



# ***The Care Record Guarantee***

Our Guarantee for NHS Care Records  
in England

# Introduction

In the National Health Service in England, we aim to provide you with the highest quality of healthcare. 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.

This guarantee is our commitment that we will use records about you in ways that respect your rights and promote your health and wellbeing.

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.

You have the right:

- to confidentiality under the Data Protection Act 1998, the Human Rights Act 1998 and the common law duty of confidence (the Disability Discrimination and the Race Relations Acts may also apply); and
- to ask for a copy of all records about you held in paper or electronic form (you may have to pay a fee); and
- (from October 2007) to 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 full and accurate records of the care we provide to you;
- keep records about you confidential, secure and accurate; 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.

## The NHS Care Records Service

Some of your health records are already held on computer, but many are still kept on paper. While the paper records we keep are protected by strict confidentiality and security procedures, these records are not always available to healthcare professionals looking after you. Handwritten entries in the record may be difficult to read and important information may be missing.

Modern computer systems called the NHS Care Records Service are being introduced in the NHS over the next few years. The service will hold electronic health records about you securely, making them available to the right people where and when they are needed for your healthcare, while maintaining your confidentiality.

This new service will:

- hold electronic records about your healthcare in national systems so that, wherever in the country you need care, healthcare professionals can have access to the most up-to-date information;
- allow you to control whether the information recorded about you by an organisation providing you with NHS care can be seen by other organisations that are also providing you with care;
- show only those parts of your record needed for your care;
- allow only authorised people (who will need a 'Smartcard' as well as a passcode) to access your record;
- allow only those involved in your care to have access to records about you from which you can be identified, unless you give your permission or the law allows;

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- allow us to use information about your healthcare, in a way that doesn't make your identity known, to improve the services we offer or to support research;
- keep a note of everyone who accesses the records about you; and
- be operated in line with internationally approved information security standards.

## 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 its quality (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, 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/en/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians](http://www.dh.gov.uk/en/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians)

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

1 Sometimes we have a legal duty to give information about people. Examples include:

- births of children;
- reporting some infectious diseases;
- reporting gunshot wounds to the police; or
- because a court orders us to do so.

2 Sometimes special permission will be given to use your information 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 independent Patient Information Advisory Group (PIAG).

3 Special permission may also be given when the public good is thought to be of greater importance than your 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.

This permission is given by the Caldicott Guardian, who is normally the senior clinician in charge of protecting your privacy in each health or care organisation.

- 4 Under current law, no-one else can make decisions on your behalf, about sharing health information that identifies you. At the moment, the only exceptions to this are parents or legal guardians, or people with powers under law, for example, that relating to mental health.

From October 2007, you can appoint someone to have a lasting power of attorney to make decisions for you if you lose 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 Patient Information Advisory Group can give special permission to share any health information that could identify you.

- 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 electronic care record 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 which can answer questions, point people toward 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.

Organisations under contract to the NHS must follow the same policies and use the same controls as the NHS does. We will enforce this duty at all times.

- 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.
- 11 We will keep a record of everyone who accesses the electronic information the NHS Care Records Service holds about you. You will be able to ask for a list of everyone who has accessed records that identify you, and when they did so. There may be times when someone will need to look at information about you without having been given permission to do so beforehand. This may be justifiable, for example, if you need emergency care. We will tell you if the action cannot be justified.
- 12 We will take action when someone deliberately accessed records about you without permission or good reason. This can include disciplinary action, ending a contract, firing an employee or bringing criminal charges. We will tell you if this happens.

## Six things that you can do in return

- 1 Help us to make sure that we have identified you correctly.
- 2 Tell us if any information in your record is wrong.
- 3 Allow us to share as much information about you as we need to provide you with healthcare.
- 4 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.
- 5 Only let others – insurers, mortgage lenders, employers, solicitors – look at your records as long as 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.
- 6 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.

## The Summary Care Record

Your Summary Care Record contains information from your care record (current prescriptions, allergies, reactions to treatment) and any other information that you have agreed should be included. Summary Care Records are being introduced in England over the next few years as part of the NHS Care Records Service.

Before we create your Summary Care Record, you can decide not to have a Summary Care Record at all.

After we have created your Summary Care Record, you can decide:

- not to share the information in it;
- to share the information in it with others providing you with care; or
- to add information from your record that you would like included.

# 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.connectingforhealth.nhs.uk/crdb](http://www.connectingforhealth.nhs.uk/crdb)

## 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, we will let you see your record or give you a copy if you ask.

You can ask someone giving you care not to share information with your parents. We can agree to your request unless we think that it is not in your best interest.

## 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 – which may include sharing it with people who are not in the NHS – we will always ask you or your child before we do so. 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.

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

- By controlling access:
  - Smartcards – NHS Care Records Service systems can only be accessed using a Smartcard. We keep to the highest levels of security when we issue Smartcards. A Smartcard on its own is not enough to be able to access NHS Care Records Service systems – healthcare professionals must also identify themselves with a passcode.
  - Good reasons – Healthcare professionals have to have a good reason (for example, being involved in providing your care) before they can access information in your record.
  - Access controls – Healthcare professionals who have been issued with a Smartcard and passcode will only be able to access the information they need for your care and treatment. The amount of clinical information they can access is based on their job role.
  - Audit trails – Every time someone accesses your record, we keep a record of who they were and what entries they may have made.
- 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 contained in your Summary Care Record; and
  - decide whether some of the entries in your record are so sensitive that you want to further control who can see them by putting them in a 'sealed envelope' (this service will be available in the future).

## 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 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.

## Plans for the future

We plan to introduce the following features into the electronic NHS Care Records Service over the next few years. They will give you even more control over your record.

We plan to make your Summary Care Record available to you at all times, free of charge, over a secure internet connection through the service called 'HealthSpace' ([www.healthspace.nhs.uk](http://www.healthspace.nhs.uk))

If you agree, we will add more information to this summary over time as you receive care. You will also be able to use HealthSpace to add information to your summary about yourself and any preferences you have about your care.

If you are concerned about particular entries in your care record, you will be able to ask us to keep those parts of your record from general view.

If you ask us to do this, the entries will always be able to be seen by the care team that created them. For information that identifies you, you can decide whether you want to do the following.

- Allow other people outside the care team that created it to see that there is hidden information. This is called 'sealing'. They can ask for your permission to see sealed information, but you can refuse. In an emergency, if you are not able to give your permission, they can unseal it if they feel that your care justifies doing so; or
- Allow no-one other than the team that created it to know that there is hidden information. This is called 'sealing and locking'. Sealed and locked information will not be available to other people, even in an emergency.

We will not share those particular entries in a way that identifies you without your specific permission, except:

- when we have a legal duty to give information about you; or
- when we have special permission because the interest of the public is thought to be of greater importance than your confidentiality.

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.

Information Commissioner's Office helpline: 08456 30 60 60

Website: [www.ico.gov.uk](http://www.ico.gov.uk)

You can get more information about the Patient Information Advisory Group from their website at [www.advisorybodies.doh.gov.uk/piag](http://www.advisorybodies.doh.gov.uk/piag)

[The NHS Care Record Guarantee](#)

The NHS Care Record Guarantee for England was first published in May 2005 by the Care Record Development Board, and revised and reissued in April 2006 and August 2007. This is version 3. The NHS Care Record Guarantee is available in several languages other than English, and is available to download from:

[www.connectingforhealth.nhs.uk/crdb/docs/crs\\_guarantee](http://www.connectingforhealth.nhs.uk/crdb/docs/crs_guarantee)

The Care Record Development Board is grateful to everyone who helped revise this version of the guarantee.

You can contact the Care Record Development Board, until the end of September 2007, by e-mail at [crdb@nhs.net](mailto:crdb@nhs.net)

From autumn 2007, responsibility for reviewing and updating the Care Record Guarantee will move to the new National Information Governance Board for Health and Social Care.

You can contact the board:

- by e-mail at [nigb@nhs.net](mailto:nigb@nhs.net); or
- by writing to:  
Harry Cayton, Chair  
National Information Governance Board  
7th Floor  
New King's Beam House  
22 Upper Ground  
London SE1 9BW.

You can order printed copies of the NHS Care Record Guarantee, through the online publication system at <http://information.connectingforhealth.nhs.uk/>

