



Keeping your
online health and
social care records
safe and secure

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By 2015, everyone in England will have access to their GP medical records online. Many other health and social care organisations are providing access to records too, and some people are creating their own health records online.

Having access to 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.

Your records contain personal information, so 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.

We have written this guide for people who are accessing their own records and who may want to share them with others. 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** refers to the electronic (computerised) records kept about you by health or social care professionals.

Record provider means the organisation that gives you access to the records they hold about you (for example, your GP practice, hospital or social care provider).

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Summary of the main points in this guide

- Your password and other information for logging in are important for keeping your records safe and secure. Set up a strong password and keep it secret. (See pages 9–11.)
- Protect the computer or other device you use to access your records – for example, by using a password or PIN and antivirus software. (See page 11.)
- If you think someone might have seen your records without your permission, change your password straightaway and contact your record provider. (See page 12.)
- Be particularly careful about the security of your records if you use a shared computer or a mobile device. (See page 12.)
- Before you share your records 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 records, and how you would feel if it was shared more widely. If you're in any doubt, don't share. (See pages 13–15.)
- If someone is trying to force you to share your records with them, tell your health or social care professional. (See pages 14–15.)
- There are organisations you can contact for more help and information. (See pages 17 and 18.)

About your records

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

- details of consultations you've had with doctors and other care professionals
- test results
- details of medicines you have been prescribed
- your medical history, including illnesses, accidents and operations you have had
- treatment goals and care plans, including details about your choices, preferences and any special needs, and
- letters between your GP, specialists and any other health and care providers.

If you sign up to have access to your records, you will be able to see your records online 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 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 records will depend on what your record provider is offering and the system they use. You may be able to:

- see the full information 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 records 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, and
- carry out tasks such as booking and cancelling appointments or ordering repeat prescriptions.

Being able to see your records can help you to remember and understand the discussions you have had with care professionals. It can be useful when you are preparing for your next appointment. It can also save you time (for example, if you want to remember when you had a vaccination or treatment).

By looking at your records, you can also help to make sure they are accurate. You can't change anything that has been added to your records by a health or social care professional, but if you see a serious mistake you should tell your record provider and they will correct it, if possible. (For more information, see 'National Information Governance Board for Health and Social Care' on page 18.)

True or false?

If I decide to access my records online, new electronic records will be made for me

False. There are already computerised records 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 to have access now, I won't be able to sign up later.

False. Deciding whether to be able to access your records online isn't a 'now or never' opportunity. If you decide not to do it now, you can change your mind in the future. You may still be able to use online services, such as booking appointments, without signing up for online access to your records.

Why might my records be at risk?

Most people who access their records online 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 records could be 'hacked'. This is when someone illegally breaks into your records, either to steal your identity or to get other personal information about you.
- It's possible that your records might be seen by someone that you don't want to see them.

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 records 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, if your GP refers you to a specialist, they will pass on relevant information.

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

Record providers must:

- store records safely, on secure systems
- keep a list (an audit trail) showing who has changed or added to the information in your records, and
- make sure that only authorised staff have access to your records.

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 see your records, 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 having access to your records involves. The record provider can also 'switch off' your access to the records if you change your mind.

Summary Care Records

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

Using your records safely and securely

There are three things you can do to help keep the information in your records safe.

1. Create a strong password and keep it safe.
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 records, and how it might be used, before sharing.

1. Create a strong password and keep it safe

When your access is switched on, your record provider will give you log-in details. This is usually a username and a PIN (personal identification number) or password. You will need to enter these details when you access your records for the first time. They are unique to you and your records, so keep them safe. You may be able to create your own password or PIN. If you were given a password, you should change it as soon as you can.

Record systems are designed so that your information is secure. However, **your password is only as strong as you make it.** On the next page there's a list of the main differences between a 'weak' password and a 'strong' one.

You can change your password whenever you want. So if you have given it to 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 records 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, this might make it possible for them to see your records. For example, they could try to log in to your records 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 records.

<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 and nobody can see it 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 (see the examples on page 11).
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 without changing it.	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 for online banking.	You only use it for your health or social care records 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, 'MyDogLikesBiscuits!'.

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 'LBPhIhsadkwftt'.

2. Get into good habits online

Getting into some good habits will help to make sure your records stay safe. The Get Safe Online website (see page 17) has more information.

General tips

- Always log out of your records when you have finished using them.
- 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 make sure nobody can see your password or log-in details when you type them in, in the same way you would shield your PIN 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.
- Lock your computer or mobile device with a password or PIN.
- Keep all software on your device regularly updated.

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

It's best to view 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:

- ✓ use the 'incognito' or 'private browsing' option to stop the browser saving your browsing history; or delete your browsing history
- ✓ close the browser window when you have finished (to avoid someone using the 'back' button to access your information), and
- ✓ make sure that the computer doesn't store your password. Do this by making 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 nobody is watching over your shoulder. If you think that someone may have seen your password, change it.
- ✓ Use a well-known commercial Wi-Fi provider for wireless access, rather than logging on to an unsecured network you know nothing about.

Look out for any unauthorised access

Someone may have seen your records without your permission if:

- they have information about you which they shouldn't have and which is likely to have come from your records, or
- the record system shows that someone has accessed your records at times that you didn't expect.

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

Be careful with copies and printouts

You can print information from your records, or copy and save it. This can be useful – for example, when you travel. 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 records, 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 in the following circumstances.

- 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 elderly and have 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 records is something to think carefully about.

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

What information in my records might be sensitive?

For most people there is little or no information in their records that would cause more than embarrassment if someone else saw it. However, for some, records contain very sensitive information that could cause serious problems if someone else saw it. Remember that your records may include information taken from documents written many years ago.

Some record systems may allow certain information to be hidden, such as information about mental health 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 a contraceptive or that you have a health condition such as HIV.

Sensitive information could include the following.

Sexual health and pregnancies	Genetic conditions
Mental health issues	Experience of abuse
HIV status	Alcoholism or drug use

How do I share my records safely?

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

If you think that someone else might pressure you to share your records with them, 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. These organisations are listed at the end of this guide. If you're in any doubt, don't share.

Are there any times when I must share my records?

You can refuse to give access to your records to anyone outside the NHS, unless your information has to be shared by law. 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, ask yourself the following.

- **Is sharing information in my best interests?**
For example, giving a health professional access to your record to help you get the right care when you're away from home.
- **What information is in my records?**
Think about the consequences of other people seeing it.
- **Could sharing my records affect other family members?**
For example, do you have a genetic condition that could be passed on through the family?
- **Do I need to share my 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 for the information, rather than giving access to your records. Or you could print out just part of the records, or cut and paste it into a file (perhaps one that you secure with a password) and email it to them.

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

So, in summary...

There can be great benefits from having access to 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 keep it safe.**
- ✓ **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 records, and how it might be used, before sharing.

Further information

If you have any problems with your password or viewing your records, contact your record provider. 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 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, safely.

Website: www.getsafeonline.org

Help for older people

If you're not confident using the internet, ask your local Age UK for help – many branches offer training sessions and advice for older people on getting online. UK Online Centres also help people who want to learn simple computer skills. Your local library may also offer computer training. Read Age UK's free guides 'Making the most of the internet' and 'Internet Security' for more information.

Website: www.ageuk.org.uk

Help for anyone being pressured to share records

These Freephone helplines offer advice if someone close to you is trying to make you give them access to your records. They can also give advice to family or friends calling on your behalf. You should also tell your care professional if you're being pressured.

Age UK Advice Line (for older people)

Phone: **0800 169 65 65**

Men's Advice Line

Phone: **0808 801 0327**

Website: **www.mensadviceline.org.uk**

National Domestic Violence Helpline for women

Phone: **0808 2000 247**

Website: **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.

Website: **www.nigb.nhs.uk/pubs/crgengland**

Information Commissioner's Office (ICO)

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

Website: **www.ico.gov.uk**

National Information Governance Board for Health and Social Care

The National Information Governance Board for Health and Social Care (NIGB) sets the standards that the NHS needs to meet to make sure that information is handled legally, securely, efficiently and effectively. It will be transferring its responsibilities to another organisation in 2013. The NIGB website has a guide called 'Requesting amendments to health and social care records'. It also has guidance on how information about you can be shared when it's in the public interest.

Website: **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', an app is a piece of software that can run on your computer, phone or other device.

Browser

Short for 'web browser', this is 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 browser. There is usually a button you can click on to clear or delete your browsing history. Look 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 something 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.

USB stick

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

Wi-Fi

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

My record provider is:



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