



Confidentiality – it's your right

How the NHS protects your personal health information

Under the Data Protection Act 1998, you have a right to know who holds personal information about you. This person or organisation is called the data controller. In the NHS, the data controller is usually your local NHS board and your GP surgery.

Who is this leaflet for?

- This leaflet is for anyone who uses the NHS in Scotland.
- There is also a version of this leaflet for people under 16, called '**Confidentiality – your rights**'. See page 11 for where to get a copy.

What is this leaflet about?

It tells you:

- what your personal health information is
- how the NHS keeps this information confidential
- how this information is used

- who this information is shared with and why
- what your rights are, and
- what you can do to help the NHS.

Why has this leaflet been produced?

The NHS must keep your personal health information confidential. It is your right. The leaflet explains how the NHS does this.

What is my personal health information?

It is information that identifies you. It includes things like your name, address, date of birth, and postcode. It can be linked to, for example:

- information about any care and treatment you have received
- information about your health and lifestyle, and
- results of tests you have had.

How and where is my personal health information kept?

It is kept in records. Records can be written on paper, held on computer or both. Records are stored securely in different parts of the NHS.

- You have a record at your GP surgery.
- If your GP refers you to a hospital, the hospital will keep a record there.

- Records can also be held in other places, for example, at your dental surgery or at a clinic you have been to.

The NHS is storing more and more of your personal health information on computer. Eventually all your records may be held on computer. This will make it easier for NHS staff to share information about you so that you get the treatment you need, wherever you are.

Your electronic (computer) record will be stored securely. Only staff who are involved in your care should look at your record. And it will be possible to check who has looked at your electronic record.

Your Emergency Care Summary

Most patients in Scotland now have an Emergency Care Summary. This gives basic information about your health (for example, your medication) that may help NHS staff if you need urgent medical care when your GP surgery is closed, or if you go to an accident and emergency (A&E) department.

NHS staff can also use your Emergency Care Summary if your GP refers you to an outpatient clinic or for admission to hospital. For example, it will help NHS staff check whether your medication has changed since the GP wrote your referral letter.

Before any member of staff looks at your Emergency Care Summary, they will usually ask your permission. If you are too unwell to give permission they may need to read your Emergency Care Summary without your agreement, to give you the best possible care.

For more information, see the leaflet '**Your Emergency Care Summary – What does it mean for you?**' You can get a copy

from your GP surgery, by phoning the NHS inform Helpline on 0800 22 44 88, or on the internet (www.hris.org.uk).

The Key Information Summary

Patients with particular needs (for example, palliative care, support at home or care from family members) and patients living with long-term conditions may also have a Key Information Summary. This includes information that patients want NHS staff looking after them to know (for example, who should be contacted in an emergency, what conditions they have and what treatment they receive).

Your GP will discuss with you what information can be included in your Key Information Summary, if you need one.

How does the NHS keep my personal health information confidential?

- All NHS staff have a legal duty to keep information about you confidential.
- The NHS stores your personal health information securely.
- Only relevant information about you is shared inside the NHS or with other organisations. We explain when and why it's shared later in the leaflet.
- The NHS won't give information that identifies you to organisations such as employers, insurance companies or the media without your permission.

How is my personal health information used?

NHS staff use your information to give you the care and treatment you need. They may share relevant information about you with other staff involved in your care. This makes caring for you safer, easier and faster.

For example, information is shared if:

- your GP refers you to a hospital
- you attend hospital without being referred by your GP
- you are moved from one hospital to another
- you need support at home, such as a visit from a district nurse, or
- NHS 24 refers you to a GP or another part of the NHS.

If you attend a sexual health clinic, information that identifies you will not usually be shared without your permission.

If you are concerned about your information being shared, see 'Your right to object' on page 8.

How else does the NHS use information about my health?

The NHS uses relevant information about your health to help improve NHS services and the health of the public. The NHS may use it, for example:

- to find out how many people have a particular illness or disease
- to look at how safe and effective a treatment is, for example cancer treatment
- to check that the NHS is providing a good service
- to plan how many beds, wards and staff are needed

- to train students and staff
- to check that the NHS spends public money properly, and
- for research.

When using information about you, your name, address and other information that identifies you is removed wherever possible. Sometimes the NHS uses information that does identify you. If they do this, they will usually explain how and why your information will be used. If they want to use information that identifies you for teaching or research, they must ask your permission first.

If you don't want the NHS to use your information to help improve public health and NHS services, you can object. See page 8.

When can my personal health information be shared outside the NHS?

Your personal health information may be given to other people who need to know relevant information about your health – for example a carer, a home help, or a social worker. Usually, it will only be given to them if:

- you have agreed, and
- they need it to be able to give you care and treatment.

Usually the NHS won't share your personal health information with people who don't need it, such as a relative, carer or friend, without your permission. However, there are exceptions:

- **If you are a child**, and your doctor doesn't think you can make decisions about your health care, someone with parental

responsibility for you may be allowed to see your records and discuss your care.

See page 11 for where to get more information about the rights of young people under 16.

- **If you are an adult** who cannot make decisions for yourself, or cannot tell others your decisions, the law allows someone to see your records and discuss your care, if:
 - you have given them a welfare power of attorney, or
 - a court has given them a welfare guardianship or a welfare intervention order.

In these cases, the person allowed to see your health information:

- will only be able to see information that is necessary for them to make particular decisions for you about your health care, and
- will not receive information that staff feel would be harmful to your health or the health of others.

Sometimes the law allows the NHS to share your personal health information without your permission, for example, to investigate a serious crime or to protect a child or vulnerable adult from harm.

What are my rights?

As well as your right to confidentiality, you have the rights below.

Your right to know

You have a right to know how your personal health information is used. You can ask a member of NHS staff providing your care.

Your right to see

You have a right to see your health records and, if you wish, to get a copy. Wherever possible, you should be given your health records in a format that meets your needs. The leaflet '**How to see your health records**' explains how to do this. See pages 11 - 12 for where to get a copy.

Your right to object

If you don't want your health information to be used or shared, tell a member of NHS staff providing your care. If you do this, the NHS has to limit how it uses your information where possible.

Your right to complain

If you are unhappy about how your health information has been used or protected, first talk to a member of NHS staff involved in your care. If you are still unhappy and would like to make a complaint, the leaflet '**Making a complaint about the NHS**' explains what to do. See pages 11 - 12 for where to get a copy.

What can I do to help the NHS?

- Tell NHS staff if there is someone you want them to share your information with – for example, if you go to hospital, you may want staff to let a neighbour know about this. You should also tell NHS staff about anyone they should not share your information with – for example, you may not want your partner to know about your ill-health.
- If you change your name, address or phone number, tell your GP practice, dental practice, optician, and any hospital or clinic you go to.
- If you think any information in your health records is incorrect, let NHS staff know.

How to find out more

- For more information about anything in this leaflet, contact:
 - a member of NHS staff involved in your care
 - the NHS inform Helpline on 0800 22 44 88 (textphone 18001 0800 22 44 88; the helpline also provides an interpreting service), or
 - your local citizens advice bureau (find your nearest bureau on the internet at www.cas.org.uk or in your local phone book).
- For more information about how the law affects children and young people, contact:

The Scottish Child Law Centre

54 East Crosscauseway Edinburgh EH8 9HD

Information helpline **0131 667 6333**

Freephone number for under 18s **0800 328 8970**

Free text enquiry service: text 'SCLC' followed by your question to **80800** (replies will be sent to your mobile)

Email **enquiries@sclc.org.uk**

Website **www.sclc.org.uk**

- For general information about becoming a legal proxy, contact:

The Office of the Public Guardian (Scotland)

Hadrian House, Callendar Business Park, Callendar Road
Falkirk FK1 1XR

Phone **01324 678 300**

Email **opg@scotcourts.gov.uk**

Website **www.publicguardian-scotland.gov.uk**

- For more information about the rights of people with a mental illness, learning disability, dementia or other mental disorder, contact:

Mental Welfare Commission for Scotland

Thistle House, 91 Haymarket Terrace, Edinburgh EH12 5HE

Freephone number for service users and carers **0800 389 6809**

Email **enquiries@mwscot.org.uk**

Website **www.mwscot.org.uk**

The Mental Welfare Commission for Scotland can also give you information and advice on people's rights under the Adults with Incapacity Act.

- To find out more about how your personal information is used and protected, contact:

Information Commissioner's Office – Scotland

45 Melville Street, Edinburgh EH3 7HL

Phone **0131 244 9001**

Email **Scotland@ico.gsi.gov.uk**

Website **www.ico.gov.uk**

You can also contact this office to complain about how the NHS has used or protected your information, but only if you have already used the NHS Complaints Procedure.

Information about health rights

- **The NHS and You** explains what you can expect from the NHS in Scotland, and what the NHS expects from you.
- **Making a complaint about the NHS** tells you how to complain using the NHS complaints procedure.

- **Consent – it's your decision** explains how you should be involved in decisions about your health care and treatment.
- **How to see your health records** explains your right to see or have a copy of your health record.
- **Health care for overseas visitors** is a set of factsheets explaining what NHS services overseas visitors can expect to receive while they are in Scotland.
- **The Charter of Patient Rights and Responsibilities** is a summary of the rights and responsibilities patients have when using NHS services in Scotland (available from October 2012).

Information for young people

- **Consent – your rights** explains how you should be involved in decisions about your health care and treatment.
- **Confidentiality – your rights** tells you how the health service keeps information about you private.
- **Have your say! Your right to be heard** tells you how to give feedback or make a complaint about the NHS.

Information for carers

- **Caring and consent** explains your right to be involved in decisions about the health care of the adult you care for.

Information about eHealth

- **eHealth – using computers to improve your healthcare** tells you how eHealth will affect the service you receive from the NHS, how your information will be stored and shared safely and legally, and what may happen in the future.

You can get this information from:

- GP and dental surgeries, hospitals and other places where you get NHS care
- the NHS inform Helpline on **0800 22 44 88** (textphone 18001 0800 22 44 88; the helpline also provides an interpreting service)
- **www.hris.org.uk**
- your local citizens advice bureau (find your nearest bureau on the internet at **www.cas.org.uk** or in your local phone book).

Your comments please!

We want to know what you think about this leaflet.

Please give us your comments:

- by post to **NHS inform**, NHS 24, Golden Jubilee National Hospital, Beardmore Street, Clydebank G81 4HX
- by emailing us at **nhs.inform@nhs24.scot.nhs.uk**
- by visiting our website at **www.nhsinform.co.uk** and clicking on the 'contact us' link, or
- by phoning us on **0800 22 44 88**.

We have tried our best to make sure the information in this leaflet is correct. However, the leaflet is for guidance only so you should not rely on it as a full statement of the law. If you are thinking about taking legal action, you should contact a solicitor, a citizens advice bureau, the Patient Advice & Support Advice or other advice agency.

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To get this leaflet in another language or format phone your local NHS board. If you need help to do this contact the NHS inform Helpline on 0800 22 44 88 (textphone 18001 0800 22 44 88).

وصول على كراسة 'الحفاظ على السرية - إنه حقك' باللغة العربية اتصل بهاتف المكتب
لمحلي لهيئة الرعاية الصحية الوطنية NHS board. وإذا احتجت للمساعدة للقيام بذلك، اتصل
بخط الاستعلامات التابع للهيئة NHS Helpline على رقم 0800 22 44 88

'গোপনীয়তা - এটি আপনার অধিকার' তথ্যপত্রটি বাংলায় পেতে চাইলে আপনার স্থানীয় এন.এইচ.
এস বোর্ডে ফোন করুন। এটি করার জন্য আপনার সাহায্যের প্রয়োজন হলে, এন.এইচ.এস
হেল্পলাইনে 0800 22 44 88 নম্বরে ফোন করুন।

如欲索取《資料保密 - 這是你的權利》資料單張，請致電你當地的NHS管
理局。如需協助致電管理局，請致電NHS求助熱線 0800 22 44 88。

Pour obtenir « Confidentialité – c'est votre droit » en français, téléphonez
à votre bureau NHS local. Si vous avez besoin d'aide pour cela, contactez
l'assistance téléphonique de la NHS au 0800 22 44 88.

'गोपनीयता - यह आप का अधिकार है' हिंदी में पाने के लिए, अपने स्थानीय
NHS बोर्ड को फोन करें। अगर आपको ऐसा करने के लिए मदद चाहिए, तो
0800 22 44 88 पर NHS हेल्पलाइन को कॉल करें।

Norėdami gauti informaciją 'Konfidencialumas – tai jūsų teisė' Lietuvių
kalba, skambinkite į savo vietinę NHS tarybą. Jei tai padaryti jums
reikalinga pagalba, kreipkitės į NHS pagalbos liniją telefonu
0800 22 44 88.

Aby otrzymać broszurę "Poufność – to Twoje prawo" w języku polskim,
prosimy o telefoniczny kontakt z lokalnym oddziałem NHS. Więcej
informacji można uzyskać dzwoniąc pod numer linii informacyjnej NHS:
0800 22 44 88.

Для получения «Конфиденциальность – это ваше право» на русском
языке, позвоните в местное управление Государственной Службы
Здравоохранения. Если Вам для этого нужна помощь, обратитесь в
телефонную службу помощи по номеру телефона 0800 22 44 88.

Para obtener una copia del folleto 'Confidencialidad – es su derecho'
en español llame a su oficina local del NHS. Si necesita ayuda para
hacerlo puede llamar al teléfono de asistencia del NHS: 0800 22 44 88.

رازداری- یہ آپکا حق ہے 'اردو میں حاصل کرنے کیلئے اپنے مقامی این ایچ ایس بورڈ
کو ٹیلیفون کریں۔ اگر اس کیلئے آپ کو مدد درکار ہو تو این ایچ ایس ہیلپ لائن پر
0800 22 44 88 پر ٹیلیفون کریں۔

www.hris.org.uk