

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 health care. 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 care 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 health care;
- teach health care workers; 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 (you may have to pay a fee).

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 staff looking after you.

Handwritten entries in the record may be difficult to read and important information may be missing. A modern computer system is being introduced in the NHS over the next few years. It will hold electronic health records about you securely, making them available to the right people where and when they are needed for your health care, while maintaining your confidentiality.

This new system will:

- hold records about your care in a national computer system so that, wherever in the country you need care, health care professionals can have access to the most up-to-date information;
- allow you to control whether information in electronic records made about you by the organisation providing your care can be seen elsewhere in the NHS;
- 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 records;
- 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 health care, to improve the services we offer or to support research, in a way that doesn't reveal your identity;
- 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 health 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 health care, we will share health records about you with the people providing care or checking its quality. They must keep the information confidential, whether shared using the computer system or in any other way (such as on paper).

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

- 3 We will not share information (particularly with other government agencies) that identifies you for any reason, 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 interests of the public are thought to be of greater importance than your confidentiality.

If we share information without your permission, we will make sure that we follow the NHS confidentiality code of practice and other national guidelines on best practice. There is more information about existing guidelines at: www.connectingforhealth.nhs.uk/r/1

- 4 Under current law, no-one else can make decisions about sharing health information about you on your behalf. At the moment, the only exceptions to this are parents or legal guardians, or people with powers under mental health law or an independent body called the Patient Information Advisory Group (see the box below).

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 interests of the public are 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 senior clinician in charge of protecting your privacy in each health or care organisation, called the Caldicott Guardian.

However, if you are not able to make decisions about sharing information, a senior health care 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 relatives and carers, and any views you have already recorded.

- 5 Sometimes your health care will be provided by members of a care team, which might include people from other services, such as social services or education. We will tell you if this is the case. When it could be best for your care for us to share health information 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 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 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 would 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 are suffering distress or harm as a result of information being 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 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 information the NHS Care Records Service holds about you. You will be able to ask for a list of everyone who has accessed records about 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 has 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.

Six things 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 records is wrong.
- 3 Allow us to share as much information about you as we need to provide you with health care.
- 4 If you have decided not to allow us to share records of your care with others, tell us if you change your mind. Preventing us from sharing information may make diagnosis difficult and treatment dangerous, and could prevent research. And, in extreme circumstances, we might not be able to offer you the most appropriate treatment.
- 5 Only let others – insurers, mortgage lenders, employers, solicitors – look at your records if you are sure it is necessary. 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 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.

Plans for the future

We plan to introduce the following features into the NHS Care Records Service over the next few years. They will give you even more control over who will be able to use records about your care.

We plan to make a summary of information from your care record available to you at all times, free of charge, over a secure internet connection through the service currently called 'HealthSpace' (www.nhs.uk/healthspace).

If you are concerned about particular entries in the record about your health care you will be able to ask us to keep those parts of the record about your health care from general view. We will not share those particular entries if you refuse your permission, except:

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

Health care professionals will be able to hide information from you that either reveals confidential information about someone else or might reasonably be considered to cause serious harm or distress to you or to someone else. This facility will make it easier for staff in the NHS to keep to the Data Protection Act.

As computer systems change to allow this to happen, we will ask you to check that the records about you are correct and add your own comments where appropriate.

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

The Office of the Information Commissioner,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire, SK9 5AF
Phone: 01625 545 700
Website: www.informationcommissioner.gov.uk

You can get more information about the Patient Information Advisory Group from their website:
www.advisorybodies.doh.gov.uk/piag/

The Care Record Guarantee for England was first published in May 2005 and was revised in May 2006. It will be reviewed at least once a year by the Care Record Development Board.

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

You can get more information on the Care Record Development Board from our website: www.connectingforhealth.nhs.uk/crdb

You can contact the Care Record Development Board:

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