HIV Scotland
promoting positive change

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

YOUR CHOICE

A GUIDE TO CONFIDENTIALITY AND HIV IN SCOTLAND 2016

Important note:

This guide contains useful information but not legal advice. If you are experiencing difficulties you can find a list of organisations that offer direct support to people living with HIV at the end of this guide. We would strongly recommend that you seek specialist advice about your particular situation if you believe that your confidentiality rights have been breached.

CONTENTS

What is the law? 6

This section explains the legislation which protects your information and gives you rights.

How is my information stored?................................ 8

There are a range of systems used by the NHS to store health information. This section outlines what those systems are, who accesses them and how your records are protected. It also touches on health and social care and employment records.

Can employers and insurers access my health records?.. 21

Employers and insurers generally don't have access to health records, but your GP or consultant may be asked to provide medical information. This section looks at the circumstances in which your information may be required by employers or insurers.

Can information about my HIV be shared without my consent?... 23

It would be extremely rare for this information to be shared without your consent, but there are some limited circumstances where this may be the case. This section explains why your information would be shared without your consent.

What are my rights and what can I do if things go wrong?... 24

The final section of this guide explains your right to see the information held about you by any organisation, how to change information that isn't correct and how to stop your information being used.

Where can I find out more? 28

Details of information and support organisations are listed in this section.

With widened access to information, it's important that you understand what protects your confidentiality, and that you know your rights.

THIS GUIDE

There are lots of things that protect your confidentiality, and many people don't experience any problems, but if something does go wrong this guide will help you to understand the details of how things work.

This guide explains the rules on confidentiality. It looks mainly at health and social care services, but also covers confidentiality issues in other areas like employment.

As with any long-term condition, health and social care professionals need to keep information about your health and HIV treatment so they can provide care safely. Insurance companies might ask about your health if you apply for insurance, and employers may record information about your health relevant to your work. With widened access to information, it's important that you understand what protects your confidentiality and know your rights.

WHAT IS THE LAW?

The Data Protection Act 1998 and the Human Rights Act 1998 give us confidentiality rights and mean that we can take action if these rights are breached.

It has meant that while most people have had their records protected, for the times that things go wrong there is a way to address it.

THE 1998 DATA PROTECTION ACT (DPA)

The Data Protection Act 1998 applies to any organisation (whether public authority, third sector or private company) that holds personal information about you. It gives you rights and sets out rules for organisations that store your data:

- If data is collected about you for one reason, it must not be used for a completely different reason;
- Organisations must not give your personal data to other people or organisations unless either you agree, or they have a lawful reason for doing so;
- You have the right to ask for a copy of the personal data that any organisations hold about you;
- Organisations should only ask for and use the personal information they really need to perform a particular task;
- Organisations must not keep data about you for longer than they need to and it must be kept up to date;
- Your data must be kept secure and well protected;
- If an organisation has data about you that is factually inaccurate, then you have the right to ask them to correct it.

The Information Commissioner's Office (ICO) enforces the DPA and handles complaints. The contact details for the ICO are provided on page 28.

NB: Personal information includes things like your address, telephone number, and more sensitive information like your medical history.

THE HUMAN RIGHTS ACT 1998

In the UK, human rights are protected by the Human Rights Act 1998. All public authorities (e.g. the NHS and councils) are subject to it. The right to respect for your family and private life is one of the rights protected by the Human Rights Act. Disclosure of your personal information, such as your medical records, without your consent may be a breach of your human rights. You can find out much more about the Human Rights Act in our accompanying Rights guide.

PROFESSIONAL STANDARDS

There are lots of guidelines and codes of conduct on confidentiality which apply to different professions. If a professional breaches the standards set by their regulatory body, including by handling your information inappropriately, they can be disciplined and potentially have their right to practice removed.

HOW IS MY INFORMATION STORED AND ACCESSED?

RECORDS OF HIV TREATMENT AND CARE

Once you've been diagnosed with HIV and begin receiving treatment, records of that care will be created. All healthcare staff have a professional, ethical and legal duty to keep your information confidential at all times. In all cases, access to records is on a need-to-know basis for legitimate care. However, the answer to the question of who may see information about your HIV care and treatment is not always straightforward.

In Scotland, care for people with HIV is shared between specialists in infectious diseases, and specialists in genitourinary medicine (sexual health). While most HIV care in Scotland is delivered through hospital-based clinics, in some health boards it is provided through community clinics. Where you access your treatment and care will determine which electronic records are used. This is because the NHS uses different systems in different clinics, each with different purposes and holding different types of information.

If you access HIV treatment outwith sexual health services, then standard NHS electronic record systems will be used to record lab test results and treatment information. Details of the different standard electronic records used, what information they hold, and who can see them is provided in the table on page 10. Within some sexual health services you can choose instead to have your information recorded on the National Sexual Health System (NaSH). NaSH is specific to sexual health clinics and the information held on it is only available to sexual health staff. However, in some sexual health services standard electronic records are used, so it's important to ask about which systems are being used and who can see your information if you have any concerns.

The majority of people accessing treatment and care through the NHS will be identified using a number known as the CHI Number (Community Health Index number). The CHI register itself does not contain any clinical information, but your CHI number can be used to link up the different parts of your health record held in different places within the NHS. It is far safer to receive care using a CHI number as it means the staff looking after you are able to see previous records and results, and access important information should there be an emergency. It also helps make sure information about your healthcare is not mixed up with someone else's.

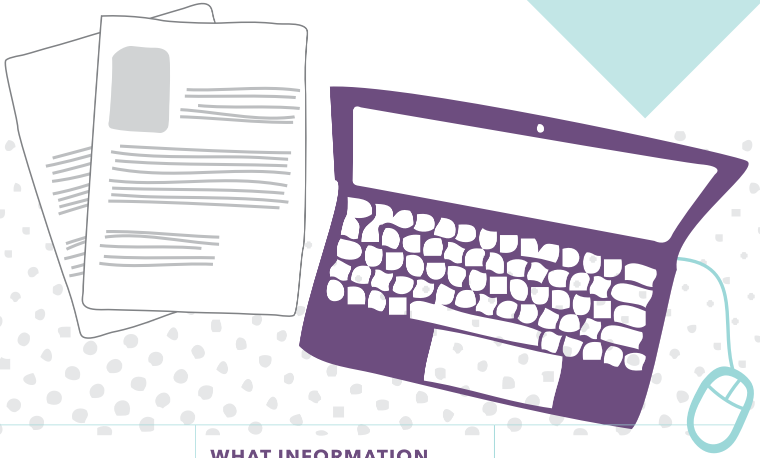
> **All healthcare staff have a professional, ethical and legal duty to keep your information confidential at all times.**

NHS ELECTRONIC RECORD SYSTEMS

The table below outlines the different electronic systems used by the NHS, the information they hold and details of who can access them.

NAME	WHAT IS IT?	WHAT INFORMATION DOES IT HOLD?	WHO CAN SEE IT?
NaSH (National Sexual Health System)	An electronic patient record system used by sexual health services.	Information about your sexual history, clinical conditions, test results, and prescriptions. This can include information about your HIV treatment and care.	Only staff working in sexual health settings. Records can be viewed by sexual health staff in different health board areas should you move.
SCI Store (Scottish Care Information)	An information store that provides clinicians with secure access to patient information at the point of care.	Stores laboratory reports, radiology reports, clinical documents and letters for admissions, discharge, and transfers. This can include HIV test results and related clinical information.	Your own GP and hospital staff. GPs can only look at information on their own patients who are registered with their practice. Hospital staff can see information for everyone in their own Health Board area.
Emergency Care Summary (ECS)	A record of basic information which might be important if you need urgent medical care.	All patients in Scotland who are registered with a GP have an Emergency Care Summary. This could include things like prescribed medication and allergies, and can include HIV medication if your GP enters it. You must tell your GP if you don't want an Emergency Care Summary to be made for you, but think carefully before doing this as having your information available in an emergency can be critically important, as demonstrated by the case study on page 14.	All GP practice clinical and admin staff can view the ECS for patients registered permanently in their own practice. Staff within Secondary Care, NHS24, the Scottish Ambulance Service, out-of-hours organisations, hospices and clinics are permitted access to a patient's ECS if in doing so it is legitimately in support of the direct care of that patient.

NAME	WHAT IS IT?	WHAT INFORMATION DOES IT HOLD?	WHO CAN SEE IT?
Key Information Summary (KIS)	A record designed to support patients with long-term conditions or who have complex care plans. Having a Key Information Summary could be useful if you have complex care needs, particularly if you take multiple medications and attend multiple specialist clinics.	This contains more detailed information than the ECS, including things like where and how you would like to be cared for. This is created using information from GP records, if agreed by you and your GP.	All GP practice clinical and admin staff can view the KIS for patients registered permanently in their own practice. Staff within Secondary Care, NHS24, the Scottish Ambulance Service, out-of-hours organisations, hospices and clinics are permitted access to a patient's KIS if in doing so it is legitimately in support of the direct care of that patient.



NAME	WHAT IS IT?	WHAT INFORMATION DOES IT HOLD?	WHO CAN SEE IT?
Trak Care	A patient administration system. In some NHS boards, it is used for making referrals electronically, producing clinical letters, and requesting and checking the results of blood tests (including CD4 and HIV viral loads).	This system holds information about all your current and future appointment details, such as your clinician and all specialists you attend, and your GP's details.	Everyone in the Health Board area who has been given a password by the Health Board e-health team. Most GPs don't have access to track care but community staff in some areas do.
Clinical Portal	Allows clinicians to look at information from multiple record systems together on their computer screen without having to log in separately to each system. Most health boards in Scotland have some form of portal system in operation.	The Portal provides a view of laboratory results, letters, notes and scanned documents along with appointment information. Portals can include links to social care, mental health, community nursing and GP systems. This can include information about HIV treatment and care, although access to this information can be restricted.	Clinical staff with appropriate role-based access can see clinical information. Access to information from the feeder systems may be further restricted by role or geographic site, and some systems permit patients to withhold information for sharing.

FAST FACTS:

Where you receive HIV care determines the IT / electronic record system that is used.

All systems are carefully governed.

Local healthcare systems usually can't offer a choice of what electronic system is used.

Talking to your consultant is important so you can understand what information is recorded where.

In all cases, access to records is on a need-to-know basis for legitimate care.

CASE STUDY

Sharing information in an emergency

Alan had a heart attack and was rushed to hospital. The hospital consultant who examined him was keen that he start taking heart medication as soon as possible. Alan was concerned by this as he had heard that certain heart medications can interact badly with HIV drugs. He raised his concerns with the consultant and refused to take any heart medication until a pharmacist had reviewed the situation. The next day a nurse informed Alan that it was lucky he had been conscious and passed on the information that he did to the consultant. One of Alan's HIV medications would have boosted the properties of the heart medication, meaning he needed to take a much lower dose than was originally advised. This highlighted for Alan just how important information sharing can be:

> *"When I had a heart attack, I could have been unconscious and the doctor who treated me would have given me his dosage of whatever this medication was, and that could have been fatal simply because he didn't have access to my medical history. Information sharing is something that is very important."*

GP RECORDS

Some people may receive HIV treatment and related care from their GP, and details of this will be kept within GP records. Your GP can only share information about your HIV status with your consent. This could mean you will be asked directly if you consent to information being shared, but it may also be assumed that you have implied your consent through your actions. For example, by saying you are willing to go to see a doctor in the chest clinic, your doctor could assume that you are happy for your health information to be shared with the chest specialist when they refer you, unless you say otherwise. You should let your GP know if you do not want other healthcare professionals involved in your care to know your HIV status. If you want to know how your information is being used, ask them to explain.

WHAT PROTECTS MY RECORDS?

NHS organisations have electronic auditing systems in place that can identify who is looking at what, and where and when this activity took place.

They closely review staff access rights – making sure that people can only access the records they need depending on their job. For example, a receptionist will not have the same rights of access to patient information as a doctor. Some information may be particularly sensitive and therefore extra security measures can be put in place so access to this information is limited to only those who require it. HIV status would not normally automatically create restricted access, but it can be restricted on an individual basis.

SOCIAL CARE RECORDS

Social work services are often provided by Local Authorities in Scotland. Most personal information collected by social work services is held electronically and all personal information will be confidential, unless exceptional circumstances apply e.g. where there may be a risk of harm should information not be shared.

If you receive social work support then your personal information will be available to social work staff who are working directly with you, and may be shared with other social work staff if they are to provide support. Social workers may also access your case file if the information is needed to help them to support someone else. For now, social work and health electronic systems are separate but over the next few years it is likely that they will be joined up, to help provide better care for people with complex needs.

A limited range of other Local Authority employees may require access to personal information stored on social work systems to carry out their duties or provide services. This could include Legal Advisers (if court proceedings arise) and staff within other council departments e.g. providing housing services.

The Scottish Social Services Council (SSSC) Codes of Practice for Social Service Workers and Employers sets out the standards that social workers, as well as social care, early years and young people's workers, and their employers should meet. Social services also have to comply with the Data Protection Act 1998 and the Human Rights Act 1998.

If your care is being provided by more than one health or care worker, you will need the teams of professionals providing care to share information reliably. This could be staff working in residential homes, providing care at home, or working in wards, clinics and communities. Confidential information must not be shared outside the care team, and only to provide a seamless service. The sharing of information in this way can occur only if you consent.

If you are unclear about what information is held about you, you can ask to see your records (more information about this is provided on page 22). Remember that all health and social care staff have a professional, ethical and legal duty to keep patient information confidential at all times. If you experience any problems, have a look at page 24 on what to do if things go wrong.

EMPLOYMENT RECORDS

It is common for people who have a good relationship with their managers to tell them things in confidence about their health and wellbeing. Employers have responsibility for the information they collect and how they use it, and any data that your employer holds is covered by the Data Protection Act (see page 6 for more information on this).

No one at any level should share your personal information beyond the organisation's procedures, for their own purposes or without your permission. Anyone disclosing personal information without the authority of the organisation may be committing a criminal offence, unless there is a legal justification.

CAN EMPLOYERS AND INSURERS ACCESS MY HEALTH RECORDS?

An insurer or employer would not normally be given access to your medical records, but they can ask your permission to contact your GP to ask for a report providing information from your records. Insurers typically request medical information based on the information you gave when you applied for the insurance, or if your level of cover exceeds certain limits.

If you give permission for a report to be provided, you have the right to see it before it is sent, to refuse consent to it being sent, and to ask for inaccuracies to be corrected. Doctors will usually exclude any health information not relevant to the request, so it may not be necessary to mention anything about HIV. However, the report must be truthful, so if you ask your GP or health professional to leave out relevant information, they may not be able to provide a report. You can find out more about disclosing your status to health professionals and insurers in our accompanying disclosure guide.

Health records being shared with employers

CASE STUDY

James applied for a job as a support worker. He was successful in his interview and was asked to provide a medical record as the final part of the recruitment process. This was the first job James had applied for since being diagnosed with HIV, so he was nervous about what information might be included in the report and the impact it might have. He decided to speak to his GP about his concerns. His GP assured him that he would not disclose James's HIV status on the report – he said this was not relevant to the job, and that James was perfectly fit for work. However, when the report was sent it did include James's HIV status. It also implied that he was not fit for work. James was understandably upset and contacted his GP for an explanation. It transpired that a different GP had completed the report and not the one that James had spoken with. The GPs could offer no valid explanation as to why his HIV status was disclosed, and why they didn't declare that he was fit for work. James believes this is a clear breach of trust and confidentiality and is seeking advice on how to have the matter investigated. James's experience highlights the importance of asking to see and reading reports before they are sent, particularly if you have any concerns about confidentiality or the information being provided.

CAN INFORMATION ABOUT MY HIV STATUS BE SHARED WITHOUT MY CONSENT?

Yes - healthcare staff could be obliged to disclose your HIV status without your consent under certain circumstances. However, this would be exceptionally rare and whenever possible you would be notified first.

Information about HIV status may be disclosed where it is in the public interest, or there is a legal duty to do so (such as a court order). Solid justification is required as to why it is in the public interest, for example to prevent a crime or serious harm to other people. In this case 'serious harm' can include the risk of passing on HIV, or any other serious infection. If a court required the information then your doctor would be obligated to confirm your HIV status.

Generally there should be no reason for employers to break confidentiality. In rare situations an employer may be obliged to share your HIV status if they felt you were a risk to yourself or others. This would only be in exceptional circumstances, particularly as most organisations have policies and practices in place to ensure safe working conditions. Your Human Resources department should be able to provide you with a copy of relevant policies.

WHAT ARE MY RIGHTS?

ACCESSING INFORMATION ABOUT YOU

Under the Data Protection Act, you have the right to see a copy of any personal information held about you. Asking for this information is known as making a subject access request (SAR). You also have the right to ask for the source of the information, and whether it will be given to any other organisations.

SARs must be made in writing and you may be asked to pay a fee (for most organisations this is a maximum of £10, for health records the maximum is £50). Once the fee has been paid and any other additional information has been provided the organisations must respond within 40 days.

There are some exemptions to the duty to disclose information. For example, if your records contain information about someone else, this part of the record will not be made available to you. An organisation may also withhold information if disclosure would be likely to cause distress to you or someone else.

CHANGING INACCURATE INFORMATION

If you discover that an organisation holds factually inaccurate information about you, including within your health records, you can ask it to correct, block or remove the information. You will need to write to the organisation and tell them of the inaccuracy, including proof where possible.

If it is agreed that the record is inaccurate then the information should be corrected. Where this happens with health records the amendment 'should clearly display the correction whilst ensuring that the original information is still legible.'

The Data Protection Act only obliges organisations to keep information factually accurate - it can't be used to alter or remove opinions, including medical diagnoses, unless those opinions themselves are based on inaccurate factual information.

If you do not get a reply or the information is still wrong, you can contact the Information Commissioner (see page 28) and ask them to consider whether the organisation has breached the Data Protection Act.

STOPPING YOUR INFORMATION BEING USED

The Data Protection Act means that you have a right to ask an organisation not to hold or use information about you that causes unwarranted damage or distress. Following your request the organisation has 21 days to respond. They can only refuse to share the information they hold if it is:

- Necessary to agreeing or carrying out a contract.
- Necessary to carry out any legal obligation that applies to the organisation.
- Necessary to protect your vital interests.

WHAT CAN I DO IF THINGS GO WRONG?

"How do I make a complaint and what is the right course of action? Do I have a casual word with my consultant, write to the chief executive or the board? Or is there an independent body? Should I contact the Information Commissioner's Office?"
Person living with HIV

If you think your information has been used unfairly, you should first approach the organisation involved, and ask them to explain how they have used your information and how they have complied with the Data Protection Act. You can raise the matter informally directly with the person involved, or go to their supervisor. Most organisations will also have an official complaints procedure. Organisations are obliged to explain how they are processing your personal information if you make a formal request.

If you aren't satisfied with their response, the Information Commissioner's Office may be able to help – it is the UK's independent body set up to uphold information rights. You can also raise concerns and complaints via the free Patient Advice and Support Service (see page 28). Our accompanying Rights guide gives more information about making a complaint and raising issues with organisations.

INFORMATION AND SUPPORT

INFORMATION AND SUPPORT

Information Commissioner's Office

The independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.
www. ico.org.uk

@ casework@ico.org.uk (please include a contact phone number in your email)

☎ 0303 123 1113

Scottish Public Services Ombudsman

The final stage for complaints about councils, the National Health Service, housing associations, colleges and universities, prisons, most water providers, the Scottish Government and its agencies and departments, and most Scottish authorities.
www.spso.org.uk/

☎ 0800 377 7330

Scottish Social Services Council (SSSC)

Information on the Scottish Social Services Council (SSSC) Codes of Practice and how to make a complaint are available on their website:
www.sssc.uk.com/

Patient Advice & Support Service (PASS)

A free service is delivered and accessed via your local Citizens Advice Bureau (CAB) and can be accessed by contacting your local CAB.
www.patientadvicescotland.org.uk

☎ 0808 800 9060

Equality and Human Rights Commission (EHRC)

Protects people against discriminatory treatment and holds organisations, such as businesses and Government, to account for what they do.
www.equalityhumanrights.com

In Scotland:

☎ 0141 228 5910
@ scotland@equalityhumanrights.com

Equality and Advisory and Support Services (EASS)

Advice and support about discrimination and human rights.
www.equalityadvisoryservice.com/

☎ 0808 800 0082

Citizens Advice Scotland

Provides free, confidential and impartial advice on a range of issues including money, benefit, housing and employment problems.
www.cas.org.uk/

☎ 0808 800 9060

Acas

Help and advice for employers and employees.
www.acas.org.uk

☎ 0300 123 1100

HIV SUPPORT

To find support services in your area visit:

NAM E-atlas service finder

www.aidsmap.com

☎ 020 7837 6988
@ info@nam.org.uk

Or:

HIV Scotland service finder

www.hivscotland.com

☎ 0131 5583 713
@ info@hivscotland.com

ACKNOWLEDGMENTS

This resource has been co-published by HIV Scotland and the National AIDS Trust after months of research. We could not have done this without a huge amount of consultation and we would like to thank the many experts who contributed to the production of this resource.

Most importantly we would like to thank community members who not only shared their stories with us, but also set the direction of the guide and provided feedback at every stage.

We would particularly like to thank:

Dr Sarah Allstaff
Dundee Health and Social Care Partnership

Dr Steve Baguley
Consultant Sexual Health & HIV Physician, Clinical Director eHealth, NHS Grampian

Isabel Brown
NHS Greater Glasgow and Clyde

Professor James Chalmers
University of Glasgow

Simon Daley

Dr Morgan Evans
Consultant HIV physician, Ninewells Hospital and Medical School, Dundee, NHS Tayside

Geraldine Haggan
Positive Life

HIV Clinical Leads Network

Dr Nicholas Kennedy
NHS Lanarkshire

Law at Work

Elin Lundkvist

Information Commissioner's Office

NHS Greater Glasgow and Clyde

NHS Lothian

Chris Morgan
Unusual Risks Mortgage and Insurance Services

Dr Libby Morris
GP NHS Lothian and Scottish Government

Linda Panton
Clinical Nurse Specialist, NHS Lothian

The Association of British Insurers

Dr Andrew Winter,
Consultant in Sexual Health & HIV Medicine, NHS Greater Glasgow and Clyde

Craig White
Scottish Government

Dr Roger Wong
Clinical Coordinator, Brownlee Centre, Glasgow

HIV Scotland
18 York Place
Edinburgh
EH1 3EP
www.hivscotland.com
Scottish charity (No. SCO 33951) Registered company (No. 242242)

National AIDS Trust
New City Cloisters,
196 Old Street,
London EC1V 9FR
www.nat.org.uk
National AIDS Trust is a Registered Charity No. 297977 and a Company Limited
by Guarantee No. 2175938, (registered in England and Wales)
Registered Office: New City Cloisters, 196 Old Street, London EC1V 9FR

Design & Illustration: Heedi Design