondary and social care. Torbay Hospital is the first to integrate their laboratory system with the application, allowing patients to receive test results directly and facilitating online consultations using Skype.

The platform is provided by the company Patient Knows Best (PKB) and has been deployed in two specialties to date, namely speech and language therapy, and colorectal surgery. A further application is being developed for respiratory medicine.

The service for speech and language therapy has been used by out-of-area patients, enabling virtual support with no face-to-face contact whatsoever. Through this platform, clinicians in South Devon are using Skype. Bowel cancer patients, for example, who are unable or have difficulty in leaving the house, can sometimes use it as an alternative to face-to-face communication.

The PHR platform is all under a patients' own control. A patient can invite in a clinician, and whoever they feel is right to participate, but they can also delete information – in much the same way that Facebook is used. After a consultation, through Skype or just face-to-face, the clinician and the patient can document what happened using the PHR.

What the PHR aims to offer, which South Devon has taken up, is a series of time-saving measures for the patient. Online meetings are now available from home or the office. PKB provides a single access point for all the professionals involved in a patient's care (both inside and outside of the NHS). It also allows patients to upload as much data as they want. For clinicians this could significantly reduce face-to-face appointments, as well as save time in written communications with the patient.



## 5 PHRs – the UK perspective

A further example is at South London and the Maudsley (Case Study 5.3), who are introducing a PHR as a way to empower patients.

### Case Study 5.3 – South London and the Maudsley NHS Foundation Trust

The vision for SLaM, South London and Maudsley NHS Foundation Trust's patient empowerment portal, was set out in the Trust's 2008 Information Strategy, which looked at how technology can enable business and cultural change to support new models of patient care. It was also a way of unlocking the wealth of health data available to researchers within a secure and governed environment.

SLaM has a long-term relationship with its patients, so the Trust wanted to accommodate an ecosystem where information from the patient, the researcher, the clinician and the commissioner could all work in harmony. This was just one of a number of initiatives by the Trust to facilitate patient empowerment, placing the patient at the centre of clinical decision-making and utilising their own personally-recorded data.

In this way, the Trust is developing a PHR based around the Microsoft Health Vault platform to support the sharing of patient care plans, which are truly portable for the patient. The project launch was in May 2012.

Part of the thinking that informed the development of the portal was the acknowledgement that NHS service users, especially those receiving care for mental health, were absent from important decision-making about the services they received. Not only would SLaM's portal facilitate an improved relationship between patient and professional, it would also foster a long-term change in healthcare generally, with much greater emphasis on effective outcomes.

In terms of what the portal can do for the patient, one important aim was to show that through empowerment comes a wider share of responsibility and control over the healthcare that the patient receives. However, clinicians do not have access to a patients' own record without their consent. When the patient is happy, it is only then that that information can flow into the wider Trust's record.

As well as visiting health facilities in the US where the personal health record has better uptake, and doing their own literary review, SLaM have engaged patients and patient groups who voluntarily want to be a part of the original pilot for the portal. Clinicians are heavily involved, too, since they must equally be enthused by changing the culture, dialogue and relationship between patient and health professional.

An evaluation after six months will take place by the Institute of Psychology, and an external agency will take an independent economic evaluation.

## 5 PHRs – the UK perspective

In conclusion, the uptake of PHRs among predominantly healthy populations remains at an embryonic stage. An ideal use of a PHR is where the patient needs to be at the centre of shared care and where there is a need to connect up information flows across organisations. The patient – or more specifically his or her PHR – could be that conduit of information.

This is especially true in cases of chronic or complex care needs, which we now discuss.

### 5.3 PHRs for complex/chronic care users

Our work suggests that PHR usage is most likely to take off amongst engaged groups of patients, committed to self-management. Those with complex, chronic conditions, often with more than one long term condition, are most likely to find a PHR useful and have the most to gain in the first instance.

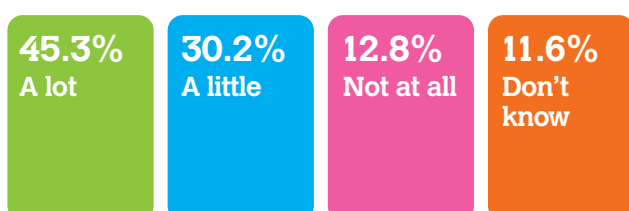
As one patient we spoke to said,

*‘Obtaining test results, clinical advice, repeat prescriptions, condition monitoring at home, the ability to correct mistakes, communicate with the clinical team are all aspects which make an individual’s life easier and it is these things which would encourage uptake. It also offers the most gain for clinicians too.’*

In our survey of 172 people with long term conditions, 39% said they would find a PHR reassuring, and 28.4% claimed they would be fairly reassured; 23.3% said they would not be reassured at all, and 9.3% didn’t know.

Of those who said they would not be reassured, 65% were very concerned that information available on their record would be accessible to health professionals for whom it was not relevant, and almost all of them (92.3%) cited security and the risk of unauthorised record access as their major concern.

When asked whether they believed a PHR would to organise and keep track of their healthcare records better, they responded:



Many respondents who believed a PHR would help organise and keep track of records better were already frequent users of online resources: 25.6% confessed to being regular users and 53.8% said they were fairly regular. This group was more likely to be concerned with accuracy of the record (76.3%) rather than security (71.1%).

Of those who did not believe a PHR would help them keep better track of their healthcare records, there was only one frequent user of existing online resources (4.8%) and 4 fairly regular users (19%), while the majority did not use these resources at all (76.2%). The clear implication is that exposure to existing online resources informs the desire to use a PHR.

## 5 PHRs – the UK perspective

To illustrate some of the potential ways in which PHRs can help patients with long term conditions, we now consider several case studies. The first, Case Study 5.4, describes the project with the largest PHR usage in the NHS, to our knowledge, which is the Renal Patient View.

### Case Study 5.4 – Renal Patient View (RPV)

Renal Patient View (RPV) is designed to help empower kidney patients by providing a secure online portal for them to view test results, find out more about their diagnosis, engage in discussion forums, and to enter their own readings. The system is designed specifically for patients to use and is available to 43 out of 52 kidney units in England. There are 17,000 current registered users, the vast majority of these with end stage kidney disease.

In a survey<sup>20</sup> published in February 2012, assessing attitudes towards the RPV, patients claimed value in having an online access point and were not concerned about privacy issues. The study was based on feedback from 257 users registered in 10 kidney units.

Patients reported that RPV ‘helps me feel involved in my wellbeing’ and that ‘it’s part of how I make sense of this awful disease’.

Healthcare staff commented, ‘RPV helps patients take control of their health and make decisions themselves’.

Patients and professionals expressed overwhelmingly positive opinions about the empowering outcomes that have followed from use of RPV, with patients more prepared for hospital visits, and better able to communicate with their doctor and follow recommendations.

Health professionals are very supportive of their patients using RPV, for example in making patients more aware of their results and the relevance of the tests done at the hospital, and in providing useful information that expanded patients’ knowledge.

Patients commented that the most important feature of RPV was access to test results, particularly after a visit to their hospital or GP. It was also found that RPV increased a patient’s sense of self control, enhanced self-care, aided shared decision-making and improved patient-professional communication. It also facilitated a sense of community, online, that encouraged learning too.

As far as privacy issues were concerned, 28% of patients said they were concerned about their privacy when they first heard about the service, particularly with the risk of personal information being accessible online. Among actual service users, the figure reduces to 15%.

20. Mukoro F ‘Renal Patient View: A system which provides patients online access to their test results’ Better Kidney Care for All February 2012

## 5 PHRs – the UK perspective

Case Study 5.5 describes the Scottish ‘My Diabetes, My Way’ project which has huge potential scale, though it is relatively early days.

### Case Study 5.5 – My Diabetes, My Way

My Diabetes My Way ([www.mydiabetesmyway.scot.nhs.uk](http://www.mydiabetesmyway.scot.nhs.uk)) is an interactive support website for people with diabetes in Scotland, where some 250,000 people live with the condition, representing approximately 5% of the population. Since December 2010, people with diabetes have been able to access their records on the website after completing an enrolment process.

The website has many features for those who sign up, ranging from tailored resources to lifestyle information and pathology test results. It is interactive with educational videos, games and tools, and is a shared platform to help improve patients’ knowledge and to facilitate dialogue between patient and professionals.

The website uses the Scottish Government Citizen’s Account Service to authenticate its users, prior to accessing their own data. This service provides a common portal for access to public service information without users having to remember different passwords to access each one. My Diabetes My Way is the first NHS system to utilise this service.

The record access system has only recently exited its pilot phase, and awareness and publicity activities are now underway. As of May 2012, there were just 718 registrants; of these, 374 had completed the enrolment process and 259 were active users, with all 14 NHS health boards in Scotland represented. By the end of 2013, the target is to reach at least 5,000 patients.

A My Diabetes My Way survey found that it was primarily used by people younger than the general diabetic population, with roughly 1/3 having Type 1 diabetes. Regarding security, 26% said they had concerns about their personal details being held on an online platform, but signed up regardless on the promise that personal information was properly encrypted.

The project evaluation, results of which were published on the website in June 2012, found that the record access system had been used by 160 different patients during its first year of use. There had been 1,425 logins, 19,497 web page views, with test results being the most accessed component and the HbA1c being the most widely viewed test.

Feedback on the resource so far has been positive. One patient explained ‘the knowledge provided helps me understand the normal parameters and where I stand/improve,’ while another noted, ‘it is great to be able to view all of my results so that I can be more in charge of my diabetes’.

## 5 PHRs – the UK perspective

Case study 5.6 describes ways in which the internationally renowned Great Ormond Street Hospital for Children is using PHRs to connect teenagers and their parents with the many clinical teams involved in their care.

### Case Study 5.6 – Great Ormond Street Hospital for Children NHS Trust

The Great Ormond Street Hospital (GOSH) gastroenterology unit has recently introduced a patient-controlled medical records system or PHR, based on the Patient Knows Best (PKB) platform. GOSH is an internationally renowned children's hospital that caters for patients from across the UK and beyond.

In GOSH, the PHR is being used for children with gut failure and is assisting with the transition of teenage patients to an adult hospital. All the patients involved in the trial suffer from intestinal failure, a highly complex condition which means that they must be given a nightly treatment of nutrients infused into the bloodstream – normally administered by their parents. For these children and their parents, the means of receiving test results and having round-the-clock communication with clinicians is of great importance.

However, the complex nature of the condition means that a patient's treatment is normally delivered by several multidisciplinary teams across primary and secondary care. It is important in any transition process that all these different people act as a 'joined up' group to ensure consistency of care – something often difficult to achieve with the current system. Dr Susan Hill, consultant gastroenterologist at GOSH explains:

*'The patient transition process is usually a fraught, emotional one that has to be approached very sensitively. Not only are you handing over people being treated by several multidisciplinary teams, you're also dealing with young people who are ... at a very vulnerable age. They need to feel that they are going to be cared for in the way they've become accustomed to when they move from one unit to another.'*

*'One of the reasons why my patients sometimes refuse treatment or fail to take it is because they don't feel they have ownership – they feel that their treatment is being imposed on them. We've been involving the patient more and more in their own care for some time now. PKB is a form of communication that teenagers are very used to dealing with. They're not used to reading long paper letters – and that means they're more likely to get involved.'*

Using the PHR, patients can have online consultations with their clinicians, and have full online access to their patient notes and clinical letters, enabling a more active role in their treatment. By taking a patient-centred approach, the PHR gives the patient more control of their treatment and more control of their lives.

## 5 PHRs – the UK perspective

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Case study 5.7 describes how the Thalidomide Trust is using a PHR as a hub to connect their beneficiaries with appropriate clinical teams.

### Case Study 5.7 – The Thalidomide Trust

The Trust now uses a PHR to assist its beneficiaries across the world to manage their health and wellbeing. The PHR is able to record and capture the often complex nature of a Thalidomide medical history, enabling attending clinicians to quickly understand the interrelated nature of a patient's health problems.

Alan Summerside, support programme director at The Thalidomide Trust said: 'We conducted research in 2006 which found that the overall health of our members was deteriorating fast. Many were living with increasingly high levels of "co-morbidity" – multiple and often interrelated health problems. Through our new eHealth platform, we now have an all-embracing system which we believe will enable users to receive better treatment and improve both their health and wellbeing'.

Thalidomide patients often have complex, interrelated healthcare needs – often too complex for a GP to get to grips with in a ten minute consultation and often too interrelated for any single specialist clinician to tackle either.

Through the PHR, Thalidomide patients control their own medical records and have an online health 'journal' which ensures that doctors who are invited to share the records can track health and wellbeing over time. Patients can contact their doctors through a secure messaging system with the option to use Skype. This ensures that an individual's different specialist clinical teams can have a shared view of their medical history.

The PHR has been tailored to provide an online library of frequently occurring Thalidomide health related conditions. The platform also gives access to a virtual health clinic, run by specialists at The Thalidomide Trust, which helps patients find the right combination of therapeutic, clinical and social care.

## 5 PHRs – the UK perspective

Our final case study, 5.8, describes how University Hospital Birmingham aims to provide patient connectivity into their comprehensive, integrated Electronic Patient Record. With the reforms introduced in the NHS Act, other leading acute trusts may follow similar suit in providing integrated patient portals.

Collectively, these five case examples demonstrate the possibilities that PHRs can bring amongst complex but discrete chronic care patient groups.

### Case Study 5.8 – University Hospitals Birmingham NHS Foundation Trust

The University Hospitals Birmingham NHS Foundation Trust has announced the roll out of Myhealth@QEHB, originally piloted with patients with a long-term liver condition. It has been developed in-house by the informatics team and IT teams at University Hospitals Birmingham.

Other patients receiving treatment in specialties in the hospital will soon have access to the web-based system. The full list that will receive access to the portal include diabetes, endocrinology, the bronchiectasis service, complex inherited bone diseases, cardiology, haematology, HIV, IMD, prostate cancer, renal, rheumatology and urology.

The portal works by giving the user a unique log-in pass, allowing access to a variety of areas including records, with individual medications, lab tests, blood tests, medical history, diagnoses, calendars, contacts and a profile.

A patient can also communicate with the professionals in charge of their care, receive helpful tips for their general health and wellbeing, and collate favourite health links. A sidebar details any upcoming events that may interest a patient, offers a rolling stream of messages and shared information from the patient's support network (which includes other patients and professionals), and collects information that is exclusive to the individual such as current medicines, health plan and diastolic BP graphs.

The patient also benefits from a live information bar that highlights new messages from health-care professionals as they come in, and user-friendly icons like a private messaging option.

## 5 PHRs – the UK perspective

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### 5.4 Cultural issues affecting PHR uptake

As is evident from the case studies, the impact and uptake of PHRs depends on social/contextual factors, such as the culture of collaborative care. For those patients with a chronic illness, self-monitoring of health data involves a complex interaction between patient and clinician as part of the wider care relationship. The QIPP Long Term Conditions programme's three priorities of risk stratification, integrated teams and self-management, rely on significant cultural/mind-set shifts, for example around the uptake of personalised care planning. This will feed into how patients may in time embrace PHRs.

Related to this, the 2010 UCL evaluation of HealthSpace included 'ethnographic observation of a sample of people with diabetes and other long term conditions [which] revealed insights about the lived reality of chronic illness'. The observations noted are relevant in considering uptake of PHRs more generally:

- 'Some people appeared to lack the health literacy or IT literacy required to use a technology-based health organiser. Others were either not motivated to reflect on the progress of their condition or felt that this was a task for their doctor or nurse.'
- 'Some had no access to computers or saw them as serving other purposes in their lives (games, shopping, social networking)'
- 'Some were already using or exploring other ways of documenting and monitoring their condition and found these more fit for purpose than HealthSpace'
- 'Many patients' needs were not primarily for codified data (e.g. blood glucose levels) but for practical knowledge of how to live with their condition and for emotional support. They tended to get this from other people (e.g. relatives, local diabetes support group, Facebook).'
- 'Some patients were constrained by poverty, an adverse physical environment (e.g. poor housing, overcrowding), major family stress, or serious disabilities related or unrelated to their condition (e.g. depression, stroke). Monitoring and managing

their long term condition competed with these other problems for emotional and material resources and was rarely top of the priority list.'

The HealthSpace programme evaluators noted in conclusion some of the reasons for its mixed success: 'Unless personal electronic health records align closely with people's attitudes, self-management practices, identified information needs, and the wider care package (including organisational routines and incentive structures for clinicians), the risk that they will be abandoned or not adopted at all is substantial'. We concur.

The Government's announcement of the '3 Million Lives'<sup>21</sup> campaign to promote the widespread adoption of telehealth and telecare by patients – particularly those with long term conditions – may be an important stimulus to the development of PHRs. (This was on the back of announcing headline findings from the Whole Systems Demonstrator (WSD) programme, the world's largest randomised control trial of telehealth and telecare services.) However, the successful deployment of telehealth solutions relies on both clinicians and patients doing things differently, and changes to this culture take time and persistence across many stakeholder groups.

While some of the projects mentioned in Section 5.3 (above) have been running for some time, with good evidence of patient experiences and clinical outcomes, most are at a much earlier stage. It will be important for many further studies to build up evidence and lessons learnt, and over time capture the public imagination about what PHRs can provide. Coupled with learning from relevant international developments so that we avoid reinventing the wheel, interest can be stimulated and stakeholders encouraged to invest in the set-up of PHRs.

As the work of the RCGP/DH stakeholder group on Record Access gathers momentum, it would be worth extending their brief to keep a watchful eye on developments with PHR projects.

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21. [www.3millionlives.co.uk](http://www.3millionlives.co.uk)



## 5 PHRs – the UK perspective

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### 5.5 Conclusion

In this chapter we have considered patient attitudes to the PHR, and have outlined how they are different to – and not just an extension of – Record Access.

From our evidence review and case studies, it is clear that the uptake of PHRs in the UK remains embryonic around predominantly healthy populations. Interest will only be captured where PHRs are demonstrably useful, fitting well into people's daily lives, particularly if they are remote to available services. Other prerequisite features are that the PHR must be secure, reliable and easy to use.

The use of apps could be key in driving uptake around PHRs for the healthy population, especially where they can integrate in with NHS health record systems.

Our work also highlighted an ideal use of PHRs amongst the healthy population, where shared care arrangements demand continuity of information around that held by the patient. Maternity and child health represent two good examples and work is underway.

Above all, PHR usage is most likely to take off amongst engaged groups of patients, committed to self-management. Those with complex, chronic conditions, often with more than one long term condition, are most likely to find a PHR useful and have the most to gain initially.

Most of the existing case studies relate to specific occurrences of complex shared care arrangements around the management of particular long term conditions. Some of these have been driven by tertiary hospitals wishing to provide remote patient access to their record. On a wider basis, where the patient cohort can be precisely identified and targeted on a regional or national basis, PHRs can also be a success.

PHRs rely on the ready integration of technology with underlying clinical record systems. However, achieving significant uptake depends most on a change in culture and mind-set around shared care and self-management. Learning these lessons and developing the evidence base, for example through the QIPP programme around long term conditions, will be of vital importance.

## Appendix A: PHR Definitions and Glossary

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### Definition

Wikipedia Definition:

*A personal health record or PHR is typically a health record that is initiated and maintained by an individual. An ideal PHR would provide a complete and accurate summary of the health and medical history of an individual by gathering data from many sources and making this information accessible online to anyone who has the necessary electronic credentials to view the information.*

The Healthcare Information Management and Systems Society have defined a Personal Health Record as follows [2007] [4]:

*An electronic Personal Health Record ('PHR') is a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The PHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations.*

The Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force also examined the state of PHRs in an extensive review in 2010. After scrutinising various existing classifications, they provided the following working definition [5]:

*Electronic personal health record (PHR): a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR. PHR sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers.*

Pagliari (2007)

*A collection of important information about your health or the health of someone you are caring for, such as a parent or child, that you actively maintain and update. The information comes from your healthcare provider, and from you.*

The Markle Foundation (an American-based charity promoting technology and healthcare):

*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.*

## Appendix A: PHR Definitions and Glossary

### Glossary

<b>A&amp;E</b>	Accident & Emergency	<b>PKB</b>	Patients Know Best, a patient-controlled medical records system
<b>BMA</b>	British Medical Association	<b>RCGP</b>	Royal College of General Practitioners
<b>BMI</b>	Body Mass Index	<b>RPV</b>	Renal Patient View
<b>CFH</b>	Connecting for Health	<b>SCR</b>	Summary Care Record
<b>CIO</b>	Chief Information Officer	<b>SLaM</b>	South London and Maudsley NHS, a Foundation Trust
<b>DALLAS</b>	Delivering Assisted Living Lifestyles at Scale, a Technology Strategy Board initiative	<b>Spine</b>	Single NHS-wide reference point for patient information
<b>DH</b>	Department of Health	<b>SHA</b>	Strategic Health Authority
<b>DHID</b>	Department of Health Informatics Directorate	<b>SNOMED</b>	Systematized Nomenclature of Medicine
<b>EC</b>	European Commission	<b>UCL</b>	University College London
<b>ERDIP</b>	Electronic Record Development and Implementation Project	<b>Vista</b>	Veterans health information systems and technology Architecture
<b>EHR</b>	Electronic Health Record (a longitudinal record, straddles across health organisations)	<b>WSD</b>	Whole Systems Demonstrator
<b>EMIS</b>	Egton Medical Information Systems Ltd		
<b>ePCHR</b>	ePersonal Child Health Record		
<b>EPR</b>	Electronic Patient Record (to support treatment within an organisation)		
<b>EU</b>	European Union		
<b>FT</b>	Foundation Trust		
<b>GOSH</b>	Great Ormond Street Hospital		
<b>GP</b>	General Practitioner		
<b>HealthSpace</b>	Online personal health manager, and patient window into the SCR		
<b>HCP</b>	Healthcare professional		
<b>HIV</b>	Human immunodeficiency virus		
<b>HL7</b>	Health Level 7 interoperability standard		
<b>ICT</b>	Information Communications Technology		
<b>IMD</b>	Inherited Metabolic Disorder		
<b>ITK</b>	NHS Interoperability Toolkit		
<b>KP</b>	Kaiser Permanente		
<b>N3</b>	NHS National broadband Network		
<b>NPFIT</b>	National Programme for Information Technology		
<b>NHS</b>	National Health Service		
<b>OPCS</b>	Office of Population, Censuses & Surveys		
<b>PCT</b>	Primary Care Trust		
<b>PCEHR</b>	Person-controlled Electronic Health Record		
<b>PHR</b>	Personal Health Record		

## Appendix B: List of Contributors

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The following lists the individual contributors to our work. For focus groups, please see Appendix D.

**Dr Mohammad Al-Ubaydli**

Founder and CEO, Patients Know Best

**Jane Baker**

Clinical Lead in Disorders of Fluency, Highly Specialist Speech and Language Therapist, Kingsteignton Medical Practice

**Alan Craig, Trustee**

Addenbrooke's Kidney Patients Association

**Scott Cunningham**

Technical Consultant, University of Dundee

**Michael Denis**

Chief Information Officer, South London and Maudsley NHS Foundation Trust and Special Advisor, London Connect

**Bruce Elliott**

Health Informatics Development Programme Manager at NHS Connecting for Health

**Dr Brian Fisher**

GP; Co-director PAERS Ltd; Patient and Public Involvement Lead at NHS Alliance, Clinical Commissioner at RCGP

**Dr Richard Fitton**

GP and ex-Caldicott Guardian, NHS Tameside and Glossop

**Arif Govani**

Director of HealthVault, Microsoft UK

**Dr Amir Hannan**

Full-time GP, Haughton Thornley Medical Centres and Member, Health Informatics Clinical Advisory Team, NHS North West

**Libby Morris**

GP Lothian and Primary Care eHealth Lead, Scottish Government

**Dr Donal O'Donoghue**

National Clinical Director for Kidney Care and Consultant Renal Physician

**Claudia Pagliari**

Senior Lecturer in Primary Care, eHealth Research Group, Centre for Population Health Sciences, The University of Edinburgh

**Wai Keong Wong**

Haematology Specialty Registrar, NHS Medical Director Fellow in Leadership and Management (until Aug 2012 only), Chair of the Project Board (for the joint BCS/ Safe Record Keeping Project)

## Appendix C: Online Polling Analysis

This appendix summarises the results of the online polling 2020health undertook between 12 April and 15 May, 2012. During this period, 2020health ran an online survey using the Survey Monkey Tool for samples of patients to respond anonymously to questions on their attitudes towards electronic health records.

There were two versions of the survey: one for people with long term conditions, the other a more general survey. Similar questions were asked in each – we were interested to understand if there was any evident difference in attitudes between the two. The total number of respondents was 262, split 172 for the Long Term Conditions version and 90 for the generic one.

The Long Term Conditions survey can be viewed at <https://www.surveymonkey.com/s/DCTYGVN>

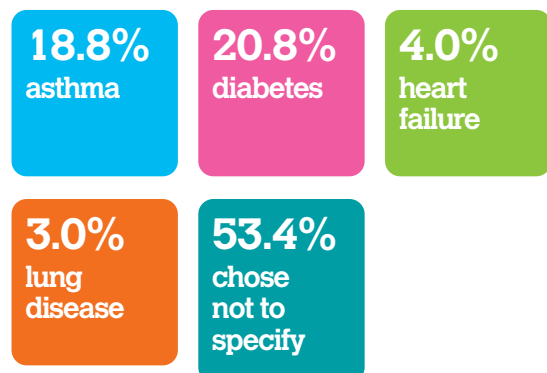
The generic survey can be viewed at <https://www.surveymonkey.com/s/CXP9D59>

The survey was publicised through four mediums: Twitter, Constant Contact, Email, and word-of-mouth.

Seemingly, the most successful of these methods was word-of-mouth. In particular, through the Primary Care team in NHS North West, the survey was distributed to colleagues in Tameside & Glossop and Derbyshire health communities. The most active patient group responding to the survey was the Kidney Alliance.

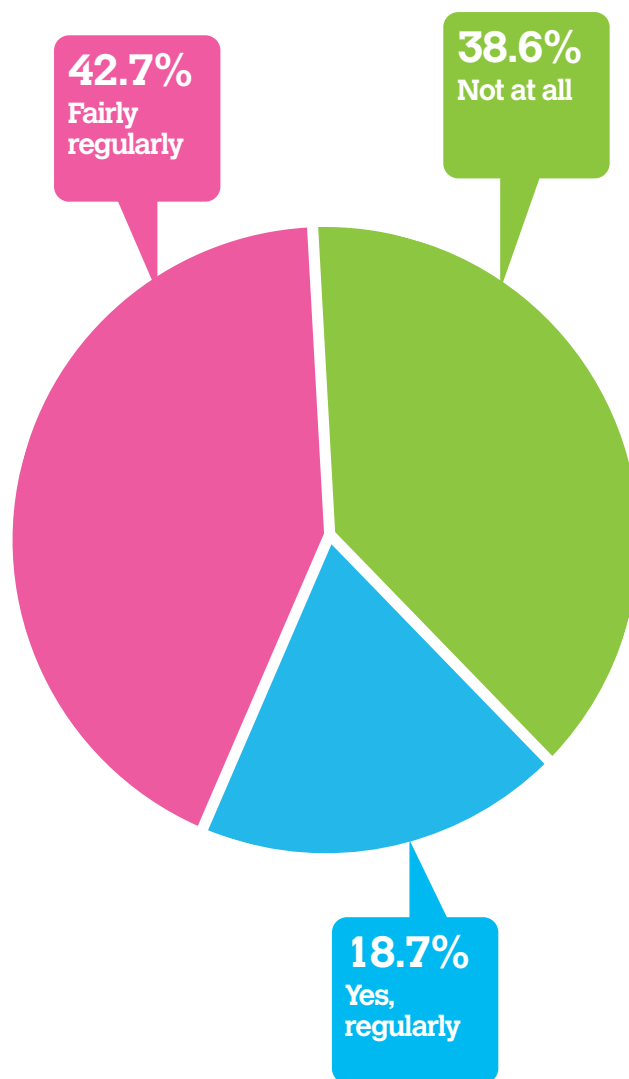
### Long Term Conditions

Respondents reported their prevalence of long term conditions as follows:



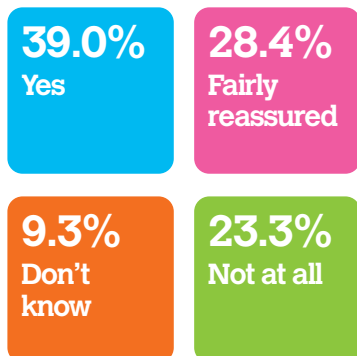
Among the LTC respondents, 89 specified ‘Other’ which included Fibromyalgia, Kidney Disease and Crohns Disease.

**On whether they were active users of online resources to help manage their health better:**

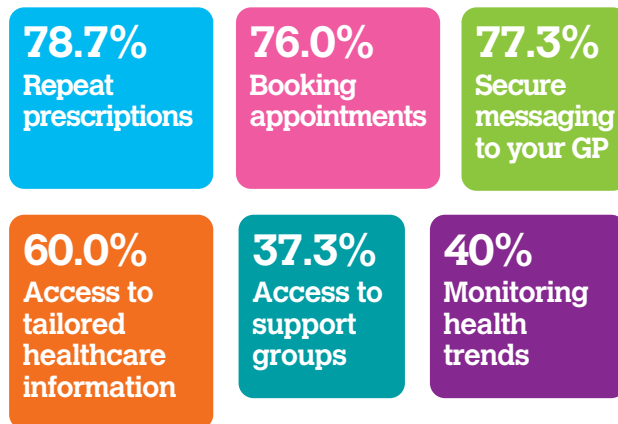


# Appendix C: Online Polling Analysis

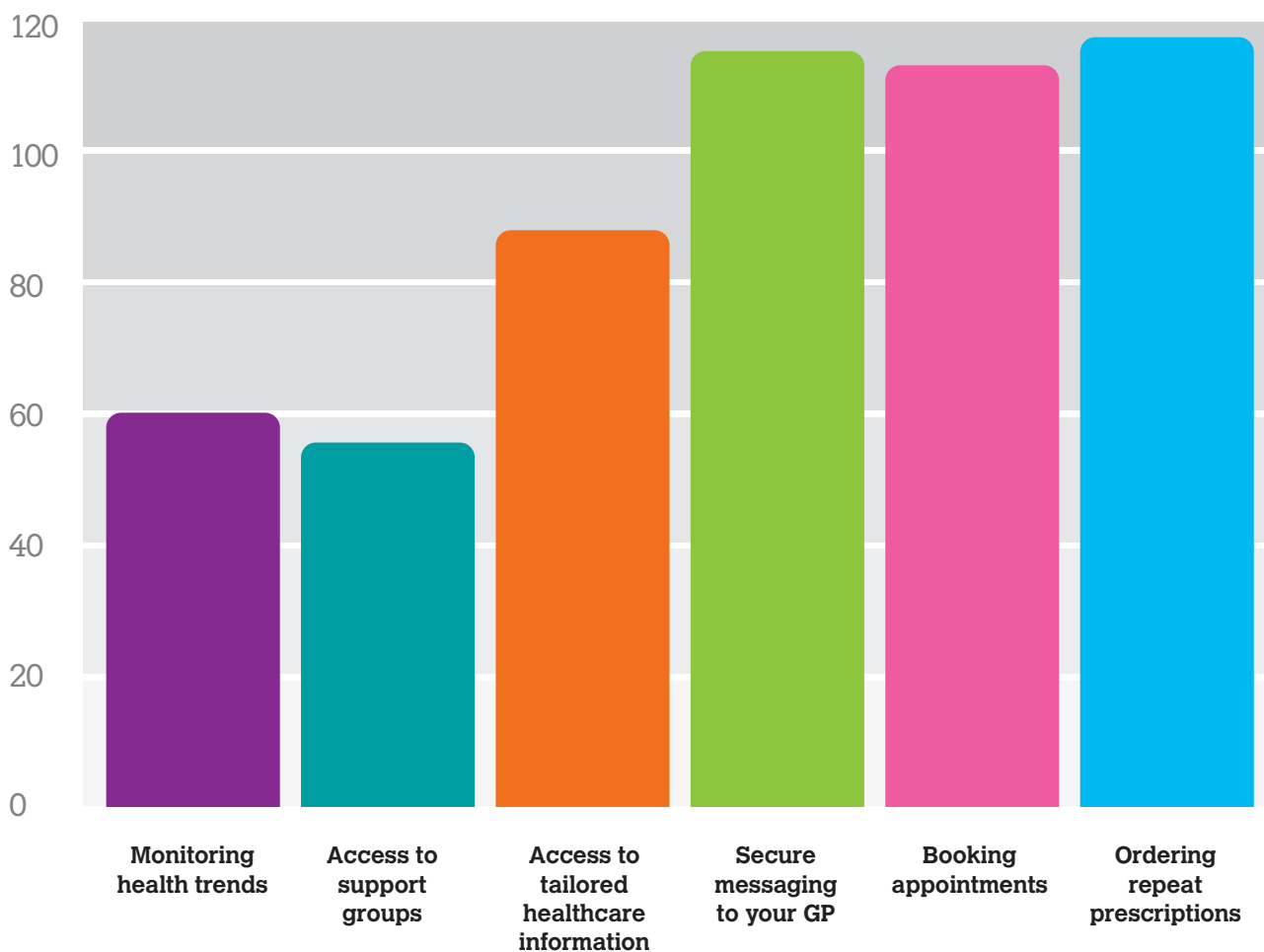
**On whether they would be reassured by using an electronic health record:**



**On what functions they would find most useful with an electronic health record:**

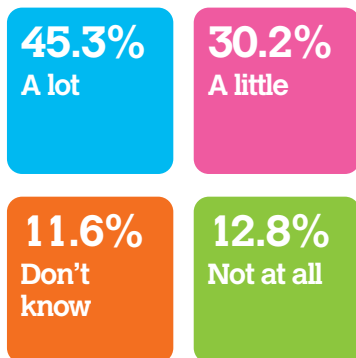


**In what way(s) do you think using an electronic health record could help you manage your long term condition better?**



# Appendix C: Online Polling Analysis

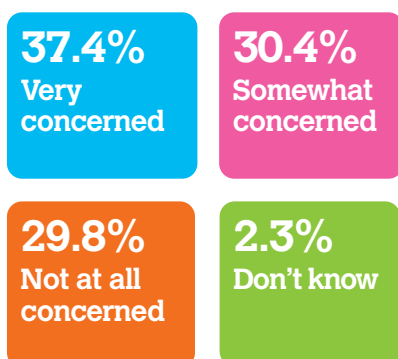
On whether an electronic health record will help you to organise and keep track of your healthcare records better:



On who should have access to their electronic health records:



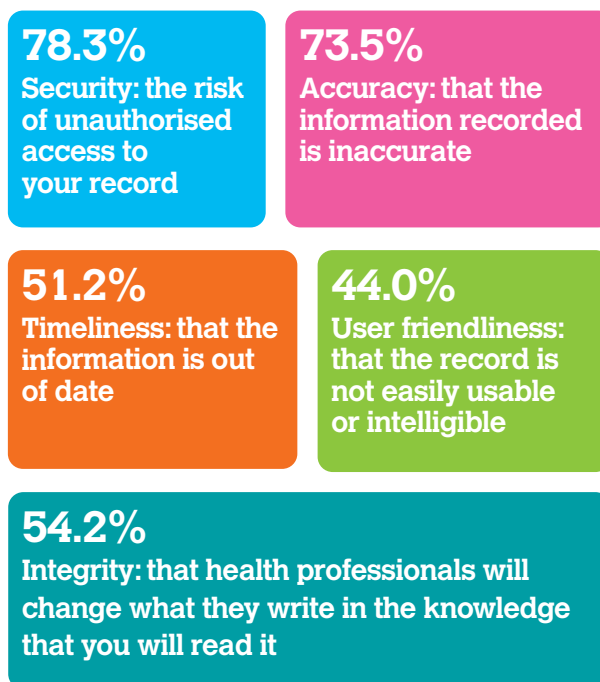
On how concerned they would be if information on their personal health record was accessible to health professionals for whom it was not relevant:



On what other privacy concerns they had. Answers included:

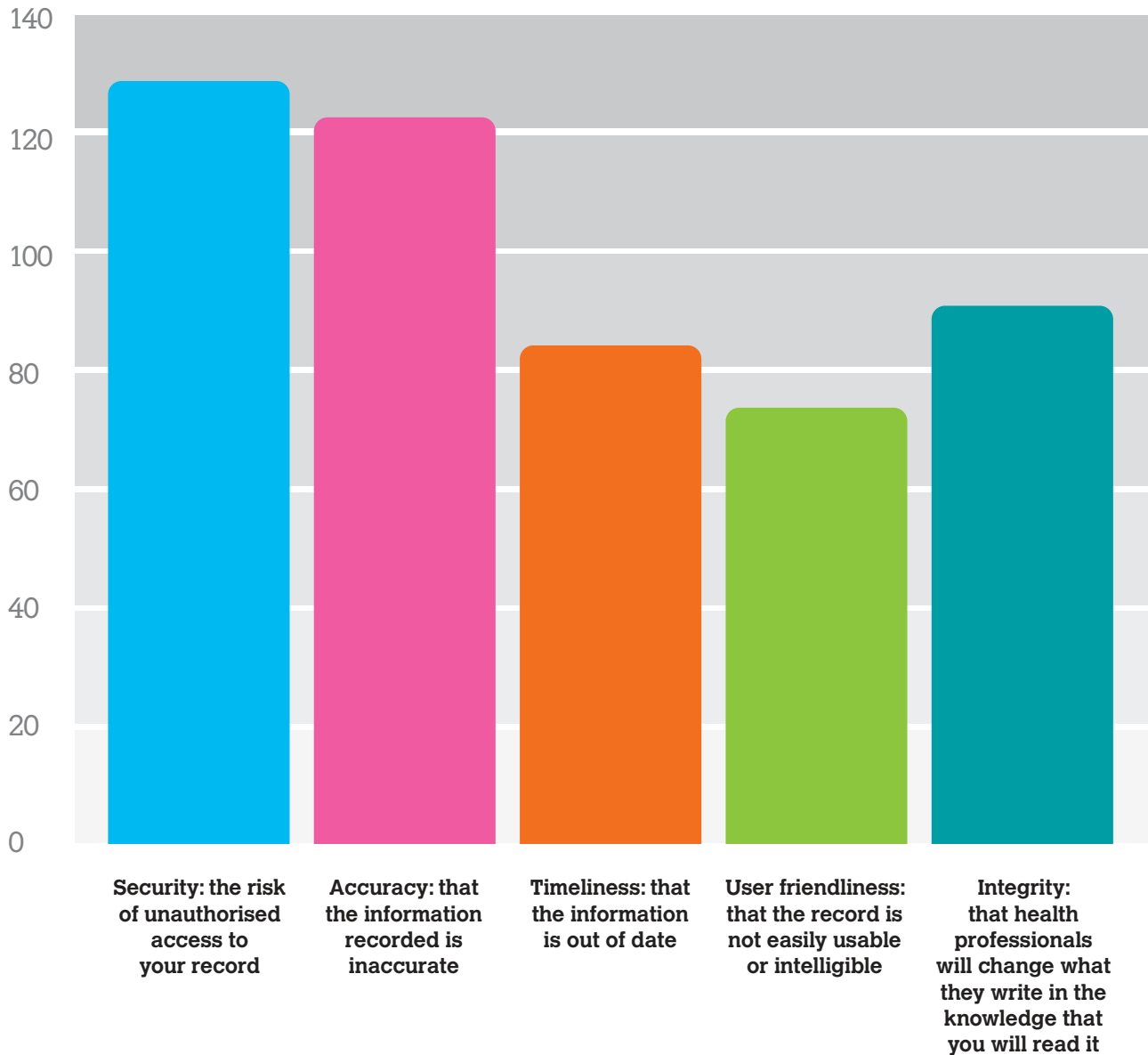
- That it would be disclosed to family or private sector organisations, for example insurance companies, who do not have a role in my healthcare
- Personally I have none but there may be medical history available that a patient does not want to share, such as abortion, depression or family problems
- It is vital for the integrity of any system that confidentiality is secured

On what other matters regarding usage concerned them:



## Appendix C: Online Polling Analysis

As well as privacy, people are concerned about other matters involving the usage and accuracy of the electronic health record. Please tick which of the following issues concern you most.



In brief, respondents were split between fairly regular and fairly irregular users of online resources to better manage and organise their health. More often than not they were reassured by this medium of data and enthused by its time-saving functions, such as the ordering of repeat prescriptions, over and above how the record could facilitate things like support groups.

The overwhelming majority were content with GPs having access to their records, but not family members. For most, the concerns were around accuracy and security, rather than user-friendliness.



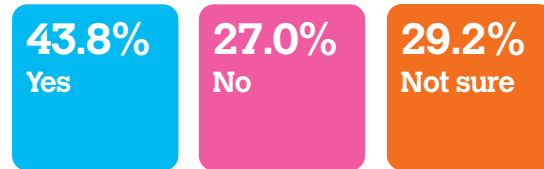
# Appendix C: Online Polling Analysis

## Generic survey:

On whether you are an active user of online resources to help manage your health better:



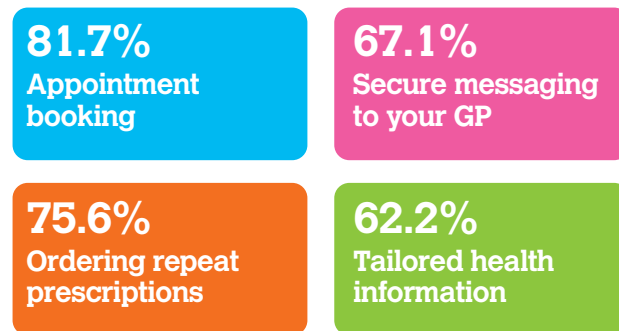
On whether they thought an electronic health record could keep them fit and healthy:



On whether through managing their own electronic health record, they would be reassured that their overall care and safety would be improved:

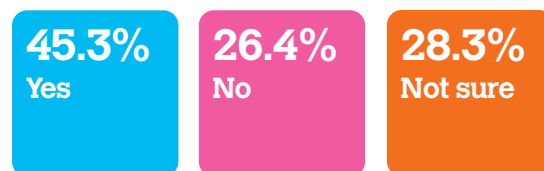


On what health applications (apps) within your electronic health record would be useful to manage your health better:



Respondents who opted for 'Other' mentioned information on self-management, dietary tips, condition monitoring apps and test results with longitudinal data tracking, linked to care management algorithms.

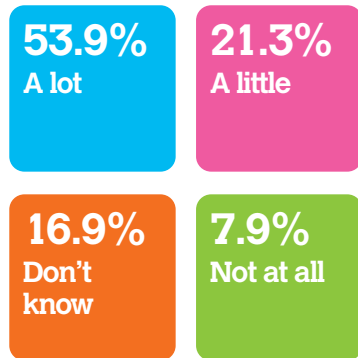
On whether they felt an electronic health record would be helpful for managing a child's health record:



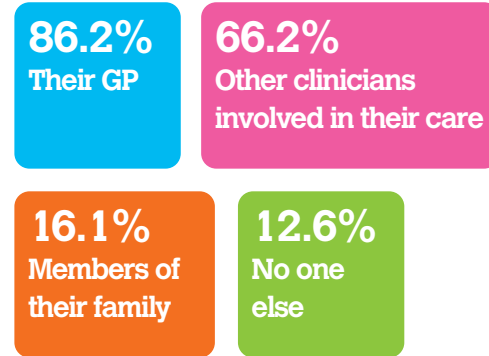
Note: 37 people skipped this question.

# Appendix C: Online Polling Analysis

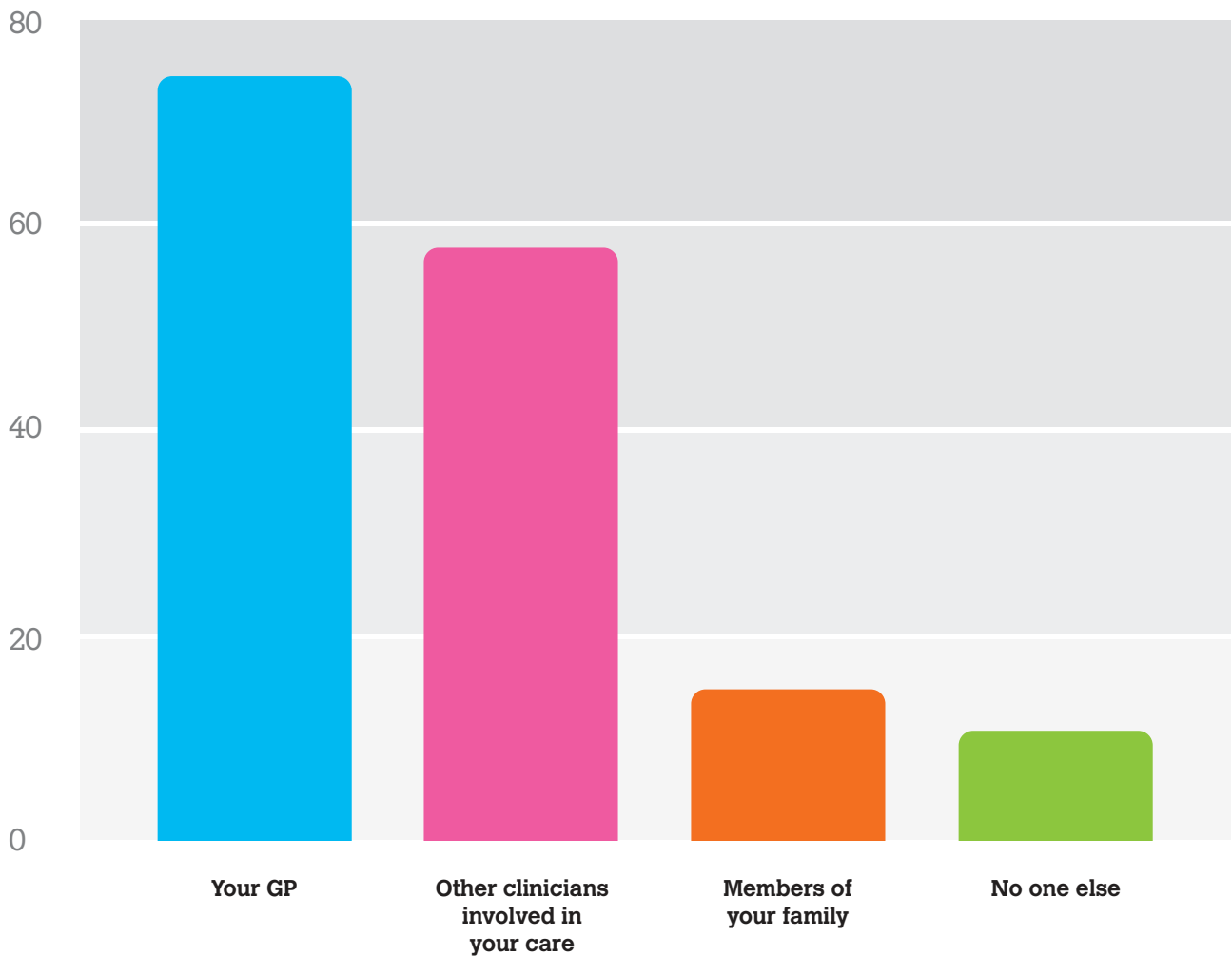
On whether an electronic health record will help you to organise and keep track of your healthcare records better:



On who, other than themselves, should have access to their electronic health records:



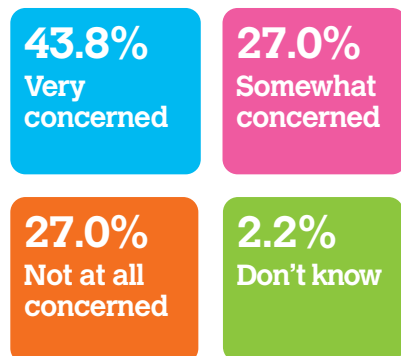
Who do you believe, other than yourself, should have access to your electronic health records?



## Appendix C: Online Polling Analysis

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On how concerned they would be that information available on their electronic health record would be accessible to health professionals for whom it is not relevant:



Respondents were asked to list any other concerns about the privacy of the information on their electronic health record. Responses included:

- Judging from past events, I believe it's entirely possible that some health worker or civil servant will leave my private information on a train or in a taxi, or allow it to be lost in the post, or make it available in any one of a dozen other irresponsible ways.
- The editing rights of unauthorised health workers
- I think that access levels should be explicit and relevant to need across the range of health professionals and where possible permission sought to extend access if 'fuzzy'. Records should show details of all access by any professional by name, date and information accessed so that I can challenge if appropriate.

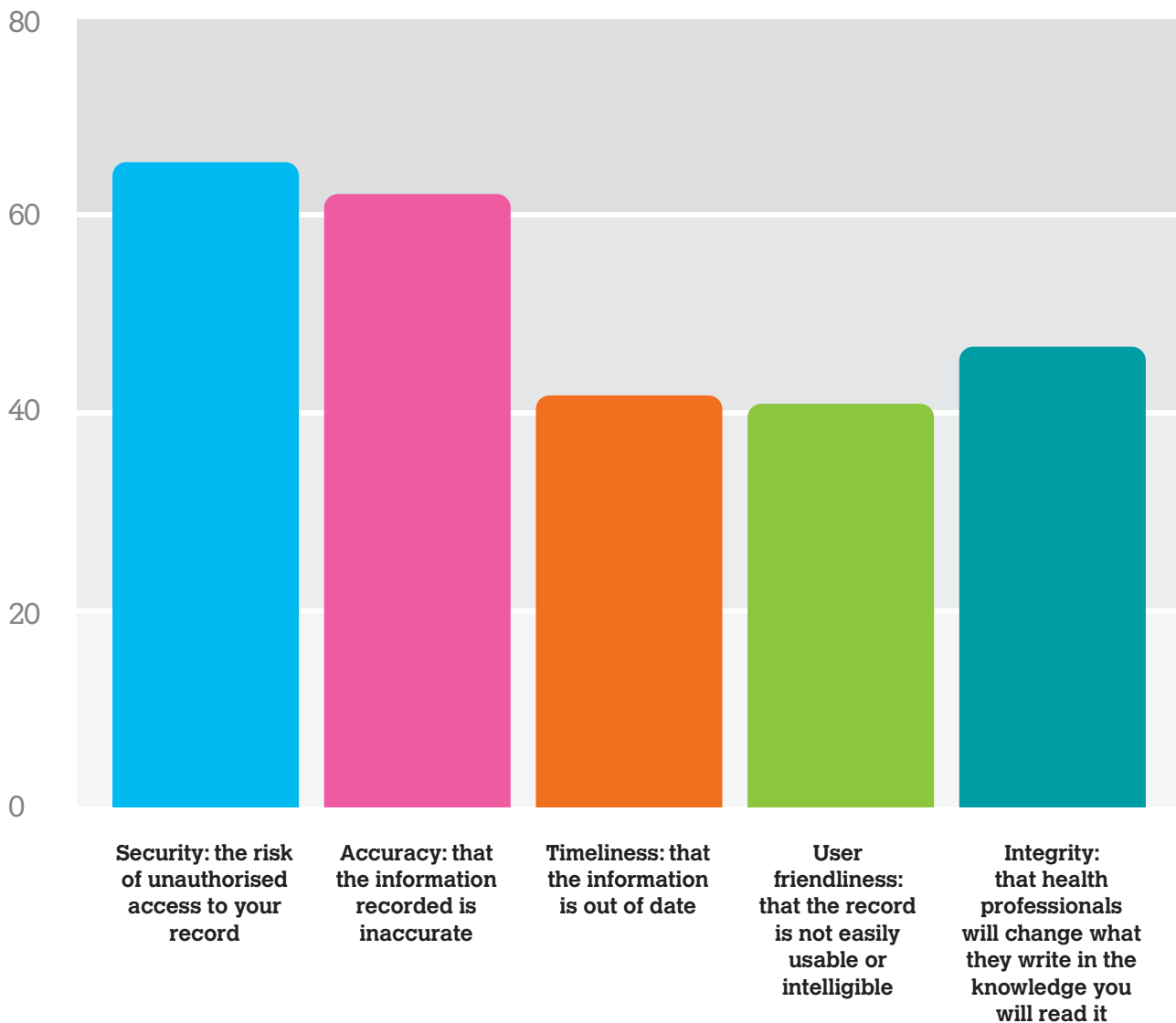
On what other matters involving the usage and accuracy of the electronic health record concerned them:



When choosing 'Other' on this question, respondents listed access to computers being an issue, as well as jargon and wrong information.

## Appendix C: Online Polling Analysis

As well as privacy, people are concerned about other matters involving the usage and accuracy of the electronic health record. Please tick which of the following issues concern you most.



In brief, the majority of respondents were regular or semi-regular users of online resources to manage their healthcare. Most of them felt access to their electronic health record could help them self-manage their own healthcare.

Most would want to use PHRs as a way to book appointments with their GPs and order repeat prescriptions. Most respondents were happy with their GP seeing their records, but not family, and of the issues that were presented, security and access seemed to resonate the most.

## Appendix D: Off-Line Polling Analysis

This appendix summarises the results of three face-to-face surveys that 2020health conducted during the course of the study (April – May 2012). The surveys were conducted at the following institutions:

- **Open Age Centre**
- **Sure Start Centre**
- **Public gym**

### Open Age Centre

On 20 April 2012, 2020health interviewed ten attendees of a coffee session at an Open Age centre in Westminster, London. The attendees were all female and between the ages of 45–85. Many of them had recently had a form through the post asking whether they would like institution-owned access to their health records, so the subject was on their mind.

A few had positive things to say about access to online records:

*‘If you had an accident in Wales or something, they would take those electronic records so they’d know how to treat you – to see what you were allergic or medication that you are already on, and they’d have access to have to that ... if you’ve had an accident then you’re not in a fit state to talk about it.’*

*‘it’s good that we’re able to see our records at any time without fuss ... when I was working in a maternity ward you used to have to pay £10 to see your record ... but to actually be in charge of them is a very bad idea’*

Concerns raised were more prevalent, for example:

*‘What is the point?’*  
*‘Someone could lose it’*  
*‘Doctors are getting more money for doing less and less and less’*  
*‘Majority of people don’t even care about what’s on their records’*

On the subject of privacy and risk, the answers were varied:

*‘If you haven’t got a computer, you’ve got no control’*  
*‘Nothing is private anymore; hackers can get into the US government’*  
*‘Business people might want to get hold of it to find out information about who they will employ’*  
*‘It’s like when Robert Oppenheimer said after inventing the atomic bomb ‘I have become death’ – whoever invented the internet has done worse than that’*  
*‘The older ones, they’re much more private’*

But, again, not all respondents saw a more open access culture as a bad thing:

*‘Why should we be concerned with privacy when medical personnel want to help you?’*

When asked what other concerns were on their list of priorities, the responses included:

*‘My son has learning difficulties; he wouldn’t know what to do with his own records’*

*‘When you tell doctors when you last had a drink, I don’t think they actually believe you’*

*‘Insurance companies, on finding out something, even something like flying that you haven’t disclosed – maybe they would be interested in your records. Insurance companies will often twist things anyway, but having access to your record will give them more chance to.’*

*‘I’m not likely to get a computer in my 80s am I?’*

*‘I could put information on someone else’s record – it could say I’m dying of cancer and I’ll say I didn’t know I had that’*

Overall the fear stemmed from access to something new electronically, with which they were largely unfamiliar. But this was matched by a curiosity about what positive benefits online access could have, particularly when thinking about previous access to paper records.

### Sure Start Centre

On 24 April 2012, 2020health interviewed eight parents at a Sure Start Centre in Westminster, London.

On being asked whether they were users of the internet and resources online for health, many said (enthusiastically) that they did log on, but seldom for health reasons.

*‘I sometimes find dieting tips’* (Female, late thirties)  
*‘I do but not for things like banking, it’s not secure enough is it? You get these people who are having their identities stolen online. But with my health, that’s neither here nor there is it?’*

(Female, early thirties)

*‘Only really use it to look at Facebook’* (Female, early thirties)

To the question of whether they would be reassured of the benefits of online access to their health records, most responded yes. One noted:

*‘Could be good for them who lack confidence’* (Female, late thirties)

## Appendix D: Off-Line Polling Analysis

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Asked how they thought access to their record could keep them fit and healthy, most were initially sceptical that it could help in any way. One who did, however, said:

*'It could give you information on healthy eating stuff'*  
(Female, early forties)

On the topic of what concerns people had about having records online, available for access, the answers were more varied:

*'They could be looked at by health insurance companies'*  
(Female, late thirties)  
*'It could be needed by a boss in future job applications'*  
(Female, thirties)

However access by different professionals had its upsides, according to some:

*'My friend had food poisoning and she made a claim, so it would be good if, say, lawyers could get access to your records'*  
(Female, late thirties)

All of the parents agreed that it would be helpful to have their child's records easy to access. One parent said:

*'My child's Red Book would be useful to see so I can easily show other hospitals what injections he's had'* (Female, early thirties)

When asked who they did and didn't want seeing their own records, the answers were varied:

*'My GP and me – no one else'* (Female, late thirties)  
*'My family – I would show them, that's if they wanted to see it'*  
(Female, late thirties)  
*'My GP, hospitals, family, I don't mind really'*  
(Female, early thirties)  
*'I wouldn't be happy if just anybody could see it'*  
(Female, early thirties)

### Public gym

2020health surveyed approximately ten users of a public gym in West London on 10 May 2012. All were regular users of the gym, visiting it between 2 to 4 times per week.

On being asked whether a personal electronic health record would appeal to them, the vast majority answered yes, with only one person outright saying no.

*'Yes of course it would'* (Male, mid-twenties)  
*'Only if I didn't have to pay for it'* (Male, mid-twenties)

On whether the electronic health record could work as a way to reassure them about their overall care and safety? The overwhelming response to this was no, with one respondent explaining:

*'I can't see how it would'* (Female, late twenties)

Interviewees were asked if they had any major concerns about privacy. The response was varied, but most replied yes.

*'With online stuff you leave yourself open'* (Female mid-thirties)  
*'It wouldn't be secure enough for me'* (Male, mid-twenties)  
*'If it is password protected then I'm not too fussed'*  
(Male, late thirties)

On being asked if they had had any other concerns about a PHR, most couldn't think of anything, but of those who did the answers were mixed:

*'Someone could hack into it and take out some of the details and use them'* (Male, mid-twenties)  
*'Safety is worry – people could end up finding out what's wrong with you'* (Female, late twenties)  
*'A bunch of things could happen – domestic abuse relationships could put the person in jeopardy if they are blackmailed into giving over information they don't want shared.'* (Female, early thirties)

To the question of whether it would be a concern for other health professionals not involved in their direct care to access the record, most answered no.

*'We have that risk already don't we'* (Female, early twenties)  
*'No, they're all professionals aren't they'* (Female, early twenties)  
*'Well, it would be nice if we lived in a professional and consensual culture, but unfortunately we don't do we'* (Female, early thirties)

Finally, on whether an electronic health record could help keep one fit and healthy, the answer was that it couldn't.

*'Would it be a help? Not especially'* (Female, late twenties)  
*'Down to the individual isn't it'* (Male, mid-twenties)  
*'If you're overweight, you can tell anyway'* (Male, late twenties)  
*'This is down to the exercise I do, not a record per se'*  
(Male, early thirties)

# Personal Health Records

## Putting patients in control?

'Personal Health Records: putting patients in control?' is our fourth report in two years examining how the NHS can best exploit some of the latest developments in IT. The timing of this report is significant, with the Coalition Government's stated objective to give all NHS patients online access to their GP health records before the end of this parliament. Despite the turmoil in recent years surrounding the roll-out of care records by the National Programme for IT in the NHS, the ethical rights and potential long-term benefits of allowing patients access to, and ultimately more control over, their personal health records are simply too important to ignore. The new initiative is called 'Record Access', which in time may well evolve into the more dynamic Personal Health Record (PHR), the likes of which are currently available to several million consumers in the USA, though only to a limited few in England.

Our report examines the scope and potential benefits of both Record Access and the PHR. It appraises current patient attitudes toward online health record access, both in theory and in practice, and identifies fundamental prerequisites for the mass uptake of such services. The evidence-base is admittedly limited at this present time, so we take into account developments from abroad, as well as findings from our own surveys of patients and potential users in England. Indications overall are that where we find increased patient involvement in personal healthcare, so we expect to find better health outcomes alongside lower service costs.



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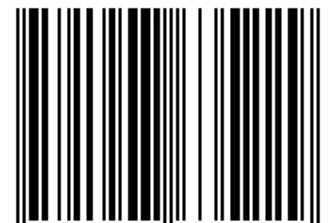
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