

# **Patient Rights and Responsibilities**

A draft for consultation

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# **PATIENT RIGHTS AND RESPONSIBILITIES**

## **A DRAFT FOR CONSULTATION**

**Deadline for responses: 20 June 2003**

Responses should be sent to:

**Mrs E Neil  
Area GER  
St Andrews House  
Edinburgh  
EH1 3DG**

(Business reply envelope supplied)

or to: [liz.neil2@scotland.gsi.gov.uk](mailto:liz.neil2@scotland.gsi.gov.uk)

We are grateful for the support of the Scottish Consumer Council in developing this document.

# **HEALTHY EXPECTATIONS FOR SCOTLAND: A NEW STATEMENT OF RIGHTS AND RESPONSIBILITIES FOR EVERYONE WHO USES THE HEALTH SERVICE IN SCOTLAND**

1\*. Health is important to everyone in Scotland. Without good health, individuals, families, carers and communities can suffer. The NHS in Scotland has two responsibilities.

- To help you stay healthy.
- To care for you if you become ill.

2. It is your health service, and we<sup>†</sup> want you to be confident that we will work to improve the health of everyone, but that if you become unwell or are worried about your health, we will care for you every step of the way.

## **What is this document for?**

3. This statement of rights and responsibilities is for everyone who uses, or who might want to use, the NHS in Scotland. It describes what you can expect in any part of the health service anywhere in Scotland. This could be in your own community, in a doctor's or dentist's practice, or in hospital. Every part of the NHS must work to ensure that the standards described in this leaflet are being met. It also sets out what to do if you want to make a comment on the service you have received, or if you want to complain.

## **Our vision**

4. We are committed to providing a safe, high quality service that is designed around the needs of patients and their carers and families. We will:

- work towards improving everyone's health;
- provide a universal service for everyone based on need;
- provide treatment which is safe and effective, based on the best available evidence;
- communicate effectively and sensitively with patients and their families and carers;
- listen to the views and concerns of patients

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\*Paragraph number inserted for ease of commenting only.

†Throughout the document where there is a reference to "we", it is referring to NHSScotland.

- treat patients with dignity and respect
- understand the wants and needs of patients in order to improve the quality of services
- inform and involve patients in all decisions about their care and treatment;
- involve the public in helping to shape local health services for the future;
- work with individuals, communities and groups to identify their needs;
- work jointly with other services in the public, private and voluntary sectors;
- provide information about services and treatment; and
- respect patients' rights to privacy, dignity and confidentiality.

## **OUR STANDARDS OF CARE: WHAT DO THEY MEAN IN PRACTICE?**

### **Responding to your needs**

5. You can expect to have access to health services which take account of your individual needs and, as far as possible, your preferences.

6. If you have a carer (that is, someone who regularly helps you) we will look at their needs separately from your needs to make sure that you both have the help you need.

7. If you are going into hospital and have special needs, for example, a special diet, we will discuss this with you and make sure that you get the food you need.

8. If there are any other parts of your care or circumstances that you are worried about because of your culture or beliefs, you should discuss this with the people caring for you, and they will respect your views.

### **Communicating with you**

9. The health professionals caring for you will talk to you about your health and the care you need. If you need treatment (and there are different courses of action that could be taken) they will explain these clearly to you. We will give you information to help you understand what is happening to you, and ensure you are involved in decisions that may need to be made about your care and treatment. This will include the benefits and drawbacks of different courses of action. We will give you

the Information in a way that is easy to understand, and that meets your needs, for example, on tape or in a language other than English.

10. If you need help from an interpreter or sign-language interpreter, staff will be able to arrange this if you let them know.

11. Sometimes, you may feel that you need someone to support you or speak for you. This may be a carer, a family member or a friend. If you do not have anyone who can help you in this way, you should ask the person providing care to help you get access to an independent advocacy service.

12. We will tell you the name of the person who is responsible for your care, and tell you how to contact them.

13. You may have to wait for an appointment or for treatment, but we will tell you how long you will have to wait and ensure that action is taken to reduce long waits. We will give patients a guarantee that our national targets will be met, starting with coronary heart disease procedures within six months in 2003 and all inpatient procedures within nine months by the end of 2003.

### **Listening to what you have to say**

14. You have a right to comment on the care you have received, and we will tell you what will happen to any comments you make.

15. If you are not happy about any area of your care, you should always speak to someone as soon as possible so the problem can be put right. You also have a right to complain. You first need to take up your complaint locally. Your hospital, clinic or surgery can tell you how to do that. You can ask them for a leaflet that will have the details.

16. We will investigate your complaint and give you an explanation and an apology where appropriate.

17. The Scottish Public Services Ombudsman can help if you are still unhappy about the way your complaint has been handled - contact details are at paragraph 41.

## **Health records**

18. We shall keep accurate and up-to-date records of the care you receive and make those records available to NHS staff who are directly involved in your care. All are bound by a strict code of confidentiality. Information can be shared with staff from other organisations, such as social care staff, if you have given permission. Similarly, we will not share information about your condition and care with a relative, carer, or friend without your permission. Information may also be used to audit and check care standards, plan local services and to improve health care for everyone. We will not share this information more widely, for example for research, without your permission, although there are a few circumstances in which we do not need your permission (for example, following a court order or notifying a birth or some infectious diseases).

19. You have the right to know how we will use your personal health information and to see your own health records. For more information about this right, see our leaflet "*How to see your health records*"<sup>1</sup>. You also have the right to object to us making use of your information. Guidance on this can be obtained from the local Data Protection Officer.

## **Leaving hospital**

20. If you have been in hospital and are about to leave, we will give you information to give to your own doctor. If you need care and support when you get home, all the people who will be involved in your care must plan this. You and any carers you have must be told about the plans, and you will receive a copy of your plan at the time you are discharged. If you discharge yourself, this will not apply.

## **Quality of care**

21. Your care and treatment will be based on best available evidence about the kind of care and treatment for people with conditions and needs that are similar to yours.

22. You have a right to receive care and treatment that is safe in a setting which is clean and meets hygiene standards. We shall take steps to keep the risk of infection as low as possible.

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<sup>1</sup> A draft of "*How to see your health records*" has been issued for comment as part of this consultation.

23. You can expect that people working in the health service and involved in your care will be competent and well trained, so they are able to provide services to meet your needs and the needs of other patients and their families and carers.

24. Staff will work closely with other organisations that are involved in providing care and support in the community to make sure that your needs are met.

### **Standards about particular kinds of care and treatment**

25. As well as the general standards described above, there are detailed standards about what you can expect from particular services (for example, if you have kidney disease or diabetes). The person responsible for your care will be able to tell you how you can find out more about these standards (which are known as clinical standards). You can find out yourself by contacting NHS Quality Improvement Scotland. The contact details are at the end of this leaflet.

### **Locally-set standards**

26. Your local NHS services also set standards about what you can expect in your area, and about how long you will have to wait for treatment. You can find out more about these standards from your local health council or in “Your Local Guide to the NHS”.

### **What to do if you think any part of the NHS has not met these standards**

27. If you think that we have not done anything that we have said we should do in this leaflet, you should mention this to the people providing your care.

### **Improving services: involving you**

28. We are committed to improving the services we provide. We do this in a variety of ways, but one of the most important is by finding out about people’s experiences of the NHS, by talking to them about how services could be designed to meet their needs better, and by involving them in decisions about how services are delivered.

29. We will do so by:

- involving patients and members of the public in the decision-making process;
- listening to the individual views of patients and their carers and families;
- encouraging input from patients' councils or forums;
- carrying out surveys of patients;
- working closely with patient groups and communities;
- learning from complaints which patients make; and
- acting on the feedback we receive from patients.

If you want to know more about how we are involving people in your area, contact your local health council.

30. As a patient, you have certain other rights and entitlements.

- ***Access NHS services***

To use the NHS and to be treated equally, no matter what your income, race, sex, age, sexuality or disability.

- ***Confidentiality***

To your health records being confidential. We will only give information about you to NHS or social care staff involved in your care, and only if you have given your permission. There are only a very few exceptions to this, for example, if there is a court order.

- ***Consent***

To accept or refuse treatment including examinations, tests and diagnostic procedures. You must be given enough information to make an informed choice about whether to accept or refuse treatment.

- ***Contraception and Maternity Services***

To receive free contraceptive advice and maternity care from your GP or from a family planning clinic.

- ***Emergency medical care***

To go to your local accident and emergency department in an emergency or to phone 999 for an ambulance. For more information

on how to get access to emergency care, see “Your Local Guide to the NHS”.

- ***Family Doctor (GP)***

To be registered with a GP and to have information about GPs in your area, and the services they offer. You can get this from your NHS board. The Practitioner Services Department of the Common Services Agency must help you find a GP within two days if you are not able to do this yourself. (Their contact details are at the end of this leaflet.)

- ***Health records***

To see your health records, and any medical reports prepared for an insurance company or employer. For more information about how to get access to your records, see the separate leaflet “How to see your health records”.

- ***Information***

To receive information on local health services. You can get this from your GP, NHS trust, your NHS board, your local health council or from the NHS Helpline<sup>2</sup> (see paragraph 33) or NHS 24<sup>3</sup> (see paragraph 34).

- ***Research or training***

To choose whether or not to take part in research, and to pull out of the research at any time. You have the right to choose not to be examined or treated by a student. This will not affect the way you are treated.

- ***Second opinion***

To ask for a second opinion from a different GP if you feel that the decision made about your treatment by your usual GP does not suit your treatment needs. This should not be unreasonably withheld.

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<sup>2</sup> the NHS Helpline will be absorbed into NHS 24 later this year

<sup>3</sup> NHS 24 is a rolling out across Scotland over the next 18 months

- ***Complaints<sup>4</sup>***

To complain if you are not happy with the treatment or service you have received. Please discuss the complaint with the people caring for you. You can discuss this with your local health council who can help you with your complaint if you want to do that.

31. These rights are balanced by responsibilities which can help the health service work more efficiently. You can help yourself and health service staff if you do the following.

- ***Be on time***

Be on time for appointments and tell the clinic, practice or hospital if you cannot keep your appointment.

- ***Treat healthcare staff politely and with respect***

Healthcare staff have demanding jobs to do, often under stressful circumstances. Help them by treating them considerately. Violence or racial, sexual or verbal abuse is completely unacceptable.

- ***Follow the advice and treatment you receive***

Try to follow any advice given to you. If you are worried about doing this, discuss it with the person giving you the advice at the time.

- ***Information***

Make sure that your doctor, dentist or any hospital or clinic you are going to has up-to-date information about how to contact you.

- ***Medicines***

Try to take any medicine which is prescribed and finish the course of treatment. Do not take medicine which is out of date, and give old medicine to your pharmacist to get rid of.

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<sup>4</sup> a consultation paper on a revised NHS Complaints Procedure is available from 0131 244 2839

- ***Pass on your comments to healthcare staff***

Improving services is helped if the people providing them know what you think about the services. Help staff by filling in surveys if you are asked to, and use any other ways of providing feedback.

- ***Using emergency services***

Only use emergency services in a real emergency. Don't forget that there will be seriously ill people who need to use these services.

- ***Self care***

Look after your own health and think about how you could have a healthier lifestyle.

## **FOR MORE INFORMATION**

### **Local Services**

32. To find out more about local services and how to get access to them, look out for "Your Local guide to the NHS". You can phone NHS24 or the NHS Helpline to get phone numbers for particular services. You should be able to find local phone numbers in the phone book under 'health services'.

### **General information about the NHS**

33. The NHS Helpline provides in-depth information about health services and the NHS in Scotland. The Helpline covers health education, patients' rights, waiting times, GPs, pharmacists, opticians, community, hospital and social care services. Free leaflets on a wide range of health topics are also available. Calls to this information service are free and confidential. You can phone the NHS Helpline on 0800 22 44 88.

### **Online health information**

34. There are a range of sites which can give you information about health services, how to keep yourself healthy and a range of conditions and treatment options. They can also give you information on self-help groups and voluntary organisations.

Visit:

[www.scotland.gov.uk](http://www.scotland.gov.uk)  
[www.show.scot.nhs.uk](http://www.show.scot.nhs.uk)

[www.hebs.scot.nhs.uk](http://www.hebs.scot.nhs.uk)

Scottish Executive information  
national and local health service  
information  
health promotion information

## **NHS 24<sup>5</sup>**

35. NHS 24 is a new nurse-led information and advice service which aims to give people across Scotland equal access to health advice, information and help, when they need it and as far as possible in one phone call. This service which is being rolled out across Scotland, can give you advice about what to do if you are ill, or have concerns about someone close to you. They can also help if you need information about local health services or any other useful contacts.

## **Scottish Blood Transfusion Service**

36. The Scottish Blood Transfusion Service relies on donations of blood made by the public. If you are interested in becoming a blood donor, you can obtain more information on the Scottish Blood Transfusion Service website at [www.scotblood.co.uk](http://www.scotblood.co.uk) or you can telephone to register to become a blood donor on 0845 90 90 999.

## **Organ Donor Cards**

37. Carrying a donor card and/or putting your name on the NHS Organ Donor Register confirms your decision to be a donor if the time ever comes. If you are interested in becoming an organ donor, you can obtain more information on the NHS Organ Donor website at [www.nhsorgandonor.net](http://www.nhsorgandonor.net) or by calling the Organ Donor Information Line on 0845 60 60 400 between 7am and 11pm 7 days per week.

## **Practitioner Services Division (Common Services Agency)**

38. This organisation can help you find a GP if you are having difficulty in finding one in your area. It has three local offices:

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<sup>5</sup> This section will be update at publication to reflect the current coverage of NHS 24.

Stevenson House  
Gorgie Road  
Edinburgh  
EH11 3LG  
Phone: 0131 537 8473

Summerfield House  
2 Gairsay Road  
Aberdeen  
AB15 6GF  
Phone: 01224 558529

Clifton House  
Clifton Place  
Glasgow  
G3 7LN  
Phone: 0141 300 1300

## Standards

39. For information about standards of care, you can contact:

NHS Quality Improvement Scotland  
Elliott House  
8-10 Hillside Crescent  
Edinburgh  
EH8 9RS  
Phone: 0131 623 4300  
Email: [comments@clinicalstandards.org](mailto:comments@clinicalstandards.org)  
Website: [www.clinicalstandards.org](http://www.clinicalstandards.org)

40. The job of NHS Quality Improvement is to make sure that the services provided by the NHS are safe and that they are of the same quality no matter where they are provided in the country. To do this, it sets standards for services which have been agreed throughout Scotland by people working in the health service and by members of the public. It also visits health services to make sure that these standards are actually being met.

## The Scottish Health Council<sup>6</sup>

41. This organisation will encourage more public and patient involvement in the NHS in Scotland, and will monitor how well the health service is doing this. It has local offices which are known as local health councils. To find the phone number for your local health council, please contact the Scottish Health Council on xxx xxx xxx.

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<sup>6</sup> This section will be update at publication to reflect the outcome of the consultation process on the proposed Scottish Health Council.

## **The Scottish Public Services Ombudsman**

41. This new post came into being in October 2002. The Health Service Ombudsman for Scotland is at 1st Floor, 28 Thistle Street, Edinburgh EH2 1EN. Phone: 0131 225 7465

### **Alternative versions of this document**

42. This document is available in the following languages:

English, Gaelic, Arabic, Urdu, Punjabi, Gujerati, Bengali, Hindi and Cantonese.

This document is also available on audiotape, in Braille, in a version for people with learning difficulties and on video for British Sign Language users. If you would like a copy of this document in another format please contact Ms Jan Quinn on 0131 244 2839 or [jan.quinn@scotland.gsi.gov.uk](mailto:jan.quinn@scotland.gsi.gov.uk).

**HOW TO ACCESS YOUR HEALTH RECORDS**

**A Patient Information Leaflet**

**A DRAFT FOR CONSULTATION**

## HOW TO ACCESS YOUR HEALTH RECORDS

1\*. This guide explains your legal right to see your health records, and any medical reports made about you for an insurance company or an employer.

2. However, it does not give a full explanation of the law. If it does not answer all your questions, you can get more detailed guidance from your local health council or the UK Information Commissioner (see the end of this leaflet for the contact details).

### Your general rights

3. NHS staff will keep personal information about your health strictly confidential.

4. The Data Protection Act 1998 gives you the right to see personal health information about yourself. This Act aims to protect your personal privacy. Personal information includes records held by hospitals and health professionals.

### Health records

5. A **health record** is any record, whether on computer or paper, which includes information about your physical or mental health or condition, and is made by, or for, a health professional involved in your care. So it includes your case notes, letters to and from other health professionals, x-rays, results of laboratory tests and MRI scans.

### A health professional includes

- Pharmacists
- GPs
- dentists
- opticians
- chiropractors
- speech therapists (employed by an NHS organisation)
- Health visitors
- midwives
- physiotherapists
- osteopaths
- hospital doctors
- scientists employed as head of department by a health service organisation
- dieticians
- orthoptists
- clinical psychologists
- physiotherapists
- nurses
- art or music therapists (employed by an NHS organisation)
- podiatrists
- child psychotherapists
- occupational therapists

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\* Paragraph number inserted for ease of commenting only.

6. The person who holds your records (the health professional or the person responsible for this at the hospital or health board) is known as the **data controller**.

### **How to apply**

7. You can ask the health professional responsible for your care if you can look at the records for your current treatment. Otherwise, you must apply in writing, by post or by e-mail.

8. You should write to the person or organisation you believe holds the information about you (known as the **data controller**). If you want to see your hospital records, or if you are not registered with a GP, contact your NHS board [local number] or trust and ask them who you should write to. You may need to fill in an application form and give proof of your identity. They may ask you to provide enough information to help identify your records.

9. **You do not need to give a reason for wanting to see your health records.**

### **Who can apply?**

10. You can apply to see your records as long as the data controller of health records is satisfied that you understand what this means. In Scotland, we assume that you understand what this means if you are over 12.

11. Someone else may apply for you if:

- you have agreed to this;
- you are under 16, and the other person has parental responsibility, or
- you are an adult, and are not able to look after your own affairs and you have given that person a power of attorney, or if he or she has been appointed by the courts. Under the Adults with Incapacity (Scotland) Act 2000, someone can be given the right to help you under an intervention order, or a guardianship order. For more information about the Act, contact the Office of the Public Guardian (their contact details are at the end of this leaflet).

12. Under the Access to Health Records Act 1990, you can apply to see the record of a person who has died. You can only see records made after 1 November 1991. You can only access that person's

records if you are their personal representative, executor or administrator, or if you have a claim for compensation as a result of that person's death. If you are claiming compensation, you can only see information which is relevant to the claim.

13. The data controller of health records will only let someone apart from you see the information if he or she is satisfied that when you gave the information, you would have wanted it to be given to that person.

### **What can I see?**

14. You are entitled to see your record and get a copy. The data controller will tell you where the information has come from, and who has access to it.

15. You may receive the information as a computer printout, in a letter, or on a form. It should be easy to understand, and any abbreviations, codes or jargon should be explained.

16. Some information on your record may be withheld from you. This includes information that:

- could cause serious harm to your, or someone else's, physical or mental health;
- could identify someone else, unless that person gives their permission; or
- is legally sensitive, for example, a pre-adoption report, or a report to a children's panel.

17. The data controller does not have to tell you if information has been withheld. If you suspect that information has been withheld without a good reason, you should contact the Information Commissioner's information line (see the end of this leaflet for details).

### **How long does it take?**

18. Once the data controller has enough information to identify you and to find the records, and you have paid any fee, he or she must give you the information within 40 days.

## **What does it cost?**

19. You can be charged a fee of up to £10 for each request if your record is held on computer. If your record is held on a paper file or a mixture of paper and computer files (and you want a copy of the information), you can be charged a fee of up to £50.

## **Corrections**

20. If any information about you is incorrect or misleading, you are entitled to have it corrected or removed. If the data controller agrees with you, it must be corrected. If the data controller refuses your request to amend your record, you can ask the Information Commissioner (see the end of this leaflet) to consider whether inaccurate information can be corrected or removed.

## **Compensation**

21. If you suffer physical or financial damage as a result of inaccurate information, you have a right to compensation. If it is proved that you have suffered damage a court may also order compensation for any associated distress you have suffered.

22. You can also claim compensation if your information is lost, damaged, destroyed or given to someone else without the data controller's authority.

## **How can I complain?**

23. If you are not happy about the way your application has been dealt with, you can:

- write and complain to the data controller, using the NHS complaints procedure; and
- complain to the Information Commissioner (details on last page) if you are not happy with how your complaint has been sorted out.

As a last resort, you can go to court.

## **Medical reports**

24. The Access to Medical Reports Act 1988 gives you the right to see any medical report on you that a doctor has written for an insurance company or an employer.

25. This includes any doctor who is, or has been, responsible for your medical care - your GP, hospital doctor, consultant, or any other doctor who has treated or advised you. It does not include an independent doctor acting for the insurance company or employer.

## **How do I apply?**

26. You don't have to apply. Before an insurer or employer contacts a doctor for a report on you, they must get your written permission and explain your rights under the Access to Medical Reports Act 1988.

27. The insurer or employer must ask you if you want to see the report before the doctor sends it. If you do, the doctor must be told this. You then have 21 days to arrange to see it. If you have not contacted the doctor by this time, the report can be sent off.

28. Even if you do not tell the insurer or employer beforehand, you can still see the report as long as you ask the doctor for it before it is sent off.

29. Once you have seen the report, the doctor must get your written permission before sending it.

30. The doctor must also keep a copy of any report for six months, and you have a right to see it during this period.

## **How much does it cost?**

31. There is no charge for inspecting the report. You are entitled to a copy, but the doctor can charge a reasonable fee for providing it.

## **What information can't I see?**

32. You can be refused access to any part of a report if it would:

- in the doctor's opinion, cause serious harm to your or someone else's physical or mental health;
- show how the doctor planned to treat you in the future; or

- reveal information about someone else or the identity of another person, unless that person has given their permission.

The doctor must tell you if, and why, any information has been withheld from you.

### **How can I correct mistakes?**

33. You can ask the doctor to correct any part of the report that you believe is wrong or misleading. If the doctor refuses, you are entitled to prepare a written statement of your views, which must be attached to the report when it is sent.

34. You can refuse to allow the report to be sent. However, this may mean that you are refused insurance cover or a job offer.

### **How can I complain?**

35. If you believe that someone has broken the Act (for example, the doctor, insurer or employer), you can go to court for an order to make them keep to it.

### **Help and advice**

36. You can get independent help and advice on getting access to your health records from your local health council [local info].

37. For help and advice on getting access to your records, or to complain, you can contact:

The Information Commissioner  
Wycliffe House  
Water Lane  
Wilmslow  
SK9 5AF.  
Phone: 01625 545700  
Information line: 01625 545745  
E-mail: [mail@dataprotection.gov.uk](mailto:mail@dataprotection.gov.uk)  
Website: [www.dataprotection.gov.uk](http://www.dataprotection.gov.uk)

38. You can also get advice from [*local NHS board, trust, practice information would be inserted here*].

39. For advice and information on how to take legal action, including making an application to a court, contact your local citizens' advice bureau or other advice agency. [*Local information would be inserted here*]

40. For more information about the Adults with Incapacity (Scotland) Act, you can contact

Office of the Public Guardian  
Hadrian House  
Callander Business Park  
Falkirk  
FK1 1XR.  
Phone: 01324 678300

41. This leaflet is available in various other formats, including on Braille, audiotape, and in ethnic minority languages. If you would like one of these, please contact Ms Jan Quinn on 0131 244 2839 or [jan.quinn@scotland.gsi.gov.uk](mailto:jan.quinn@scotland.gsi.gov.uk).

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