



# Your health information, confidentiality and the NHS Care Records Service

Answers to your questions

This leaflet is a guide to the information we hold about your health and how we will get access to that information in the future as we introduce the NHS Care Records Service.

This leaflet answers the following questions.

- What information is in your health records?
- How do we use your health information?
- How will we access your information in the future?
- What measures are in place to keep your information safe and confidential?
- Who can get access to your information?
- What are your options?

***Visit our website:***

**[www.nhscarerecords.nhs.uk](http://www.nhscarerecords.nhs.uk)**

NHS Connecting for Health is supporting the NHS to deliver better, safer care by providing linked computer systems.

# Improving the way we care for you in England

## Why are you changing the way you store and access health care information?

In England, we are introducing the NHS Care Records Service. This will give health staff faster access to reliable information about you, whenever and wherever they need it to treat you. It will also mean that you will have better access to your own health information, to help you manage your own health.

Currently, all the places where you receive care keep records about you. They can usually only share information from your records by letter, e-mail, fax or phone. At times, this can be slow and sometimes things get lost on the way. Now there will be quicker ways for the staff treating you to get important information about you using the NHS Care Records Service, including in an emergency.

## How we use your health information today

### What information do you keep in my health care records?

We keep information about you so we can provide you with safe, effective care. The information we keep falls into two categories – **demographic information** and **clinical information**.

## What is in my demographic information in the NHS Care Records Service?

- Your name (including the name you prefer to use) and any other name you may have used in the past
- Your main or temporary address (and where to send post, if this is different)
- Your contact details (phone, fax, e-mail), how you prefer us to contact you and the time of day you prefer us to contact you
- The way you prefer us to write to you (in Braille or large print, for example)
- The language you prefer to use and if you need an interpreter
- Your place and date of birth, sex, age and NHS number (page 7)
- Your GP practice and the pharmacy you want us to send your prescriptions to electronically (where available)
- Whether you have registered for HealthSpace (where available) (page 12)
- If you have asked us (and we agree) to stop anyone being able to see sensitive demographic information about you (page 17)
- Death records

## What clinical information will be included in the NHS Care Records Service?

- Your medicines and any bad reactions you have had to any medicines you have taken
- Any allergies you may have
- Health conditions such as asthma or heart problems
- Reminders for health care staff about future plans for your care

- Your health care records may also include other details you have told a clinician (for example, about your family or work) but only if this is relevant to your health care

## How do you use my health information?

The people caring for you use your information to provide treatment, check the quality of your care, help you make good decisions about your health and to investigate complaints. This will continue when we begin to link your electronic records (records we keep on computer) through the NHS Care Records Service.

We sometimes use your information more generally to:

- check the quality of care we provide to everyone;
- protect the health of the general public;
- monitor how we spend public money;
- plan and manage the health service;
- train health care workers; and
- carry out research.

If we use your information for these reasons, we normally remove your name and other details which could identify you. If we need the information in a form that identifies you, we usually ask you first.

## When might you use information that identifies me without asking my permission?

In very limited circumstances, the law allows us to use your information without asking you first. This happens today and will continue when we start to use the NHS Care Records Service.

In limited circumstances the independent Patient Information Advisory Group (a group of health care staff and patients (PIAG)) can give us permission to use your information without asking you, if they think it is very important and it would not be practical to get your permission. For example, some important health research involves thousands of patients. In these cases, contacting every patient for their permission may not be practical.

In other very limited situations, we may need to (by law) give out information about you without your permission. In all cases, we will only provide the information needed. Wherever possible, we will tell you. For example, we may need to:

- tell authorities about the birth of a child;
- report food-poisoning cases to authorities;
- report some infectious diseases;
- provide information to be used in court; and
- give information to the police to help detect or prevent a crime.

## When will we start using the NHS Care Records Service?

### How and when will you start accessing my health care information differently?

The NHS Care Records Service has already started developing in some parts of the country and will continue across England over the next few years. There will be small improvements at first and we will gradually link more information across our organisations.

## What information will you include in my NHS Care Record?

In the future, you can have an electronic NHS Care Record made up of a 'Summary Care Record' and, over time, more detailed records.

### Your Summary Care Record

You can have an electronic Summary Care Record, which those treating you can get access to anywhere in England. At first, your Summary Care Record will only include basic details from your GPs record about allergies, current prescriptions and any bad reactions you have had to medicines.

Then, each time you use any NHS services, we may add information about your current health problems, care you are receiving and the health care staff treating you.

As we add new information, you can discuss which details are added to your Summary Care Record with the health care staff treating you, and how we handle sensitive information about you (for example, about mental or sexual health or certain infections). Health staff should always ask you when they add sensitive information to your records. You should let them know if anything they add concerns you.

Since 2007, we have gradually been introducing Summary Care Records. It will be several years before everyone can have one. We will also tell you before your Summary Care Record is ready so that you have time to think about your options. For example, if you want to put limits on who can have access to your information, you will have time to speak to health care staff.

## Detailed records

In the future, instead of having separate records in all the different places where you receive care, NHS organisations which normally work together in a local area – such as hospitals, clinics and GPs – will gradually be linked electronically, so staff caring for you have access to the information they need.

We will tell you when we do this and what you can do to prevent sharing your information in this way (page 15). Depending on where you receive care, you may have more than one linked record.

Your detailed records will contain:

- your name, address, date of birth and NHS number;
- details of any medicines you are taking (or have taken), allergies, test results and x-rays;
- details of any health conditions such as asthma or a heart problem;
- notes of any diagnoses, treatments or operations; and
- plans or reminders for your care in the future.

We will link detailed records locally over several years. We have already started to do this in some places. As we link your records in your region, we will give you information about this when you go for treatment.

## How up to date will my linked electronic records be?

Health care staff will add information to your linked electronic records as they treat you. When the NHS Care Records Service is fully up and running, the NHS will take information (such as current health problems) from your detailed records and add it to your Summary Care Record.

## **Will you transfer all my paper records into electronic health care records?**

We will not transfer all of the information we hold on paper. We will try to transfer the details that may be relevant to your health care in the future.

## **Will you destroy my old paper records?**

By law, we must keep your old records, usually for 10 years after the last entry. Then we must either destroy them, or store them.

## **Keeping your information secure and confidential**

### **How secure are the new ways you get access to my health care information?**

All health records are private and personal, so it is a key priority to make sure the way we access your electronic information is secure.

The NHS Care Records Service will use the strongest national and international security measures for handling your information (see the end of this leaflet for more details). These measures make sure that we store your information safely, that it stays private and that we get access to it appropriately.

Every patient registered with the NHS has a unique NHS number. We use your NHS number to link all of your health information together, to make sure it is put into the right NHS Care Record.



## Could you accidentally delete or lose my linked electronic records?

When the NHS Care Records Service is fully up and running, we will have very strong protection in place to make sure it does not lose any information, even if the system stops working temporarily. It has been designed to recover any information as quickly as possible.

We will constantly update and copy all the information we store to a separate, secure site. If the system stops working (for example, there is a power failure) the system should automatically recover the information as soon as possible.

## What are my rights about how you keep my information confidential?

You have the right to expect us to keep your health information private. You also have rights to make sure we keep your details confidential under the Data Protection Act, human rights legislation and the common law. In every place we treat you, there are people who are responsible for making sure your details are kept confidential. They are sometimes known as Information, or Caldicott, Guardians.

Your rights to privacy and our commitment to protect them are set out in the leaflet '**The NHS Care Record Guarantee for England**'. See the end of this booklet for details of how to get a copy.

# Who has access to your NHS Care Records?

## How will you control access to my NHS Care Records?

Anyone wanting to look at your clinical care records:

- must be involved in caring for you;
- must have an NHS Smartcard, with a chip and a passcode;
- will only see the information they need to see to do their job; and
- will have **their** details recorded – who they are and if they added or changed any of your information (you can ask to see this).

Different NHS organisations work in different ways to provide the best possible care for you. This means staff in different organisations doing a similar job may see more or less of your information. This depends on how the organisation chooses to work to provide the best care for you.

Although how much information a member of staff may see can change from organisation to organisation, each organisation is responsible for keeping your information safe and secure.

Every NHS organisation will have very strong security methods in place. Before any member of staff in an NHS organisation or GP practice can see the clinical information in your Summary Care Record, their employer has to confirm that they need to see it to do their job.

All staff who are able to see patient information have a professional, ethical and legal responsibility to keep your details confidential and keep to the NHS confidentiality code of practice.

You can see information about who has had access to your Summary Care Record and what they did, if you ask. Each NHS organisation has a 'privacy officer' who can check whether anyone has looked at a Summary Care Record when they should not have.

If you have concerns about who can see your record, you should speak to a member of staff where you are receiving care. They will discuss your concerns with you.

If you think that somebody who should not have seen your information has been able to see your record, the organisation treating you will be able to look into this. If they find that someone who should not see your information has been able to see your records, they will also be able to tell you how this will be dealt with.

Until we put these controls fully in place across England, your local NHS organisations will have their own measures to make sure they keep your information confidential. Your local NHS can give you more details.

If a care team is looking after you, it may include care staff such as people from social services, education or a private hospital. If they have access to your NHS Care Records, we should tell you.

Anyone caring for you outside the NHS must still meet all of our conditions for keeping your information confidential and secure, if they have access to your NHS Care Records.

## **Will I be able to see my own NHS Care Records?**

Yes. As now, you will have the right to see your health care records. At the moment, you need to apply direct to the NHS organisations where you have received treatment, although this may change as we link our records. You may have to pay a small charge for this.

Once you have a Summary Care Record, you will be able to see it online at any time by visiting [www.nhs.uk/healthspace](http://www.nhs.uk/healthspace). You will be able to make sure it is accurate and, in time, add things yourself (for example, if you prefer us to contact you in a certain way or you use a wheelchair and need special access). You will need to register to use HealthSpace.

If you do not have access to the internet at home or at work, you can use Healthspace at a number of public places, such as internet cafés and libraries. You may also be able to see your Summary Care Record using HealthSpace at some surgeries and hospitals.

You will not be able to read your detailed records using HealthSpace, but you can apply to see them by asking the places which treated you.

## Can I change my electronic records?

You will not be able to change the information other people write. You will be able to ask the member of staff treating you to correct any mistakes. If they are satisfied the information is correct, they should add a statement to your NHS Care Records, saying that you disagree with the information.

## How old do I have to be to see my own records?

If you are interested in seeing your own records, you can ask to see them at anytime. As long as you are mature enough to understand your condition and treatment (we may call this your 'competence'), then you have the right to see your records. But it is good practice for us to show you your records and explain them where necessary, even if the member of staff treating you feels you are not yet mature enough for this to be your right.

We would only not show you your records if the member of staff treating you feels that it would harm you or someone else if you saw them (see also page 14).

## **Can parents or legal guardians see their child's records?**

Currently, parents or legal guardians have the right to have access to their child's records if their child is under 16.

Their child has the right to ask us not to give their parent or guardian access to their records. Their child also has the right to give information to us and to expect that access to that information will not be given to their parent or guardian.

However, even if a child has asked us not to give access, we may give parents and legal guardians information if the reasons for giving them access are more important for public good than keeping the child's information confidential. This will still be the case with the NHS Care Records Service.

## **Can I have access to my NHS Care Records online, if I am under 16?**

If you are under 16, you won't be able to see your Summary Care Record using the HealthSpace website.

This does not affect your rights to ask us for access to your information under the Data Protection Act. For information on how old you have to be to see your own records, see page 12.

## **Can I give other people outside the NHS access to my NHS Care Records?**

You might want to give a family member, friend or carer access to your records to help them care for you. Normally, we will not give them access to your NHS Care Records, unless you ask us to.

If you want to give someone access to your records in this way, you should discuss it with health care staff first. They can advise how to give access, so that you control your own information and keep it confidential.

You can also ask the organisations which have given you care to provide information to other people. For example, this could be to your solicitor for a court case, or a medical insurer to help you apply for insurance. We need your permission to do this. You may want to limit their access to just part of your NHS Care Records.

## **Will other people have access to my NHS Care Records without my permission?**

No. The rules for this remain the same as they are today. Other organisations outside the NHS cannot usually have access to your NHS Care Records without your permission. For example, the police, your insurance company or employer have no direct access to your NHS Care Records. Currently, in limited circumstances, allowed by law (through a court order, for example), we may give copies of selected information in your records to the police and other authorities.

## **Are there any situations where you will keep information in my NHS Care Records from me?**

You usually have the right to see everything in your NHS Care Records.

However, in special circumstances, health care staff may keep information from you. There are very limited reasons for doing this. We may keep information from you if we:

- think seeing the information is likely to cause you or someone else serious harm to your or their physical or mental health; or

- have been given the information in confidence by someone other than health care staff caring for you (for example, information a member of your family has given to us and asked us not to tell you).

Health care staff may also keep information from you until you can discuss it together, for example, a test result which may upset you. This will be particularly relevant when you can access your own Summary Care Record by computer.

## Your options

### What are my options if I decide to limit who has access to my NHS Care Records?

First, you should get more information about the NHS Care Records Service (see the end of this booklet). If, after finding out more, you want to limit who has access to your electronic care records (detailed and Summary) you will need to talk to a member of staff.

There are a number of ways to limit access to your NHS Care Records. This may affect the care you receive (see page 16).

- **Limiting who has access to your NHS Care Records**

You can ask that only people in the organisation that created your information can have access to it, such as your Primary Care Trust or local Hospital Trust. So, unless information is sent in a clinical communication (like a referral), a clinician in one organisation won't be able to see clinical records created in another organisation.



- **Giving people access to parts of your NHS Care Records**

As the service develops (although not right away), you will also be able to ask that we keep certain information hidden. This will be called a **'patient's sealed envelope'**.

You will have two options for sealing information.

**Seal** – if you 'seal' the information, health care staff will only have access to it if you agree (except in special circumstances (see page 4)). If somebody from outside the care team that sealed the information tries to get access, they will see a flag, showing that some information has been hidden. They might then ask you about it.

**Seal and lock** – if you 'seal and lock' information, no one can have access to it outside the team that sealed and locked it, even in an emergency. It will be 'invisible' and no one outside the team that sealed and locked it, will know that it exists.

If we find that someone in the NHS has had access, without good reason, to any information that you asked us to seal or seal and lock, we will tell you and, where appropriate, take disciplinary action. This could include dismissing the person who had access or gave someone access. Your clinical NHS Care Records automatically record who has accessed your information – who they are and what they did. You can ask to see this.

- **Not having an electronic NHS Care Record**

You can ask us not to upload your Summary Care Record to the NHS Care Records Service. You can get a form for this from your GPs surgery. This would mean that you won't have any of the benefits of having essential information about your care available throughout England. This may affect care you need out-of-hours, in an emergency or outside of your local area.



Your local detailed records will still be available for any care you need in your area. In some circumstances, however, you may ask that we record the clinical information in your local detailed records either on paper or on computer systems not linked to the NHS Care Records Service. The health care staff and the NHS organisation treating you will make this decision. The Department of Health will look into this option further in a national consultation.

We still need to hold basic information on our computers, so we can manage your care. We hold this information in the Patient Demographic Service (PDS) and Patient Administration Systems (PAS). You do not have a legal right to prevent us from holding **demographic information** (see page 3).

However, if we need to, we can take steps to make sure we do not display your address. For instance, if you are a victim of domestic violence who may be in danger if your partner finds out where you live. In very special cases, we can give you an alias (a false name).

## **If I have asked you to limit access to my records, could you refuse this in certain circumstances?**

Once your information is part of the NHS Care Records Service, if you ask us to limit access to all or parts of your electronic health care records, we will only overrule this request in special circumstances. Only health care staff involved in your care can do this. This will alert the person in the organisation where you are being treated, who is responsible for patient confidentiality (often called an Information, or Caldicott, Guardian). They will look into what happened and take appropriate action, which may include telling you.

Your request to limit access would only be overruled if we considered it to be in the public interest, if the courts order us to, or if we have to by law.

If we feel you are not able to make the decision to limit access (because of your mental health), it is good practice for us to consult your family and carers, or anyone given power under the Mental Capacity Act to act for you or make decisions for you.

## What control will there be over my NHS Care Records after I die?

It is unlikely that, after you die, anyone would need to have access to your NHS Care Records in a way which identifies you. One exception might be if there was an inquest into your death. Although you have no absolute right to keep your information confidential after you die, we will only give access to your confidential information if it is necessary.

## When will people treating me be able to access my records in different ways?

Your GP practice or Primary Care Trust will tell you before this is about to happen in your area. Unless you do not agree, we will automatically make your records part of the service over the next few years.

If you are happy for this to happen, **you don't need to do anything else**. If you would like to know more or talk to someone about the service, see the section 'Further information' at the end of this booklet.

## Can I decide now about limiting access to my NHS Care Records and change my mind later?

Yes, you can decide now or later. You can also change your mind about your decisions at any time.

The NHS Care Records Service will gradually link your records over the next few years, so that we can access them differently from the way we access them today.

If after finding out more (see below) you decide you want to see what is in your Summary Care Record, ask at your GP practice who can arrange this for you. You will have a number of options to limit who has access to your information.

You can ask those treating you not to include certain information in your Summary Care Record. Your GP practice will note your decision for the future when we create your Summary Care Record. If you change your mind at any time, tell your GP practice.

You can ask that those treating you cannot have access to your Summary Care Record. This will also affect your local detailed records. You will need to ask someone in your GP practice to do this.

You can choose not to have a Summary Care Record at all. You will need to ask for this by filling in a form you can get from your GP.

## Further information

If you would like advice or more information about the NHS Care Records Service, you can:

- get a copy of the leaflet 'The NHS Care Record Guarantee for England' from our website ([www.nhscarerecords.nhs.uk](http://www.nhscarerecords.nhs.uk)), from your GPs surgery or by calling 08453 700 750;
- phone the NHS Care Records Service information line on 0845 603 8510; or
- contact your local Patient Advice and Liaison Service (PALS) office (ask your local NHS for contact details or visit [www.pals.nhs.uk](http://www.pals.nhs.uk)).

You can get leaflets in other languages and formats, at the website ([www.nhscarerecords.nhs.uk](http://www.nhscarerecords.nhs.uk)) or by calling 08453 700 750.

Note for readers (see page 8):

The key security standards the NHS Care Records Service will meet are:

- ISO 27000 (previously BS7799) – the main Information Security Standard;
- Federal Information Processing Standards (FIPS) – the main standard for cryptography, which gives codes to your information so that only people with the key to the code can read it;
- the electronic Government Interoperability Framework (eGIF) standards – which make sure people register before they are allowed access to secure information and have to prove who they are;
- the Common Criteria standard – which covers Evaluation Assurance Levels of information technology hardware and software. For example, this recommends keeping local and national computer systems separate for security reasons; and
- the Communications and Electronic Security Group (CESG) – which provides our NHS Care Records Service with Information Technology Security Evaluation Criteria (ITSEC) assurance levels and advice on security. See [www.cesg.gov.uk](http://www.cesg.gov.uk) for more details.



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