

The care record guarantee : our guarantee for NHS care records in England / NHS.

Contributors

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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. 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.

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.



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Guarantee

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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 Act 2005 and the Race Relations Act 1976 and Amendment 2000 may also apply);
- to ask for a copy of all records about you held in paper or electronic form (you may have to pay a fee); and
- 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 the care team looking after you. Handwritten entries in the record may be difficult to read and important information may be missing. The National Programme for IT is introducing modern secure computer systems into the NHS over the next few years.

Some of these will hold electronic health records about you, making them available to the right people where and when they are needed for your healthcare, while maintaining your confidentiality and keeping your information secure. They are often referred to as the NHS Care Records Service.

This new system will:

- 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 password) 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;
- 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;

The NHS Care Record Guarantee

- keep a note of everyone who accesses the records about you; and
- be operated in line with internationally approved information security standards.

The Summary Care Record

Your Summary Care Record is part of the NHS Care Records Service. It contains information from your care record (current prescriptions, allergies, reactions to treatment) and any other information that you have agreed should be included. This means that wherever in the country you need 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 in an emergency when you are unconscious, we will tell you later.

You will be informed when Summary Care Records are introduced into your area. Before we create the 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 other health records that you would like included.

If you have a Summary Care Record, it is available to you at all times, free of charge, over a secure internet connection through the service called 'HealthSpace' (www.healthspace.nhs.uk).

The NHS Care Record Guarantee

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 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/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/index.htm

- 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 mental health or other law. 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 7), the Ethics and Confidentiality Committee of the National Information Governance Board for Health and Social Care can give special permission to share any health information that could identify you.

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:
 - births of children;
 - 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 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 Ethics and Confidentiality Committee of the National Information Governance Board for Health and Social Care.
- 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.

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. 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 your diagnosis, care and treatment. 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 If we find that someone has deliberately accessed records about you without permission or good reason, we will take action. 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 by letting us know when you change address or name and keeping a note of your unique NHS number.
- 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 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.
- 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.

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, 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 with people who are not directly involved in their treatment or not in the NHS (such as social services or education), we will always ask you or your child before we do so. If you or your child don't 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 7. 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 – everyone with a Smartcard has a password which also identifies them.
 - **Good reasons** – There has to be a good reason (for example, being involved in providing your care) for someone to access the information in your record.
 - **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** – 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.

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 'sealed envelopes' into the electronic NHS Care Records Service over the next few years. This new feature will give you even more control over your record.

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 in a sealed envelope.

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

You can get more information about the Ethics and Confidentiality Committee of 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, and revised and reissued in April 2006, August 2007 and July 2009. This is version 4. The NHS Care Record Guarantee is available in several languages other than English and is available to download from www.nigb.nhs.uk

In autumn 2007 the Care Record Development Board closed and responsibility for reviewing and updating the NHS Care Record Guarantee for England moved to the National Information Governance Board for Health and Social Care.

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:

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7th Floor
New King's Beam House
22 Upper Ground
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You can order printed copies of the NHS Care Record Guarantee for England through the online publication system at <http://information.connectingforhealth.nhs.uk>

