

It's your record

A guide to accessing
health records online

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INTRODUCTION

“I shop online, I communicate online, I control my finances online; It’s only right that I look after my health online” —Patient



In many ways, online access to your medical records is about convenience. Many patients can already order repeat prescriptions online without leaving the comfort of their sofa, and the prescription can be sent electronically to a chemist near your place of work. I know how difficult it can be to get through to your surgery on the phone, so just think how much easier life would be if you could obtain your test results online, or check that your kids’ vaccinations are up-to-date.

Online access to medical records can also give better and safer care. You can be sure your forgetful mother has ordered her regular medications, and have the information you need for your next hospital appointment, or for an emergency doctor if you are away from home.

As doctors, we know that we get the best results for our patients if we work in partnership with them, and by helping them to be as well informed as possible. Having online access to your records can really help with this. So I suggest you ask your GP when you will be able to see your own records online.

— Dr Rosemary Leonard

Your health records online

What's the story?

Nearly twenty years ago, online banking was introduced in Britain. The idea of accessing your own money whenever you wanted was new at the time but now we all take it for granted. Now online access to your medical records is fast becoming a reality. Some Londoners are already looking at and using their medical records online; some are even able to create their own personal health records to sit alongside their medical records. Why? What will it mean for you?

Over the next few years, it is going to become more common for Londoners to access some health and care services online. This won't change our need to see doctors, nurses and social workers face-to-face, but it could kick-start a change in how we relate to doctors and other health and care professionals. It's about supporting patients to have more control. In fact some Londoners are already doing it now.

Ordering repeat prescriptions online

More than a quarter of all GP surgeries in London already allow patients to order repeat prescriptions online. There's no need to call the surgery or make an appointment.

Booking appointments from your computer

Patients at around a third of all GP surgeries in London can book and cancel appointments online. No more hitting the phones at 8.30am – and fewer people tend to miss their appointments too.

Getting your test results online

By 2015, you will be able to access your test results and check notes of discussions you have had with your doctor, in a secure place online.

Online access to your medical records

It's not that being able to see your records is new – you already have that right. Nor is it new that your records are kept electronically. Most GPs and health organisations keep medical records on a secure computer. Letters and other paperwork are coded or scanned and put into electronic format. This makes for far more accurate and speedy organisation of your healthcare.

What is changing is that you will be able to have online access to your records. You will also, in some cases, be able to have secure email conversations with your doctor.

You won't have to do any of this but if you need to use the NHS and social care a lot, it should make you feel more informed and therefore more in control. More importantly, it will make for a far more efficient and convenient service. After all, the information held in our health notes is about us and for us.

COMING TO YOUR GP SURGERY BY 2015

You will have the ability to book appointments, order repeat prescriptions and communicate with the surgery online, as well as the option of viewing your records electronically.

Accessing your GP records online



Logging on

- Wherever and whenever suits you on a computer or smartphone
- Remember your password and PIN



What's in your online medical records

- Appointments – dates, who you saw, notes* on reason for visit, history, examination, outcome
- Medical diagnoses, investigations, procedures
- Allergies
- Medications
- Vaccinations
- Test results
- Letters between your GP and others such as hospital consultants*
- Links to information about your diagnoses/ treatments

* Some practices will allow you to see these only from a specified date; some may exclude these. This is to reduce the small chance of seeing something that may concern or upset you



What you can do

- Read what your doctor has written – your diagnoses, advice and treatment
- Check your test results
- Check whether a referral has been made
- Spot any inaccuracies and tell your GP or practice
- Print information off to take to an appointment
- Remind yourself of what happened when
- Read letters to and from your GP
- Prepare for your next appointment
- Get key medical information fast if something happens to you away from home or when the surgery is closed
- Find out more through links to trusted resources

People use their records in a number of ways, from checking test results to reminding themselves about what was discussed during an appointment. Here's how it works.

KEY FACTS

- Currently 60% of GP surgeries have records systems that allow patients online access; at the moment less than 1% offer this service.
- Most frequent uses of online records access are: accessing test results, viewing letters the GP has received or sent about you; checking information about your condition

WHAT YOU NEED TO KNOW

- Medical records are already kept on secure computers
- You will be able to get a secure login to see the records held by your GP
- No one else sees your records without your consent
- It's entirely up to you whether you want to look at your records online or not
- It won't make it harder to see your GP when you want to

CASE STUDY

The doctor who has been showing his patients their records for 25 years

myRecord in Lewisham

Dr Brian Fisher, a Lewisham GP, started giving people access to their records 25 years ago simply by handing people their paper records as they sat in the waiting room. He has always summed up the point as “It’s a question of ethics – your health, your data”. When electronic records arrived, he devised a system for giving his patients online access.

This system is now being used by around **50 GP practices in England.**

“Doctors who have seen my patients elsewhere have been in touch to say how great it was that my patient could call up their records at the touch of a button. They could make safer and faster clinical decisions as a result.”

Dr Brian Fisher

Who uses record access?

People who use the NHS a lot are the ones that find records access most useful. This tends to mean people with long term conditions like diabetes, asthma or heart conditions or people who find they are having to go in and out of hospital regularly for a while.

People who travel a lot or who need medical attention out of hours use it to make sure doctors get the information they need there and then.

Parents find it useful to be able to check their children’s records – most practices allow parents to view a child’s records until he or she is twelve; useful for checking immunisations are up-to-date.

Some people log in occasionally just out of interest or to check details such as travel vaccination history and past operations when applying for life insurance, or filling in benefits forms.

WHAT IS MYRECORD?

- *myRecord is a project working with Lewisham GPs and patients to promote and evaluate records access*
- *myRecord enables patients in 15 Lewisham practices to see their patient records online*
- *The PAERS/EMIS system, through which myRecord is provided, has been running since 2007*
- *More practices are offering online access to records in Lewisham than anywhere else in the country*

In a 2012 survey of patients accessing their electronic records in Lewisham, **46%** **46 per cent said that they felt more confident about their health** and half said they felt more able to help themselves.

“I think it’s more transparent than in the past. I like to feel that I am trusted with the information.”

Patient

“I have been able to have some control over my illness rather than allowing it to control me – a very important thing when dealing with long term illness/pain”

Patient

Accessing your GP records online

Q&A

How can records access help you?

BY SAVING TIME

- Not having to phone reception or book appointments to get routine test results (a big bonus if you are diabetic, say, and have to have regular tests)
- Not having to phone reception to check whether a referral letter has been sent or what it says

MAKING CARE SAFER

- Being able to access your notes there and then whether at an outpatient clinic or abroad

PROMPTING ACTION

- Seeing what the doctor has advised in black and white often makes it more real (making you more likely to take your medications or to take the right exercise)

BETTER UNDERSTANDING

- Being able to see things like letters between GPs and consultants helps you understand the health and care system that bit better
- Being able to look back over your medical history (comparing past symptoms or test results) can help you understand your health better

What do people worry about?

Q: Do I have to do this?

A: No, and either way, your decision will not affect your care or your relationship with your GP surgery

Q: Is it secure?

A: Think of it like online banking. See over the page for more on this

Q: What if I don't understand what's in my records?

A: Around 30% of people find something they don't understand. There are links to useful information and explanations of medical terminology. You can also ask your surgery.

Q: What if I find a mistake?

A: Around ten per cent of records contain errors, usually details like your age and where you live. You should tell your surgery and ask for it to be corrected.

Q: Will I get bad news online?

A: Test results are only filed into your record after the GP has seen them and had a chance to contact you first.

Q: Will it upset my GP if I check my records?

A: There is no reason why it should. The evidence suggests that it saves your GP's time and makes for better consultations too.

"I have a chronic disease and feel a real partner in the management of my health. Whether I am at home or abroad I can monitor information and share it with any other health professional involved in my care. I would be lost without it now!"

Patient

"Accessing my GP records online has been great! Not only did I find it easy to use, but personally very helpful. You can check your notes, your next appointment, without having to call and check with reception. Requesting a repeat prescription was great, done within seconds! As I am currently working through my depression, reading through my previous appointments really helped me realise just how far I have come over the months and gave me that little extra positive boost."

Patient

Accessing your online records

Is it secure?

When people first hear about this, their first concern is understandably about security, privacy and confidentiality. Should you be worried?



Your records are already on a computer

Many of us think of our health records as a tightly packed clutch of papers, often in a series of brown cardboard folders. In fact, in the vast majority of cases, GPs already keep your records on a computer in a secure system. Many hospitals are working to do the same. Computerised health records are safer and more secure than paper records. It is easier for your care professionals to access them when they need to with much less risk of your health records going missing. All that's changing is that you will be able to see these records too if you want to.

How secure is the log in process?

The security is very similar to online banking. In most cases, you need to register in person and with a photo ID at your GP surgery to get started, you'll then set a personal password and PIN. It is your responsibility to look after and protect your own log-in details. You should never share these with other people. If you need help and support, you may find it helpful to ask a well-trusted carer or family member. They may help you when you are feeling particularly unwell and frail, for example to keep track of your medications, appointments and understand what care you are getting.

Are my records safe?

A lot of effort goes into making secure systems. Specialists apply very high security standards and test them thoroughly. Just like in online banking, there are exceptional cases where things can go wrong. Keeping your password and PIN secure and taking extra care when you use shared or public computers will help prevent security breaches.

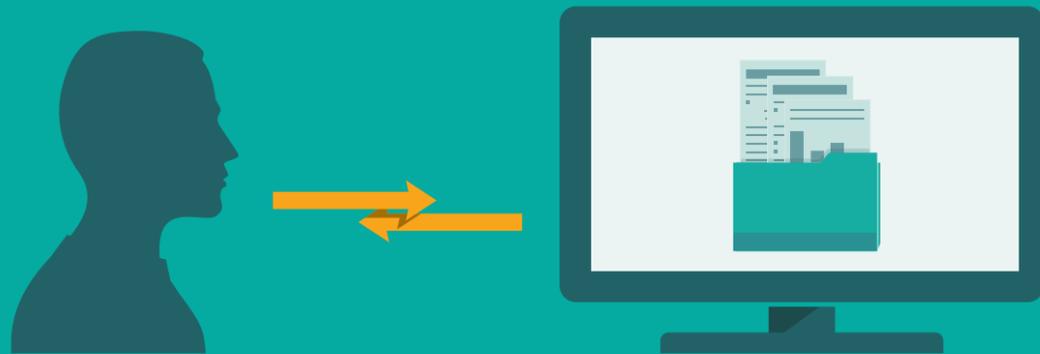
There are additional measures to protect your personal information even if someone manages to access it. To take the PAERS/EMIS system used by myRecord as an example, you can only ever bring up one page of your medical records at a time when you access them online and you can't download your records onto your computer.

Could my employer or insurer get online access to my records?

No. Your records continue to be governed by the Data Protection Act, which means that your personal information cannot be shared without your explicit permission.

Personal health records

Creating your own online account



“Our patients are typically involved with us for a long time. They get the best results when we make them part of their own clinical team. Personal Health Records are key to this.”

Mike Denis, Director of Information Strategy, South London & Maudsley NHS Foundation Trust

What are personal health records?

Personal Health Records (PHRs) are a step beyond just getting access to your GP records. They are online accounts which you set up and manage yourself, choosing to whom you give access. The key thing is that as well as importing your medical records, you can also save and share your own health-related information. They are yours to own and use as you see fit, so you can take more control over your care.

There is no one type of Personal Health Record, and a number of different ones are being developed around the NHS for different types of patients. Over the page, we tell you more about one being offered to people with mental health conditions at the South London and Maudsley NHS Foundation Trust.

RENAL PATIENTVIEW

This is one of the most widely used Personal Health Records in the UK – with around 19,000 registered users. Kidney patients can view their test results, see information about their medicines, add their own data such as blood pressure, glucose and weight readings and share this information not only with their renal specialists but others who may be involved in their care. Ask your hospital if you want to access your kidney test results.

These kinds of Personal Health Records are really useful for people with long term health conditions. They are helping people to take more control over their healthcare and to make sure all the different people involved in their care are working with the same information.

PATIENT PORTAL – CHILDREN AND YOUNG PEOPLE’S DIABETES SERVICE, UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

This web-based portal gives children with diabetes and their families access to information, advice and training in managing the condition. It provides tools and apps to calculate insulin dose, track progress and submit blood glucose and insulin pump data to their clinical records.

It provides a secure means of real time collaboration with clinical staff, including creating care plans, booking appointments, and noting what you want to discuss at the next appointment. Around 300 children with diabetes and their families use the UCLH service.

HOW ARE PERSONAL HEALTH RECORDS DIFFERENT TO ONLINE ACCESS TO GP RECORDS?

- You can add your own notes or other information
- You can access medical or care records not just from your GP but from hospital or other care providers
- You own them and share them with whomever you choose
- They enable and encourage two-way sharing of information between you and your clinical team

CASE STUDY

Keep it in your health locker

myhealthlocker in South London and Maudsley NHS foundation trust

What is myhealthlocker?

- myhealthlocker is an electronic Personal Health Record for people using mental health services in South London
- Service users can collect, store, edit and manage their own health information, including their GP and hospital records in one place. They can choose what information is shared and with whom they share it
- myhealthlocker was developed by the hospital, service users and GPs – and is stored in Microsoft's secure HealthVault system
- It is available via five services, including psychosis outpatients and children/adolescent services. Two GP practices are participating in the pilot
- The pilot went live in October 2012 – the aim is to have 200 users by April 2013

What's in it?

As much or as little information as you want, including:

YOUR CARE PLAN

- Your diagnoses
- Your care and treatment, including therapeutic services
- Your appointments, medications and test results
- Information about your social and housing situation, where relevant
- Your care team, including emergency contact details
- Key information from GP records

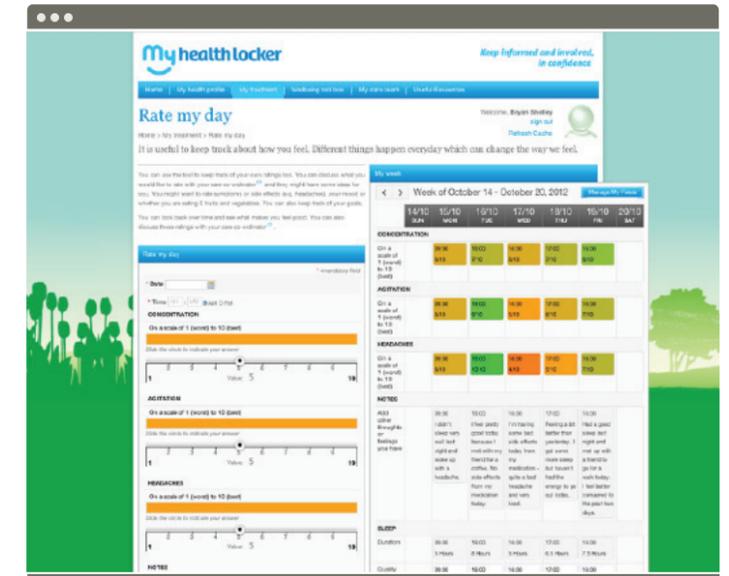
YOUR INFORMATION

- Useful tools to keep on top of your health.
- 'Rate my day' tool to track sleep, anxiety and energy levels

- Well-being survey
- Tools to track exercise, food, alcohol as well as health matters like asthma or diabetes
- Links to useful information about conditions, side effects, benefits and social networks

What can you do with it?

- Compile and print off health reports to share with people you trust
- Explore your condition and track your progress
- Think about questions to ask your care team and make decisions about your care
- Decide what information to share with your care coordinator, like how you feel based on the well-being survey, and whether to share some or all of it with a family member or carer.



"I'm more in charge of my care"

Service user

"I can access it whenever I want and there are no bits of paper to lose!"

Service user

"I like the rate my day feature – it has the facility to capture my feelings, a space to rate my mood, sleep – potentially you can put a lot of things into it"

Service user

"Once I got into the habit, logging on became a daily thing, like reading my e-mails. I have added an icon to my browser so when I log on it's there"

Service user

"It really plays an important part in taking your control back which is important for making any kind of recovery"

Service user

CASE STUDY

myhealthlocker in South London and Maudsley NHS Foundation Trust

How does it work?

In order to be as secure as possible, there are a few stages to signing up:

- Set up a Microsoft HealthVault account using your email account. At this stage there is no information in your account
- To use myhealthlocker with personal information, you'll need to get three verification codes from your care co-ordinator and your GP
- You only need these codes once. All you need to remember is your username and password

What's the point?

The South London and Maudsley had been giving patients copies of their care plan for many years, however patient surveys revealed many of them simply didn't recall this. This led the clinicians

and managers to re-think how to get people more involved with their care plan.

Mike Denis, the Director of Information Strategy at the Trust said:

"Inviting people not just to see their care plans but to contribute to them and tell us important stuff whenever it suits them creates a whole different relationship between people and their care team. It shifts the balance of power. Ultimately I think it will mean better care and better results."

For example, the well-being survey results are integrated into people's records. For the first time, clinicians can look at what their patient has to say about how they feel alongside their own clinical information.

Mike Denis' ambition is to give the people using these services the opportunity and the information they need to be active participants in their care – and to give our clinicians essential insights into

how people actually live with their conditions, what works for them and what doesn't. He commented that both clinicians and service users have worked together to develop myhealthlocker because they liked the idea. "It's not something being 'done' to them, they are active participants."

How will it develop?

Currently, people can see their care plans and other key information from GPs in myhealthlocker. This is what service users said they most wanted to see. Over time, they will be able to see things like letters between the South London and Maudsley NHS Foundation Trust and other providers.

"It's instant. If there are changes in my care plan I know about it"

Service user

"The site is easy to navigate"

Service user

"It gives information that was once held by the doctors . . . and would depend on them for it to be shared"

Service user

"It allows me to gauge my progress"

Service user

The Next Step

Accessing your social care records

What are social care records?

If you receive social care via your council, you will have a set of social care records. Social care means things like having a carer to help you with washing and dressing, or having a place in residential care; it can also mean services that help you with drug or alcohol problems, or services that help you live with a mental health condition.

At the core of social care records, like mental health records, are needs assessments and care plans, which should usually be shared with you. These are important because they describe what sort of support you need and what services have been agreed.

What's this got to do with online health records?

Most people who receive social care also have health problems, and are dealing with their GP regularly. They may also be attending outpatient clinics, being supported by community health teams or be in hospital from time to time.

Stop going to and fro

People find that they have to keep repeating the same details to each of these different services, all of whom keep their own records. Some people say they feel like a ping pong ball being sent from service to service, or worse a ball that gets accidentally dropped as it travels from one service to another.

Joined up services need joined up information

This is why you might often hear professionals talking about the need for 'integrated care' or 'joined up services'. 'Personalisation' is another key word. What they mean is that people who need health and social care should get services that are designed around them and their lives. Getting the right information to the right people at the right time – and not least to the person who needs care – is key to personalised and joined up services. We are some way from a fully integrated health and social care record that you could access as a service user, and there are lots of issues to sort out before that becomes a reality.

However, over the page we tell you about how Lambeth health and social care services are working together on a new kind of care plan both with each other and with the people using their services.

CASE STUDY

Coming to Lambeth soon: one record for each individual

The Lambeth Collaborative

A new kind of care plan

The Lambeth Collaborative is working with the South London and Maudsley NHS Foundation Trust on a new kind of care plan. This new Recovery and Support Plan is designed to help people with mental health problems get the support they need to live their lives the way they want to, once they have been discharged from hospital or are moving out of residential care.

It allows people to be clear with their care team – and other important people in their lives – about what they want to achieve, what will help keep them well and with whom they want to share their plans.

Coordinating care is tough

People with mental health problems leaving hospital or residential care need a whole range of services – from their GP, community teams and often their housing support team, not to mention friends and family. Coordinating this kind of care is tough. They will have a care coordinator but they probably see their housing support team far more often and may well have crises which take them to their GP. For this to work, everyone involved needs to be aware of what each other is doing and why.

One plan held by you, the service user

The new Recovery and Support Plan will be held by the service user and each service provider will work off the same plan. At the moment, the Recovery and Support Plan is being piloted in paper form but the aim is to get it online. If all goes well, it will be incorporated into myhealthlocker (see page 9) during 2013.

CO-PRODUCTION means service users and professionals working together as trusted partners. It means unlocking the capabilities and strengths of individuals and communities, recognising their expertise as well as that of the professionals.

“This is all about making services work better for people – by co-producing their support and creating one record that works for everyone involved in their care. It will give people one plan, one set of messages. No having to repeat the same things over and over, no multiple versions and no risk of misinterpretation.”

**David Singer, Transformation Projects Lead,
Lambeth Mental Health**

WHAT'S THE LAMBETH COLLABORATIVE?

- A group of commissioners, providers of health and social care services as well as service users and carers
- It includes GPs, community teams, hospital services, social services and voluntary organisations
- They are all working together to develop radically new services for people who have a mental health diagnosis

Viewpoint

People power: From now to the future

No decision about me without me

First and foremost, online access to records will give patients more control over their health. There is growing evidence that people, particularly those with long term conditions, enjoy better health and higher quality care when they are better informed and more involved in decisions with their clinical teams. Secondly, the NHS is facing escalating costs and ageing populations. More efficient ways of working are essential to making proper use of taxpayers' money. Online access is one step towards this vision of better care twinned with greater efficiency.

Action needed from GPs

How to get GPs to open up access to records? There is a commitment for GPs to do so by 2015, and promoting the benefits will be crucial to make it happen. Key amongst these is that it is simply useful and convenient. Research from the University of Edinburgh found it helped patients manage their conditions better:

- Improved their knowledge of their condition said 92 per cent
- Improved their understanding of how the system works said 77 per cent
- Encouraged them to manage their condition, e.g. by taking medication on time or following lifestyle advice said 77 per cent

There is weight to the idea that records access can make a difference to the way people approach their health. However, this is not what initially appeals most to people – a 2020Health survey (2012) tells us people are most interested in:

- Ordering repeat prescriptions
- Secure messaging with GPs
- Appointment booking

Only once these online services are widely available will online records access gain momentum amongst patients.

The challenges

These are early days. There is some way to go to solve technical glitches and design the simple, easy-to-use online systems that we have come to expect.

There are concerns about security which are being addressed through work on technical standards and requirements.

The biggest challenge may well rest in shifting culture and mindset amongst health professionals, who will be key to encouraging patients to take advantage of online services.

Towards personal health records

Personal Health Records remain rare, led by pioneering clinicians and their patients. The potential benefits of Personal Health Records are clear-cut for people with long term conditions and those who require health or care services from a range of different organisations. They

possess information that both clinicians and patients need, and are a great tool for bringing together services. However, many experts feel Personal Health Records will not fully take off until it becomes possible to link up people's health records across GPs and hospitals, let alone other health and social care providers. Nevertheless, some health organisations in London are developing this now.

The future

Access to and control of records is not for everyone. Nevertheless, this could be significant. As yet unpublished research led by GPs providing records access suggests that if 30 per cent of patients used it at least twice a year, **a practice with 10,000 patients would save 4,680 doctor appointments and 7,950 telephone calls per year.**

4,680
DOCTOR APPOINTMENTS

7,950
TELEPHONE CALLS

"... patient access to records will be a vital underpinning of a developing culture of self-care and self-management." —NHS Future Forum, 2012

"Whilst 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."

Personal Health Records: Putting Patients in Control? 2020 Health, Sep 2012

What next?

Find out whether your local surgery allows you records access at:

www.myhealth.london.nhs.uk/

For more in-depth information about the case studies featured:

myRecord: www.myrecord.org.uk

Renal PatientView: www.renalpatientview.org/

University College London Hospitals NHS Foundation Trust children's diabetes portal:

www.uclh.nhs.uk/ourservices/servicea-z/cyps/pdiab/Pages/Home.aspx

myhealthlocker: www.myhealthlockerlondon.nhs.uk

Lambeth Living Well Collaborative: www.lambethcollaborative.org.uk/

ABOUT LONDON CONNECT

This case study was produced by London Connect, an information transparency project of the London Health Improvement Board (LHIB), a partnership set up by the Mayor of London, NHS London and London Councils and their stakeholders to improve the health of the capital's population. The London Connect project is delivered by Improvement Science London on behalf of the London Academic Health Science Centres (AHSCs).

www.lhib.org.uk/information-transparency



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