

Keeping your health and social care records safe and secure

By 2015, it's planned that everyone in England will be able to access their GP record through the internet. Many other health and social care organisations are opening up access to records too, and some people are creating their own personal health records online.

Accessing your records online is a great way to get involved in looking after your health. It's natural to want to know what's in your records, and to use the information in them to help you get the best care and feel more in control.

Because your records contain personal and sometimes sensitive information, it's important to keep them safe. You should take the same care with your health and social care records as you do if you use online banking. This guide explains how to access your records safely, keep them secure, and share them safely, if you choose to.

This guide has been written for people who are accessing their own records. It doesn't include specific advice if you're using records on behalf of someone else who can't do it themselves – for example, your children or someone who needs support to make decisions.

What is a record and a record provider?

Throughout this guide the word **record** is used to mean electronic (computerised) records kept about you by health or social care professionals.

Record provider is used to mean the organisation that gives you access to the record they hold about you — for example your GP practice, hospital or social care provider.

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Summary of key points in this guide

- Your passwords and other login information are important for keeping your records safe and secure. Set up a strong password and keep it secret. [*pages 6-7*]
- If you think someone might have seen your record without your permission, change your password straightaway and contact your record provider. [*page 6*]
- Protect the computer or mobile device you use to access your records – for example, by using a password or PIN and anti-virus software. [*page 8*]
- Be particularly careful about the security of your records if you're accessing them through a shared computer or while on the move. [*page 8*]
- Before you share your record with anyone else, consider whether it's in your best interests and what they might do with the information, now or in the future. Think carefully about what sensitive information may be in your record, and how you would feel if it was shared more widely. If you're in any doubt, don't share. [*page 10*]
- If someone is trying to force you to share your record, tell your record provider – the organisation that gives you access to the record they hold about you. [*page 11*]
- There are organisations you can contact for further help and information. [*page 13*]

About your records

Each health and social care organisation that you have contact with keeps a record about you. For example, your GP practice will already have an electronic record about you, which may include:

- letters between your GP and specialists
- records of appointments you've had with doctors and other care professionals
- test results, illnesses, accidents and operations
- treatment goals and care plans.

If you sign up for record access, you will be able to see your record using a computer or a mobile device like a phone or tablet. Some hospitals, GP practices and other places such as pharmacies and libraries may have computer kiosks set up where you can see your records. In the future there may also be Apps designed so that you can access your records more easily through mobile devices.

What can I do with my records?

What you can do with your record will depend on what your record provider is offering and the system they use. You may be able to:

- See the information in it (or a summary)
- Get access to the results of tests, such as blood tests
- Click on links to helpful information, such as on health conditions or living a healthy lifestyle
- Share your record with someone else, such as a care professional or family member
- Add information, such as your blood pressure, weight, daily symptoms or plan of action
- Carry out tasks such as booking and cancelling appointments or ordering repeat prescriptions.

Being able to see your record can help you to remember and understand the discussions you have had with care professionals. It can be useful when you prepare for your next appointment. It can also save you time – for example, if you want to remember when you had a vaccination so that you can fill in a form.

By looking at your record, you can also help to ensure that it's accurate. You can't change anything that has been added to the record by a health or social care professional. But if you see a serious mistake in your record you should tell your record provider and they will correct it if possible, (for more information, see NIGB on page 14).

True or false?

"If I decide to access my record, a new electronic record will be made for me."

False. Computerised records already exist for you. GP practices have changed from paper to computerised records, and other health and social care organisations are in the process of doing this too.

"If I don't sign up for access now, I won't be able to sign up later."

False. Deciding whether to access your record isn't a one-time opportunity. If you decide not to do it now, you can change your mind in the future. You may be able to use online services such as booking appointments, without having access to your record.

Why might my record be at risk?

Most people who access their records do so safely, without any problems. However, there are two possible risks to consider:

- As with any kind of information accessed through the internet, there is a chance that your record could be 'hacked'. This is when someone illegally breaks into your record, either to steal your identity or to get other personal information about you.
- It's possible that your record might be seen by someone that you don't want to see it.

By following the advice in this guide you can reduce the chance of either of these things happening, and help keep the information in your record safe.

More about your health and social care records

Some information about you is shared routinely among the professionals involved in your care. For example, your GP will include relevant information about you if they refer you to a specialist.

More and more people in England now also have a Summary Care Record. This is an electronic record which can be accessed by NHS staff in an emergency (though they will usually ask your permission first). It shows allergies, any medicines you're taking and any bad reactions to medicines you have had before. You can choose to 'opt out' of having a Summary Care Record.

Whether you choose to access your health or social care records or not, record providers are already doing everything they can to make your records are as safe and secure as possible. They must:

- Store records safely, on secure systems
- Keep a list (an audit trail) showing who has changed or added to the information in your record
- Make sure that the only staff that access your record are those who have a legitimate reason to do so.

Any organisation that holds information about you in the UK is governed by the Data Protection Act 1998, the Human Rights Act 1998 and common law. These require that your records are kept confidential. There are similar laws and regulations in many, but not all countries.

If an organisation, such as your employer or an insurance company, asks to see information about you, you must agree to this in writing, and you can refuse.

Before you can access your record, your record provider (such as your GP practice or hospital) must 'switch on' your access to it. Before they do this, they must carefully check who you are and may ask you to sign a consent form to show that you understand what record access involves. This organisation can also 'switch off' your access to the record if you change your mind.

Using your records safely and securely

There are three things you can do to help keep the information in your record safe:

- 1 Create a strong password** — and look after it.
- 2 Get into good habits online** — protect your computer or mobile device.
- 3 Share your records safely, or not at all** — think carefully about the information in your record, and how it might be used, before sharing.

1. Create a strong password

Your record provider will give you 'login' details when your access is switched on. This is usually a username and a PIN (Personal Identification Number) or password. When you access your record for the first time you will need to enter these details. They are unique to you and your record, so keep them safe. You may be able to create your own password or PIN, but if you were given a password, you should change it as soon as you access your record for the first time.

Record systems use similar security to that of banks, so your information inside the system is very secure. However, your password is only as strong as you make it. On page 7 (overleaf), there's a list of the main differences between a 'weak' and a 'strong' password.

You can change your password whenever you want. So if you have shared it with someone and then change your mind, you can change the password to block that person's access. Or, if you think that someone has seen your record without your permission, you can change your password to stop it happening again.

If you share an email account with other people in your household, be aware that this might make it possible for them to access your record. For example, they might go to your record and ask to 'reset' your password. You would then automatically be sent an email with the new password, and they could open that email and use it to get into your record.

<input checked="" type="checkbox"/> Your password is weak if...	<input checked="" type="checkbox"/> Your password is strong if...
You tell people what it is, or you let people see it when you type it in.	It's a secret. Check that no one is watching when you type it in.
You write it down and keep it next to your computer or in your wallet or purse, where it's easy to find.	You can remember it or, if you need to write it down, you keep it where no one will find it.
It's easy to guess, such as a family birthday or name. Using 'password' as your password isn't sensible either.	You use a pass phrase or unconnected words <i>(see the box below)</i>
It's less than eight characters long.	It's at least eight characters long. The longer your password is, the more difficult it is to crack.
You use it for a long time.	You change it regularly, and make it very different from previous ones.
You use the same password as you do for other online services, such as banking.	You only use it for your health or social care record and nothing else.

Examples of strong passwords

Here are two simple ways to create strong passwords that are easy to remember:

Option 1:

Use a 'pass phrase' or series of words, linked together with no spaces. Pick something that means something to you or brings to mind a mental picture. Including capital letters, numbers or symbols make it even stronger – for example 'mydog1ikesbiscuits!' or 'Motherkn1tting5paghetti'

Option 2:

Take the first letters of words in a sentence that means something to you. For example 'Little Bo Peep has lost her sheep and doesn't know where to find them' becomes 'LBPHhsadkwtft'.

2. Get into good habits online

When you're using your records day to day, getting into some good habits will help to make sure they stay safe. The **Get Safe Online** website (*details on page 13*) has more information.

General tips

- Always log off from the record system when you have finished using your record.
- Check that the website you're using is using a secure link — there should be a padlock symbol next to the web address or it should start with 'https://'.
- Always type your password or login details so that no one else can see them, in the same way you would shield your PIN number when using a bank card.

Protect your own computers and mobile devices

- On a computer, use a firewall and install up-to-date antivirus software.
- Use a password or PIN to access your computer or mobile device.
- Keep all software on your device regularly updated.

Use your records safely if using a shared or public computer or device

It's best to access your records when you are somewhere private, and on your own computer or mobile device. However, if you do need to use a computer provided in a public place, such as a library or internet café:

- Clear your browsing history and close the browser window when you have finished (to avoid someone using the 'back' button to access your information).
- Make sure that the computer doesn't store your password. Make sure that the 'remember me' button isn't ticked when you log in.

Use your records safely when you're on the move

- Make sure no one is watching over your shoulder. If you think that someone may have seen your password, change it.
- Use a secure wireless connection — one that needs a password for you to access it.
- Use a well-known commercial Wi-Fi hotspot provider for wireless access, rather than logging on to an unsecured network you know nothing about.

Look out for any unauthorised access

There are a number of things that might lead you to suspect that someone has seen your records without your permission:

- Someone has information about you that they shouldn't have, which is likely to have come from your records.
- You may be able to see in the record system that someone has accessed your record that you didn't expect, or at times that you didn't expect.

If you're worried that someone has accessed your record without your permission, change your password straightaway. Then contact your record provider to tell them.

Be careful with copies and print outs

You can print information from your record, or copy and save it. This can be useful, when you travel, for example. But you can easily lose paper copies, and portable devices like CDs or USB sticks. Don't leave copies lying around, and dispose of them carefully. Rather than keeping copies of your record, it's usually safer to access the online version when you need it — and of course that version will always be up-to-date.

3. Share your records safely, or not at all

One of the benefits of using online records is that you can share them with family members, carers or care professionals. You might decide to share your records:

- if you're referred to a new doctor or health service. They will then have your most complete and up-to-date information.
- if you're an older person with grown up children. This can help them support you and be involved in your care.
- if you have a carer and you trust them to act on your behalf.
- in a medical emergency. Medical staff will then know about any allergies or other important information about you.

However, sharing your record is something to think carefully about.

- Your record may contain sensitive and personal information that you don't want other people to see.
- Anyone you share your record with could keep a copy.

What information in my record might be sensitive?

For most people there is little or no information in their records that would cause more than embarrassment if someone else were to see it. However, for some, records contain very sensitive information that could cause serious problems if seen by someone else.

Some record systems may allow certain information to be hidden, such as mental or sexual health. This means only certain health professionals can see those details. But most records can't hide sensitive information and access is 'all or nothing'.

Also, there could be information in your records that show something about you without actually saying it. For example, a list of your medicines could show that you're taking contraception or that you have a health condition such as HIV.

Sensitive information could include:

- Sexual or mental health issues
- HIV status
- Genetic conditions
- Experience of abuse
- Alcoholism or illegal drug use

How do I share my records safely?

You can share your records with anyone you choose, such as family or carers, by giving them your own username and password or PIN. This isn't recommended practice, but in some situations may be your only option if you want to share your record. **Only do this if you trust the person you're giving access to.**

If you want a care professional to see your records – for example, during an appointment – you can log in privately and then turn the screen to show them. Remember to log out of the system when you have finished.

With some records systems, you can 'invite' others to share access with you. They will then receive their own username and password.

What if I'm being pressured to share my record?

If you think that someone else might pressure you to share your records, such as your partner, parent or carer, you may decide that it's best not to have access to your records at all.

If you're being pressured to let someone else see your records, tell your care professional. There are also organisations you can talk to for more advice – listed at the end of this guide.

Are there any times when I must share my records?

You can refuse to give access to your records unless there is a legal requirement for your information to be shared. If the police, or any other person or organisation, wants to see your records without your permission, they must get a court order. This is only granted in the most exceptional circumstances. This might be when a crime is being investigated, when there is a serious risk to the public, or when a child or vulnerable adult may need protection.

Questions to ask yourself before sharing

When you're deciding whether to share your records, think about:

- **Is sharing information in your best interests?** — for example, sharing with a health professional to get the right care.
- **What information is in your records?** Think about the consequences of other people seeing it.
- **Could sharing your records affect other family members?** – for example, if you have a genetic condition that could be passed on through the family.
- **Do you need to share your whole record?** If an organisation, such as an insurer or employer, asks to see your records, think about why they want it and what the consequences might be. If in doubt, ask them to contact your GP to provide the information, rather than giving access to your record. Or you could print out just part of the record, or cut and paste it into a different program and email it to them.

If you're in any doubt, don't share.

So, in summary...

There can be great benefits from accessing your health and social care records online. But to protect the private information in them, you need to take care.

- ☑ **Create a strong password** — and look after it.
- ☑ **Get into good habits online** — and protect your computer or mobile device.
- ☑ **Share your records safely, or not at all** — think carefully about the information in your record, and how it might be used, before sharing.

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Further information

Contact your record provider if you have any problems with your password or using your records. Some record systems have online help pages and videos that you can use.

Online safety

Get Safe Online

Get Safe Online is a joint initiative between several Government departments and private sector businesses. It's the UK's leading source of unbiased, factual and easy-to-understand information on online safety. Get Safe Online produces *The Rough Guide to Online Safety*, which contains hints and tips on using the internet and sending and receiving emails whilst remaining protected from potential cybercrime.

www.getsafeonline.org

Help for anyone being pressured to share records

These freephone helplines offer advice if you're being forced by someone close to you to give access to your record. They can also advise family or friends calling on someone's behalf. You should also tell your care professional if you're being pressured.

Men's Advice Line

0808 801 0327

www.mensadvice.org.uk

National Domestic Violence Helpline for women

0808 2000 247

www.nationaldomesticviolencehelpline.org.uk

National standards and requirements

Care Record Guarantee

The *NHS Care Record Guarantee* and the *Social Care Record Guarantee* for England set out the rules that govern how patient information is used and what control the patient can have over this. <http://www.nigb.nhs.uk/pubs/crgengland>

Information Commissioner's Office (ICO)

The ICO is the UK's independent authority responsible for the implementation of the Data Protection Act and Freedom of Information Act. They can advise on how to protect your personal information and how to find out what information is held about you.

www.ico.gov.uk/

National Information Governance Board for Health and Social care (NIGB)

The NIGB sets the standards that the NHS needs to achieve to ensure that information is handled legally, securely, efficiently and effectively. It will be transferring its responsibilities to another organisation in 2013. The NIGB website has guidance on *Requesting amendments to health and social care records*, and on how information about you can be shared when it's in the public interest.

www.nigb.nhs.uk/

Technical terms explained

Antivirus software

A virus is a computer program produced to do harm, or for criminal activity. There are many types, but you can reduce the risk of an attack by using up-to-date antivirus software.

App

Short for *application*. It's piece of software that can run on your computer, phone or other device.

Browser

Short for *Web browser*. It's software that finds and displays content on the internet. Examples of browsers are Apple Safari, Google Chrome, Internet Explorer and Mozilla Firefox.

Browsing History

A list of web pages you have looked at, recorded by your web browser. There is usually a button you can click to clear your browsing history. Look up 'Clear browsing history' under 'Help' if you can't find it.

Character

A character is a single letter, number or symbol. So, the word 'computer' has eight characters.

Download

When you transfer data from the internet to your computer. Downloads can be things like web pages, pictures, music files and computer games.

Firewall

Connecting your computer to the internet makes it visible to every other computer on the network. A firewall sits between your computer and the network to control which computers can connect to it and what services they can use.

Hotspot

A place where your laptop or phone, for example, can get wireless connection to the internet. You can find hotspots in many places, such as cafés, libraries and railway stations.

Login

A combination of information, usually a username and password, which confirms your identity and lets you in to a computer system or website.

Log off/logout

Ending your session on a computer or computer programme. Many secure websites will have an option for you to log off or logout when you have finished.

USB stick

A small, portable device that can be plugged into a computer and used to store information.

Wi-Fi / Wireless connection

A way of transferring information, such as between the internet and your computer, without cables or wires.

Your notes

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This guide was produced by BCS, the Chartered Institute for IT, and the Department of Health. It was tested with patients and organisations that represent them. Last updated xxx 2012. For more information visit the www.xxxxxx.