



National Programme for
Information Technology

Care Record Development Board: NHS Care Record Guarantee						
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Prog. Director	Harry Cayton	NPFIT	SI	SIPROJ	0007	01
Sub Prog/Proj Mgr	Prof Joan Higgins					
Author	Nick Gaunt	Version No		1.0		
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Care Record Development Board

NHS Care Record Guarantee

Revision history

Version	Date	Author	Comment
0.1	22Dec04	Nick Gaunt	Based upon Information Sharing Guarantee, a meeting on 20Dec04 with Harry Cayton, Joan Higgins, Marlene Winfield and Jane Durkin, and comments from Phil Walker
0.2	10Jan05	Nick Gaunt	Incorporating comments from HC, JH and MW.
0.3	17Jan05	Nick Gaunt	Incorporating comments from EAG, 17Jan05
0.4	19Jan05	Nick Gaunt	Incorporating further comments.
0.5	21Jan05	Nick Gaunt	Further minor changes suggested by MW.
0.6	21Jan05	Nick Gaunt	Final draft for approval by CRDB
0.7	31Jan05	Nick Gaunt	Incorporating comments from CRDB meeting of 27 th Jan 05
0.8	2 Feb 05	Sarah Bradley	Incorporates further comments from CRDB members and from JD and MW
0.9	03Feb05	Nick Gaunt	Move provision of accessible format information from patient right to our duty
0.10	3 Feb 05	Sarah Bradley	Final draft consolidating comments received, approved by Harry Cayton for final confirmation by CRDB.
0.11	7 Feb 05	Sarah Bradley	Further change to para 8 on p5
0.12	10 Feb 05	Sarah Bradley	Further change to para 3 on p4
0.13	14Feb05	Nick Gaunt	Corrected name and URL for HealthSpace
1.0	21 Feb 05	Nick Gaunt	Approved by National Programme Board with no changes to the text

Revision Plans

Review	Planned Date	Completed
First review	By December 2005	
Second review	Within one year of first review	

Approval

For approval by	Date approved	Signature
Harry Cayton	10 February 2005	<i>Harry Cayton</i>

Obtaining copies of this Guarantee

This Guarantee will be available from:

- www.npfit.nhs.uk
- On request from [office address and telephone number]

[For information on availability of this Guarantee in other languages and formats (large print, Braille) contact the office above.]

Introduction

The National Health Service strives to provide you with the highest quality of health care. To do this we must hold records about you, your health and the care we have provided to you or intend 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 well-being.

Records about you are used by those caring for you to:

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

Others in the NHS may also need to use records about you to:

- check the quality of care (called 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 workers; and
- help with research.

You have the right to:

- confidentiality under the Data Protection Act 1998¹, the Human Rights Act 1998 and the common law duty of confidence²;
- ask for a copy of all records about you³;

We have a duty to:

- maintain full and accurate records of the care we provide to you;

¹ 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 545 740
www.informationcommissioner.gov.uk

² The Disability Discrimination and the Race Relations Acts may also apply

³ The Data Protection Act gives you this right – a fee may be charged

- keep records about you confidential, secure and accurate;
- provide information in a format that is accessible to you (e.g. in large type if you are partially sighted).

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

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

The NHS Care Record Service

Some of your health records are already held on computers, but much is still kept on paper. Whilst paper records held by the NHS 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 phased in to 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, whilst maintaining your confidentiality.

From the outset this new system will:

- hold records about your care in a national computer system so that, wherever in the country you seek care, healthcare professionals can have access to the most up-to-date information when caring for you;
- allow only those involved in your care to have access to records about you from which you can be identified;
- show only those parts of your record needed to inform your care;
- permit access only by authorised people (who will need a 'smart card' as well as a password);
- enable you to control whether information in electronic records made about you by the organisation providing your care can be seen elsewhere in the NHS;
- enable us to use information about your healthcare to improve the services we offer, in a way that doesn't reveal your identity;
- keep a note of everyone who looks at the records about you;
- be operated in line with internationally approved information security standards.

A balance must be maintained between sharing records about you in order to provide you with high quality care and preserving your confidentiality. The NHS Care Record Service has been designed with this balance in mind. However, we plan by 2008 to provide you with even more control over who may use the records held about you. A summary of future plans is given at the end of this Guarantee. Once further features are in place, this Guarantee will be updated. In any case, this Guarantee will be

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reviewed by the NHS Care Record Development Board initially six months after publication and at least once a year after that.

Our 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. There are two exceptions: 1) confidential information about other people, or 2) information a health professional considers likely to cause serious harm to the physical or mental health of you or someone else. This applies to information in paper and electronic records. If you ask us to, we will also let others see health records about you.

Wherever possible we will make health records about you 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 (e.g. in large type if you are partially sighted).

2. When we provide healthcare, we will share health records about you with those providing care or checking its quality. They must keep the information confidential, whether shared using the computer system or by other means (such as on paper).

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 information outside the NHS⁴ that identifies you for any other reason unless:
 - you give us specific permission;
 - it is required by the law;
 - we have good reason to believe that failing to share the information would put someone else at risk.

Where, exceptionally, information is shared without your permission, we will ensure that the NHS Confidentiality Code of Practice and other national guidelines on best practice are strictly followed.⁵

4. Under current law, no one is able to make decisions about sharing health information about you on your behalf⁶. However, if you are unable to make decisions about information sharing, a senior healthcare professional involved in your care may judge it to be in your best interests for information to be

⁴ Specifically, we will not share such information with other Government agencies.

⁵ More information about existing guidelines can be found at www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians.

⁶ At present, the only exception to this is parents or legal guardians who may decide on behalf of their child. This may change if the Mental Incapacity Bill becomes statute.

shared. This judgment should take into account the views of relatives and carers and any views you have recorded in advance.

5. Sometimes your healthcare will be provided by members of a care team, which might include people from other services, such as social services or education, in addition to NHS staff. We will inform you where this is the case. When it could be in your best interests for us to share health information with organisations outside the NHS, we will agree this with you before we proceed. If you don't agree, we will discuss with you the possible consequences for your care and alternatives.
6. You can choose not to have information in electronic care records about you shared. 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 open 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 is able to 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 inaccuracies. We would normally correct factual inaccuracies. If you are unhappy with an opinion or observation 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 all who work in or on behalf of the NHS understand 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 abide by the same policies and controls as the NHS itself. 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 those who have a right to see them.
11. We will keep a record of everyone who looks at the information held about you by the NHS Care Record Service. You will be able to request a list of all those who have looked at 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 authority to do so in advance. This may be justifiable, for instance if you need emergency care. Where the action cannot be justified, you will be informed.

12. We will take action when records about you are deliberately looked at without authority or appropriate justification. This can include disciplinary action, ending a contract, firing an employee, or bringing criminal charges.

What you can do in return

1. Point out any information in your records which is wrong.
2. Allow us to share as much information about you as we need to provide you with healthcare.
3. If you have decided not to allow records of your care to be shared with others in the NHS, keep your decision under review and tell us if you change your mind. Restricting us from sharing information may make diagnosis very difficult and treatment dangerous. Accept that, in extreme circumstances, we might as a result be unable to offer you the most appropriate treatment.
4. Only give others – insurers, mortgage lenders, employers, solicitors and so on – access to records about you if you are sure it is necessary. Think carefully about to whom you give permission and why. Try to restrict their access to what they need to know and no more.
5. At some time, we might ask your permission to use records from which you could be identified for important research. Give us permission unless you feel strongly that you do not want your information used in this way.

Plans for the future

The following features are planned to be introduced into the NHS Care Record Service over the next few years. They are intended to provide you with even greater control over who will be able to use records about your care.

We plan to make information from the 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).

Where you have concerns about particular entries in the record about your health care rather than about the whole record we will provide additional options. You will be able to request that parts of the record about your health care be hidden from general view and only be shared with your permission, except:

- in an emergency if you are not able to give permission;
- when allowed by or required by law;
- when health care staff have good reason to believe that failing to share the information would put someone else at risk.

We also plan to enable healthcare professionals to hide from you items in the electronic record that either reveal confidential information about a third party 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 continue to comply with the Data Protection Act.

Increasingly, as computer systems change to allow it, we will ask you to check the records about you for inaccuracies and add your own comments where appropriate.