

Personal Health Records: putting patients in control? Frequently Asked Questions

September 2012

Frequently Asked Questions and
Answers on Personal Health Records

Usage

I like the reassurance of a paper record. Why do I need an electronic one?

Paper records, especially as we get older, can run up to several dozens of sheets of paper. For people with long term conditions or who are very sick when young, files can expand up to several inches thick.

As time goes by these files get damaged or become unreadable, or worse, lost altogether. And perhaps there have been occasions when on holiday or in another part of the UK you have needed your records, but the medical professional seeing you did not have access to them because they were filed away in your local GP's surgery.

With electronic records, our personal health files can be easily accessed anywhere in the country, even from other countries if necessary.

These files don't expand to several inches or get damaged, because they are stored away on a hard drive under safe encryption.

What is a Personal Health Record and how will it benefit me?

A Personal Health Record (PHR) is a website where service users have password protected access to their personal online health profile. A service user can view, edit and share aspects of their health information via their profile and this can be done in a private, secure and confidential environment.

This online resource gives you access to and control over aspects of your personal health information held by the NHS. It allows you to view your information online whenever and wherever you want using a variety of technologies, including computers, laptops or mobile phones. And it lets you add to and update your personal information.

If you choose to use the resource, your personal profile could have a copy of your care plan, notes from your latest consultation, information about your medication and contact details for the service(s) you use.

In time, applications may be developed which may include the ability for you to add or update your information on the PHR – such as a mood diary and personal statements about your strengths, hopes and goals, spiritual beliefs or anything else that you choose to share.

The personal profile will keep all your information in one place. You and your healthcare professionals can decide what information to share with each other. It lets you stay informed about your treatment and become more involved in your own care. You can also choose to give a family member/carer access to your online personal profile account if you find this helpful.

It will also help you to see, understand and be involved in keeping track of your care plan, your consultation notes, medication and emergency contact details, upcoming appointments, resources and meetings you want to go to.

2020health.org
83 Victoria Street
London SW1H 0HW

T 020 3170 7702
E admin@2020health.org

supported by an unrestricted
educational grant from

2020health.org

 **Microsoft**

Frequently Asked Questions

Usage (continued)

How can I be confident that NHS technology has the capability to provide all of my information in a single electronic access-point?

NHS Trusts already have single points of access for many files, so there is no doubting the capability to have a single access point for all information. Informatics professionals and other industry bodies are engaged to provide the NHS with the best and most up-to-date resources to store our health records electronically and integrate these securely.

How will a PHR help me manage my long term condition better? Which long term conditions would a PHR best support?

A personal health record can facilitate better self-care and provide better communication between you and health professionals.

With certain conditions, storing health records electronically can massively reduce the amount of paper files your GP holds for you, which can stop files from being damaged or lost.

Often the time spent with the clinician involves the patient recalling a lot from memory, but PHRs can be used to record and update personal information at leisure; thus they can help maximise the precious few moments a patient has in clinic.

How will a PHR help me keep fit and healthy?

Essentially the personal health record, among other usages, can act as a sophisticated health organiser, with tailored information to suit your health needs, be that vital health tips, dietary materials and other updates to see to your general health and wellbeing.

How will a PHR help me organise and keep track of my healthcare records better?

With use of a personal health record, you will be in charge of your records. Ultimately, deciding who has access to your records will be down to you – you will be in control.

With ownership rights, you will be able to keep better track your records, oversee what is being written about you by other medical professionals and monitor your health in a far more organised way.

I like talking face to face with my GP, but I know GPs are already under pressure to see a certain number of patients every hour. How will being in control of my own records electronically affect my interactions with my doctor/GP?

They will not alter the amount of necessary time you will spend with your GP. In fact with appointment booking as an added application within your personal health record, you will find that seeing your GP may become easier and more flexible around you.

With new technologies acting as alternative ways to communicate with your GP, you may well find that face-to-face consultations are unnecessary, saving you and your GP time.

So the way in which a personal health record can affect your interaction with your GP is simple: appointments should be more productive for both of you, and it may save time if you both agree that just a telephone or email conversation, not a visit, will suffice.

Usability

Do GPs reserve the right to refuse to use the electronic record themselves? How can I be assured that the wishes I record myself are going to be responded to?

Certainly there will be difficulty in any culture change, and if a GP is refusing to work electronically then this could prove difficult to begin with. But we ought not to be so concerned. Use of personal health records should in time reduce a GPs workload, giving them more time to see more patients.

Furthermore, it avoids them from duplicating information. While we have a long way to go, GPs are seeing the difference this is making to their profession and will want to stay in that direction for the betterment of the patient.

The same goes for your wishes. Since the advent of the internet, GPs have become used to patients looking up information before their visit, so as to understand what it is they need to do towards getting better.

Recording your wishes on your personal health record is just a stage further in that process of shared decision-making, which the Government have seen fit to plan for in their strategy for the future NHS.

What advice have health professionals been given to ensure all information that they feed into the health record is written clearly and without jargon?

This feeds directly into the last point that GPs are becoming used to a change in culture around health provision, which makes room for the patient to be more involved in the care they receive and the decisions that are made about them. Reducing jargon on your record, so to help you better understand it, is just one further example of this.

Are there any special arrangements made for children?

Yes. Until such time that a child is able to take charge and participate in the health decisions that are being made about them, a family member (usually a parent or carer) can manage their personal health record for them.

Are there any special arrangements made for patients who lack mental capacity?

Yes. As long as a patient gives permission then someone else (usually a family member or carer) can manage their personal health record. This can sometimes be a good idea if the patient is not well enough to access the account themselves.

Access / Content

What regulation/standards will govern PHR development to the benefit of the patient?

We know that your privacy is important to you and we have a duty of confidentiality – this is a highly secure system that will maintain and protect your privacy.

In particular:

- The personal profile you create is controlled by you
- You decide, with your clinician, what information goes in your personal profile
- You decide who can see and access your personal profile

Some of the clinical information that the new website will hold about you may be used to help with up-to-date research. The information that can be shared will first be agreed by you and your clinician. Before researchers see your information it will be made anonymous – this means that any

Frequently Asked Questions

Access / Content (continued)

information that could identify you is removed/covered up. This will allow the NHS to carry out research that makes a real and positive difference to future treatments and care.

Though having a PHR does not mitigate human error, it does have the benefit of making information about an individual readily available to them in the quickest and most efficient time.

Patients have the legal right to access their personal information, but are there any exceptions to this which need to be taken into account with the personal health record?

The rules on this are very strict. Under the Data Protection Act 1998, you have a legal right to apply for access to health information held about you. This includes your NHS or private health records held by a GP, optician or dentist, or by a hospital.

However, as it stands today, GPs or other health professionals can refuse your request if, for example, they believe that releasing the information may cause serious harm to your physical or mental health, or that of another person.

How can I be sure that my PHR is up to date and accurate with most recent NHS information about me?

The unique change in having a personal health record is that information, such as lab results and data from blood tests, is filed as quickly and as efficiently as possible – so if the most recent data is not added then this is a workforce failure. The same rules apply to this as they have done previously, namely that an enquiry should be made by the patient as to why their information is not being updated.

Who has access and who can give consent for access to my record?

At the moment, your primary care record is held by your GP and so they have the power to consent to its access, though it is within our rights as patients to be privy to that data.

However with a personal health record, you are in ultimate control and have power to say which medical professionals ought to be able to access it – which you can then stop at any time.

Can I opt out of having control of my record if I so wish?

In the same way as you don't have to give a reason to see your health records today, if you don't want to control your records you will have the right to delegate that control to your GP.

2020health.org
83 Victoria Street
London SW1H 0HW

T 020 3170 7702
E admin@2020health.org

supported by an unrestricted
educational grant from