

The Care Record Guarantee

Our Guarantee for NHS Care Records
in England

Introduction

In the National Health Service (NHS) in England, we aim to provide you with the highest quality of healthcare. We also aim to gain evidence that will improve health and care through research. To do this, we must keep records about you, your health and the care we have provided to you or plan to provide to you. NHS care records may be electronic, on paper or a mixture of both, and organisations use a combination of working practices and technology to keep to this guarantee.

You have the right to privacy and confidentiality and to expect the NHS to keep confidential information safe and secure (the NHS Constitution for England 2010). This guarantee is our commitment that NHS organisations and those providing care on behalf of the NHS will use records about you in ways that respect your rights and promote your health and wellbeing. The Government has made it clear that patients will have control of their own health records, starting with access to the records held by their GP and extending to records held by all health providers (Equity and Excellence: Liberating the NHS, Department of Health, 2010, paragraph 2.11).

The people who care for you use your records to:

- provide a good basis for all health decisions made by you and healthcare professionals;
- allow you to work with those providing care;
- make sure your care is safe and effective; and
- work effectively with others providing you with care.

Others may also need to use records about you to:

- check the quality of care (such as a clinical audit);
- protect the health of the general public;
- keep track of NHS spending;
- manage the health service;
- help investigate any concerns or complaints you or your family have about your healthcare;
- teach healthcare professionals; and
- help with research.

The law gives you the right to:

- confidentiality under the common-law duty of confidentiality;
- protection in the way information about you is handled under the Data Protection Act 1998; and
- privacy, under the Human Rights Act 1998.

These are not 'absolute rights', as often an individual's rights will need to be balanced with those of others, but they do offer considerable protection.

It also gives you the right to:

- ask for a copy of all records about you held in paper or electronic form (you may have to pay a fee); and
- choose someone to make decisions about your healthcare if you become unable to do so (this is called 'a lasting power of attorney').

We have a duty to:

- maintain accurate records of the care we provide to you;
- keep records about you confidential, secure and accurate (including after you die); and
- provide information in a format that is accessible to you (for example, in large type if you are partially sighted).

It is good practice for people in the NHS who provide your care to:

- discuss and agree with you what they are going to record about you;
- give you a copy of letters they are writing about you; and
- show you what they have recorded about you, if you ask.

If you have any concerns about privacy and confidentiality, or want to know more about the arrangements that local organisations have put in place to follow the commitments in the NHS Care Record Guarantee, you should check with your local NHS organisation or care provider.

Our 12 commitments to you

1. When we receive a request from you in writing, we must normally give you access to everything we have recorded about you. We may not give you confidential information about other people, or information that a healthcare professional considers likely to cause serious harm to the physical or mental health of you or someone else. This applies to paper and electronic records. However, if you ask us to, we will let other people see health records about you.

Wherever possible, we will make your health records available to you free of charge or at a minimum charge, as allowed by law. We will provide other ways for you to apply to see your records if you cannot do so in writing.

We will provide information in a format that is accessible to you (for example, in large type if you are partially sighted).

2. When we provide healthcare, we will share your record with the people providing care or checking the quality of care (unless you have asked that we limit how we share your record). Everyone looking at your record, whether on paper or computer, must keep the information confidential.

We will aim to share only as much information as people need to know to play their part in your healthcare.

3. We will not share health information that identifies you (particularly with other government agencies) for any reason other than providing your care, unless:
 - you ask us to do so;
 - we ask and you give us specific permission;
 - we have to do this by law;

- we have special permission for health or research purposes; or
- we have special permission because the public good is thought to be of greater importance than your confidentiality.

If we share information without your permission, we will make sure that we keep to the Data Protection Act 1998, the NHS confidentiality code of practice and other national guidelines on best practice. There is more information about existing guidelines at: www.dh.gov.uk

4. Legally, no-one else can make decisions on your behalf about sharing health information that identifies you. The only exceptions to this are parents or legal guardians, or people with legal powers to make decisions on behalf of adults who cannot make the decision for themselves or who may be a risk to others. You can appoint someone to have a lasting power of attorney to make decisions for you if you are losing the ability to make decisions for yourself. You can decide what rights that person has in making decisions about your care record. If you do not appoint anyone, a senior healthcare professional involved in your care may consider it to be in your best interests to share information. This judgment should take account of the views of your relatives and carers, and any views you have already recorded. For medical research or other purposes (see the box on page 6), the National Information Governance Board for Health and Social Care (NIGB) advises when special permission should be given to share any health information that could identify individuals.

When we might use or share information that names you without asking you

- Sometimes we have a legal duty to give information about people. Examples include:
 - registering births;
 - reporting some infectious diseases;
 - reporting gunshot wounds to the police; or
 - because a court orders us to do so.
- Sometimes special permission will be given to use information that identifies you without your consent. This may be for medical research, keeping registers of cancer patients or checking quality of care. This permission is given by the Secretary of State for Health on advice from the National Information Governance Board for Health and Social Care under strict conditions.
- Special permission may also be given when the public good outweighs your rights to confidentiality. This is very rare, but some situations where this might happen include:
 - when a serious crime has been committed;
 - when there are serious risks to the public or NHS staff; or
 - to protect children or vulnerable adults who are not able to decide for themselves whether their information should be shared.

Other than in the most exceptional circumstances, this permission is given by the senior clinician in charge of protecting your privacy in each health or care organisation. (Often this person will be called the Caldicott Guardian.)

5. Sometimes your healthcare will be provided by members of a care team, which might include people from other organisations such as social services or education. We will tell you if this is the case. When it could be best for your care for your health information to be shared with organisations outside the NHS, we will agree this with you beforehand. If you don't agree, we will discuss with you the possible effect this may have on your care and alternatives available to you.
6. Usually you can choose to limit how we share the information in your care records which identifies you. In helping you decide, we will discuss with you how this may affect our ability to provide you with care or treatment, and any alternatives available to you.
7. We will deal fairly and efficiently with your questions, concerns and complaints about how we use information about you. All trusts have a Patient Advice and Liaison Service (PALS) which can answer questions, point people towards sources of advice and support, and advise on how to make a complaint. We will have a clear complaints procedure. We will use what we learn from your concerns and complaints to improve services.
8. We will take appropriate steps to make sure information about you is accurate. You will be given opportunities to check records about you and point out any mistakes. We will normally correct factual mistakes. If you are not happy with an opinion or comment that has been recorded, we will add your comments to the record. If you feel you are suffering distress or harm as a result of information currently held in your record, you can apply to have the information amended or deleted.

- 9.** We will make sure, through contract terms and staff training, that everyone who works in or on behalf of the NHS understands their duty of confidentiality, what it means in practice and, how it applies to all parts of their work.

All organisations providing care for the NHS or on our behalf must follow the same strict policies and controls. This is managed through the Department of Health's Information Governance Framework for Health and Social Care, and through the individual standards which make up the Information Governance Toolkit.

- 10.** We will take appropriate steps to make sure we hold records about you – both paper and electronic – securely and only make them available to people who have a right to see them.

There may be times when someone will need to look at information about you without you giving your permission first. This may be justified, for example, if you need emergency care.

- 11.** We will keep a record in the newer electronic record systems of anyone who has accessed a health record or added notes to it. Some of the older computer systems will only record who has accessed a record where they have made changes. Paper records only include where people have made notes in the record and not when someone looks at the record.

- 12.** If you believe your information is being viewed inappropriately we will investigate and report our findings to you.

If we find that someone has deliberately accessed records about you without permission or good reason, we will tell you and take action. This can include disciplinary action, which could include ending a contract, firing an employee or bringing criminal charges.

Six things that you can do in return

- a.** Help us to make sure that we have identified you correctly by letting us know when you change address or name and keeping a note of your unique NHS number.
- b.** Tell us if any information in your record is wrong.
- c.** Allow us to share as much information about you as we need to provide you with healthcare.
- d.** If you have decided to limit how we share the information in your electronic care record with others, tell us if you change your mind. We will always try to provide you with the best possible care, but bear in mind that limiting the information we can share may make it more difficult.
- e.** Only let others – insurers, mortgage lenders, employers, solicitors – look at your records if you are sure it is necessary for your purposes. Think carefully about who you give permission to and why. Try to restrict their access to what they need to know and no more.
- f.** At some time, we might ask your permission to use information from your records from which you could be identified for important research. Please give us permission unless you feel strongly that you do not want us to use your information in this way.

For parents and young people

Introduction

Care records are important for the wellbeing of children and young people. Knowing about your child's health is important for parents. Parents include birth parents and anyone else who has been granted parental responsibility for a child by a court.

As they grow up, children become more able to make decisions for themselves. They should be helped to do so and be involved in their healthcare whenever possible. You can get an illustrated leaflet about care records for younger children from www.nigb.nhs.uk

Parents

If you are a parent, we will let you see your child's care record or give you a copy if you ask. If your child is able to understand and make decisions, we will ask for his or her agreement first. Your child's care record will probably include some information about you. We will ask your permission before showing it to your child. You can choose to hide these parts of your child's record from your child.

Young person

If you are a young person capable of understanding and making decisions for yourself, you have a right to see your record or have a copy if you ask.

You can ask someone giving you care not to share information with your parents. We can agree to this unless doing so would put you at risk or cause you harm. We will discuss this with you and try to reach agreement.

Parents and young people

We will encourage you and your child to make decisions about the care record together. If you disagree about who can see the care record, your hospital or GP practice will ask the advice of the Caldicott Guardian, who is responsible for protecting the privacy of patients.

Sharing information

When it is best for your child's care to share health information with people who are not directly involved in their treatment or not in the NHS (such as social services or education), we will usually ask you or your child before we do so. If you or your child do not agree, we will discuss with you or your child the possible effect this may have on their care, and the alternatives available.

Sometimes we do have to share information without your or your child's permission, as shown on page 6. This is particularly when there is concern about the safety or welfare of the child and asking for permission could put the child at risk.

The Summary Care Record

Your Summary Care Record contains information from your GP record such as your current prescriptions, allergies, and any bad reactions to medications you have had. It may also include other information that you have agreed should be added. This means that wherever in England you need emergency care, those providing it can have access to the most up-to-date information.

We will ask your permission if we need to look at information in your Summary Care Record. When this is not possible, for example if you are unconscious, we will make a note on your record and we will normally tell you.

We will tell you when we are introducing Summary Care Records in your area. Before we make a Summary Care Record for you, you can decide whether or not you want to have one.

You can change your mind at any time:

- If you choose not to have a Summary Care Record but then change your mind later we can still make one for you.
- If you choose not to have your Summary Care Record after we have made it, we will make sure that healthcare staff who try to look at your Summary Care Record will not be able to. We will only make your record available again if whoever wants to see it asks in writing and an investigation has shown it is necessary.
- You can ask to have your record deleted, but that may not be possible if the record has already been used to give you care.

If you have a Summary Care Record you will be able to see it at any time, free of charge, at a secure website called 'HealthSpace' (www.nhs.uk/healthspace). You must register to use HealthSpace to keep it as secure as possible.

How do we make sure your electronic care record stays secure and confidential?

Local NHS organisations and care providers have different ways of protecting privacy and confidentiality. If you have any concerns or want to know more you should check what the local arrangements are. These are some of the ways that are used:

- **Smartcards** – Any member of staff being given access to national systems which hold health information will need a ‘Smartcard’ along with a username and password. Many local systems are also starting to use Smartcards. Some national demographic information systems and some local systems only need a username and password to access them but there are still tight restrictions to maintain the highest level of security.
- **Recording permission to access** – There has to be a good reason (for example, being involved in providing your care) for someone to access the information in your record. Where someone is not involved in treating you regularly, for example if you go to a GP out-of-hours service, they will ask your permission to see your Summary Care Record, or your GP record where this is available.
- **Access controls** – The Smartcard also contains information about the job of the person it has been issued to. The amount of clinical information they can access is based on their job.
- **Audit trails** – An audit trail is available in the newer electronic record systems. It shows who has accessed a record and what, if any, changes they have made. The audit trail in some older electronic record systems may only show who has accessed a record where they have made changes.

- **Further privacy controls** – Many of the newer electronic record systems can restrict access to parts of your record that you do not want to be shared. This is sometimes referred to as ‘sealing’ information. Your doctor may refuse to allow you to seal some information where it is not in the public interest, for example information about an infectious disease or other situations where there are risks to others. Some systems allow clinicians treating you to see your sealed information in an emergency if you cannot give your consent at the time and the doctor feels it is justified, while other systems do not. Because of this, it is important that you understand the possible effects of any further privacy controls that are available before you ask for them to be used.
- **Consent** – Everyone has a Detailed Care Record but you can choose whether or not to have a Summary Care Record. Asking for your permission to share information is one of the ways we protect your privacy. We will do this by asking you to:
 - tell us if you don’t want us to create a Summary Care Record for you;
 - decide whether we can share the information in your Detailed Care Record and in your Summary Care Record; and
 - decide whether or not some of the entries in your Detailed Care Record are so sensitive that you want to further control who can see them.

How to complain

If you feel we are not following the commitments in the NHS Care Record Guarantee, you should tell us. You should write to the NHS organisation or GP responsible. When they receive your complaint, they will investigate it and send you their response.

You can ask the Patient Advice and Liaison Service (PALS) office at your hospital trust or primary care trust (PCT) for information and help. They may be able to deal with your concerns there and then, or give you details of how to take the matter further.

Or, you can phone NHS Direct on 0845 4647 for information on how to make a complaint.

You can get more information about rights under the Data Protection Act from:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Phone: [01625 545 745](tel:01625545745).

Information Commissioner's Office helpline: [08456 30 60 60](tel:08456306060)

Website: www.ico.gov.uk

You can get more information about the National Information Governance Board for Health and Social Care from their website at www.nigb.nhs.uk

The NHS Care Record Guarantee for England was first published in May 2005 by the Care Record Development Board (CRDB), and has been reviewed and revised annually by the NIGB, since the CRDB closed in 2007. This is version 5. The NHS Care Record Guarantee is available in several languages other than English and is available to download from www.nigb.nhs.uk

The National Information Governance Board for Health and Social Care (NIGB) is grateful to everyone who helped to revise this version of the Guarantee.

You can find out more about the NIGB on its website www.nigb.nhs.uk or you can contact the Board:

- by e-mail at nigb@nhs.net;
- by phone on 0207 633 7052; or
- by writing to:

The National Information Governance Board for
Health and Social Care
7th Floor
New King's Beam House
22 Upper Ground
London
SE1 9BW.

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