



Your health, your rights

Confidentiality: how the NHS protects your personal health information

Who is this factsheet for and what is it about?

- This factsheet is for anyone who uses the NHS in any part of Scotland.
- The 2012 Charter of Patient Rights and Responsibilities gives a summary of what you can expect when you use the NHS in Scotland, together with your rights and responsibilities. The Confidentiality section of the Charter tells you about the right for your personal health information to be kept secure and confidential and this factsheet explains how the NHS does this.

‘You have the right for your personal health information to be kept secure and confidential.’

The Charter of Patient Rights and Responsibilities 2012

- 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 practice.

What is my personal health information?

It is information that identifies you. It includes things like your name, address, date of birth, and postcode and is 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 practice.
- If you attend hospital, a record will be kept there. Records can also be held in other places, for example, at your dental practice or at a clinic you have been to.

The NHS is storing more and more of your personal health information on computer and eventually all of your records may be held in this way. This will make it easier for staff to share information about you so that you get the treatment you need, wherever you are. Your information is stored securely. Only staff who are involved in your care should look at your record. It is possible to check who has looked at your electronic record.

The 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 staff if you need urgent medical care when your GP practice is closed, or if you go to an accident and emergency (A&E) department.

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 them to check whether your medication has changed since the GP wrote your referral letter.

Before staff look 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 practice, 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 involved in your care.
- You may give consent to your information being used or shared in different ways, for example:
 - by saying that you agree or signing a form, or
 - depending on the particular circumstances by not objecting or disagreeing if you are told or it is clear that the information will be shared.
- If you do not want your personal health information to be used or shared, tell a member of staff providing your care. If you do this, the NHS has to limit how it uses your information where possible. The NHS may, however, be required to share information in an emergency or if the law says it must, even if you do not consent.
- The NHS won't give information that identifies you to organisations such as employers, insurance companies or the media without your permission.
- Sometimes the NHS uses information that does identify you (for example to include in a disease register). Staff will usually explain how and why your information will be used. If they want to use information that identifies you for teaching or research, then they must ask your permission first.
- You can object if you don't want the NHS to use information that identifies you to help improve public health and NHS services.

'NHS staff should not give information about you to organisations such as employers or the media without getting your permission.'

The Charter of Patient Rights and Responsibilities 2012

How is my personal health information used?

- The NHS uses your information to give you the care and treatment you need. Staff 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, for example 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.

How else does the NHS use information about my health?

- Sometimes 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 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 staff 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 pages 6 & 8 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.

Can I find out how my information is used?

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

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 if I am unhappy about how my health information has been shared?

- If you are unhappy about how your health information has been used or kept, you should 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 **Your health, your rights: Feedback and complaints** explains what to do. See pages 6 & 8 for where to get a copy.

Can I see my health records?

- If you want to see, or get a copy of your health records, write to the practice manager at your GP practice or the records manager at the hospital or other NHS organisation that holds your health records.
- You may be charged a fee to see your health records, but you don't need to give a reason for wanting to do this.
- After you give the NHS enough information to identify you and your health records, and pay any fee, you will receive the information within 40 days.
- NHS staff should explain any words that you don't understand. You should say if you would like your records to be given to you in another format that meets your needs. This will be done wherever possible.

The leaflet **How to see your health records** explains how to do this. See below for where to get a copy.

‘You have the right to access your own health records.’

The Charter of Patient Rights and Responsibilities 2012

What can I do to help the NHS?

You can help the NHS to keep your health records accurate and up to date.

- Tell staff if there is someone you want us to share your information with – for example, if you go to hospital, you may want the staff to let a neighbour know about this. You should also tell staff about anyone we should not share your information with – for example, you may not want your partner to know about your ill-health.
- Tell your GP practice, dental practice, optician, and any hospital or clinic you go to if you change your name, address or phone number. This is to make sure they can contact you, for example if they need to change the time for an appointment.
- Let staff know if you think any information in your health records is incorrect. For example, tell the GP if there is a mistake in the address on your prescription.

How can I find out more?

You can find out more about anything in this factsheet, or get **The Charter of Patient Rights and Responsibilities**, the **Your health, your rights** factsheets or other leaflets and factsheets listed below from:

- GP surgeries, hospitals and other places where you receive NHS services
- www.hris.org.uk (alternative formats available) or at www.nhsinform.co.uk
- the NHS inform Helpline on **0800 22 44 88** (lines are open every day from 8am to 10pm).
- the **Patient Advice & Support Service** (PASS) at your local citizens advice bureau (find your nearest bureau on the internet at www.cas.org.uk or in your local phone book). PASS is independent and provides free, confidential information, advice and support to anyone who uses the NHS in Scotland.

- 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 legal advice, contact a solicitor or legal advisor.
- For general information about becoming a legal proxy (a person who has a welfare power of attorney, a welfare guardianship order or a welfare intervention order), 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:

The 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 Charter of Patient Rights and Responsibilities** tells you what you can expect from the NHS and what the NHS expects from you.
- The series of **Your health, your rights** factsheets explains what the rights and responsibilities included in the Charter mean for you:
 - **Access:** your rights when accessing NHS services in Scotland
 - **Communication and participation:** the right to be informed, and involved in decisions, about health care and services.
 - **Respect:** the right to be treated with dignity and respect.
 - **Safety:** the right to safe and effective care.
 - **Feedack and complaints:** the right to have a say about your care and have any concerns and complaints dealt with.
 - **Hospital waiting times:** how quickly you should receive hospital care.

For more about health rights see:

- **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.

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 health services

- **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.
- **It's okay to ask** gives useful tips and questions you can ask during your health care appointments.
- **Your emergency care summary - what does this mean for you** tells you about changes in the way your medical information is used and stored.

We have tried our best to make sure that the information in this factsheet is correct. However, this factsheet is for information only and is not part of The Charter of Patient Rights and Responsibilities. It is for guidance only so you should not rely on it as a complete statement of the law.

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