

TRANSFORMING  
THE UK'S  
RESPONSE  
TO HIV



Guidance: October 2010

# Personal information and the NHS

A guide for people living with HIV





**All of us want to receive the best possible healthcare and we know that sometimes this means that personal information needs to be shared. However we need to feel confident that our information will be shared appropriately and with our consent.**

**If you are living with HIV you might have concerns about who will know about your status and how this information will be handled.**

**This guide explains the basic principles of confidentiality in the NHS, how your information is used, and gives practical advice about what to do if you have any concerns.<sup>1</sup>**

### **What is confidentiality?**

Keeping information confidential means not sharing or disclosing this information to anyone else. In many settings there are rules about keeping information confidential and people can get into trouble if they break these rules.

Healthcare professionals, such as doctors and nurses, have to stick to confidentiality rules - if they do not, they can be disciplined or even lose their jobs.

## **Healthcare workers need your consent to share your information**

Healthcare professionals in the NHS are only allowed to tell other people information about you in two circumstances – with your consent or if it is in the ‘public interest’.

Giving consent for your information to be shared is very common when you visit the doctor. For example, your HIV doctor may ask if you are happy for your GP to know about your HIV status, or if they can refer you to another department for tests.

There are two types of consent, and the doctor needs one of them to pass on your information.

The first is called ‘explicit consent’ and means that you have made a point of agreeing to your information being shared.

This could mean that you were asked directly to give your consent and you said ‘yes’, or if you were asked to sign a form confirming that you were happy for them to go ahead.

For example, signing a form agreeing that your doctor can tell your local authority housing department about your health.

The second is called ‘implied consent’ and means that your actions show that you are consenting for your information to be shared.

For example, by saying you are willing to go to see a doctor in the chest clinic, your doctor can assume that you are happy for your health information to be shared with the chest specialist when they refer you, unless you say otherwise.

In the NHS, it is normally assumed that you have implied your consent for information to be shared with other healthcare professionals for your treatment or care.

Explicit consent is more likely to be required if your doctor is disclosing information which is not directly related to your treatment and care, such as

to someone outside the NHS like an insurance company or employer.

The only time that healthcare professionals can share your information without your consent is if they think the information is in the 'public interest'. This only happens in very unusual circumstances and is discussed on page 4.

### What about insurance?

There are certain circumstances when organisations might want to find out some medical information about you. If you apply for insurance, you might be asked on the application form if you have any pre-existing medical conditions. If you have been diagnosed with HIV you have to disclose this on the application. If you do not, the insurance company can refuse to pay you when you make a claim.

When filling out the application, you might also have to sign a form confirming that you consent to your GP disclosing health information about you. If they are contacted by the insurance company (and you have consented to your information being shared) GPs have to provide all relevant information to the insurance company, including HIV positive status.

Unfortunately, getting insurance, particularly health and life insurance, can be difficult for people living with HIV because the insurance companies think it is a significant risk. There are some providers who offer these services but they can be expensive. However, with increasing evidence that people living with HIV can lead long and healthy lives, this is gradually changing.<sup>2</sup>

### Your confidentiality is protected in lots of different ways

If you have not given your consent to your information being shared or it is not in the public interest for it to be shared, the NHS has to keep the information it holds about you confidential. There are many laws which protect your personal information including the Data Protection Act and the Human Rights Act.

Professional bodies such as the General Medical Council and the Nursing and Midwifery Council also stress the importance of confidentiality and can stop healthcare professionals from working if they are found to break the rules. In addition, the NHS has many policies in place which protect confidentiality and these apply not just to doctors and nurses but also to administrative staff such as receptionists.<sup>3</sup>

Sometimes information needs to be shared within a healthcare team, for example, between a doctor, a nurse and a member of administrative staff, and implied consent is normally assumed for this. This will be done if it is beneficial for your treatment and care. The confidentiality rules apply to the whole team and information will never leave the team without your consent. If you want to know how your information is being used, do ask them to explain.

## What about employment, benefits and housing?


There are some organisations, apart from insurance companies, which might want to know information about your health. For example, your employer might want to know medical information about you, or your Job Centre or local authority might want to ask about your health if you have made a claim for benefits or social housing because of your health.


As with insurance, no organisation outside of the NHS can find out information about you without your consent. If they are contacted by an organisation such as a local authority (and you have consented to your information being shared) GPs have to provide relevant information to them.


Organisations, such as employers, should only be asking for information which is legitimate and relevant. If you are unsure as to why they want to know the information you should ask for them to clarify and maybe seek advice from an HIV support organisation or lawyer.

You do not have to consent to your information being shared. However, if you have made an application for benefits or housing because of your health, they may decide that you do not qualify without evidence from your doctor.<sup>4</sup>

Confidentiality is protected in the NHS in the following ways:

 NHS staff should not talk about a patient to anyone else either inside or outside the NHS without the patient's consent; this includes to family members and friends of the patient

 NHS staff should not leave names visible anywhere. They should therefore cover up names on paper files or close down electronic medical records


 All paper records should be kept in a secure place and all computerised records should have electronic protections such as secure logins and passwords.


Healthcare staff should always explain to you what they are doing with your information, for example they might explain that they are going to write a letter to your GP. If you have any questions about what they are doing, or what information they are going to share, you should ask them to clarify.

You can say that you are not happy for something to be shared (and it would not be) but healthcare staff are very unlikely to suggest passing on information unless it is in your best interests. Healthcare staff are fully trained, and if they think that a piece of information should be passed on, it will be because they consider that this will be helpful in some way.

For example, they may want to make sure that a doctor in another department knows what HIV treatment you are on so that they do not prescribe you drugs which may interact badly with your HIV medication. Again, you can always ask for a further explanation if their reasons are unclear or if you are worried.

HIV clinics have a very strong confidentiality culture because of the sensitivities around HIV. This means that there are extra protections for patients who attend them. These include:

 *Patients being able to attend the clinic without a referral from a GP, which is known as 'open access'*

 *Routinely asking for consent before sending information to other healthcare professionals such as GPs.*

Other medical disciplines may not have these additional protections, but they still have to stick to all the general rules which were discussed earlier. Again, if you have any questions about how your information is going to be handled you should always ask.

### What about immigration status?

These rules about confidentiality still apply, no matter what your immigration status is. Healthcare staff should never pass information about your health, treatment or care, or your residency status to the UK Border Agency/Home Office.

## Staff can only break confidentiality if they believe someone is, or has been, at risk

In very rare situations, disclosing information without consent is seen to be in the 'public interest'. This means that sharing the information will protect society or individuals from serious harm such as a serious communicable disease (a disease which can be passed on to others) or a serious crime.<sup>5</sup>

HIV is defined as a serious communicable disease, so very occasionally a healthcare professional may break confidentiality to protect someone they think might be at risk from it.

If an HIV clinic is worried that a patient with HIV has put someone else at risk of HIV infection, or is putting someone at risk of HIV infection, they should talk with the patient about telling the person concerned. This is standard procedure and is known as 'partner notification'. Most patients either speak to the person themselves, or agree that the person can be contacted and invited to the clinic to have an HIV test. In this situation, the patient is not mentioned by name, although the person being contacted may be able to work out who it is.

Very occasionally, if someone refuses to let the clinic contact the person, the clinic has to decide whether to do it anyway. If they decide that the risk to the person outweighs the risk of breaking confidentiality, this is seen to be in the public interest and they can go ahead and contact the person. This is an unusual situation and they will not do it without clearly warning the patient that this is what they are going to do, and making every effort to get the patient to change their mind first.

### What about criminal transmission?

Although this happens very rarely, someone living with HIV can be prosecuted for recklessly or intentionally transmitting HIV.

In exceptional cases, the police might be investigating a case of criminal transmission and contact the doctor of the person who has been accused of the crime to ask for medical information.

However, healthcare professionals should not give health information to the police unless the patient has given their consent or there is a court order.<sup>6</sup>

## Electronic records will not change any of these rules

The NHS is in the process of introducing electronic medical records. These systems are going to be slightly different depending on where you are in the UK. Many GP surgeries and hospitals have already been using electronic systems for years, but now there is going to be a consistent format across NHS organisations.

So far most of the progress has been made in producing summary records - records that will provide basic information about your health, such as allergies and prescriptions - which will help

give a general overview to healthcare professionals who would not normally treat you in services like accident and emergency and out-of-hours GP services. This is so they can be better informed when providing your care. For example, if they can see on the summary that a patient has an allergy to a certain antibiotic they can ensure that they prescribe something different.

A longer-term aim is to have more detailed health information in one record which will be the main place that patients' health information will be stored.

It is hoped that healthcare professionals in different locations, for example an HIV consultant and a GP, will both be able to add your health information to the same record, giving a fuller picture of your care.<sup>7</sup> This sort of record will remain separate from the summary record as they serve different functions.

This is clearly a big change in how your information will be processed. However, it is very important to note that these practical changes do not make any difference to the fundamental rules of confidentiality which are discussed above.

The organisations which are designing and implementing these IT systems are making sure that patient confidentiality will be strongly protected in a range of ways. For example, by ensuring that

there are strict access rules so that only people with smartcards, passwords and the right level of permission can look at computerised medical records. Some of the confidentiality protections will vary in practice depending on your part of the UK and the system they are implementing.

If you want to know about how the system in your part of the UK is going to work, or what information will be put on your electronic record, you should ask for information and advice at your HIV clinic or GP surgery. You will have the right to opt-out of national shared record schemes, but the NHS does warn that they cannot guarantee the same quality of care for those who have opted-out because their information will not be so readily available when they attend or contact accident and emergency or out-of-hours GP services.

## **You have the right to ask questions, see your medical records and complain**

It is your right to ask questions about where and how your information is kept and handled. If you have concerns it is best to make this clear.

It is also your right to see your medical records. You have to contact your HIV clinic to see your HIV records, your GP surgery to view your GP records, and your local Hospital Trust to view your hospital records. They will then arrange a time when it is convenient for you to come and look at them. You may be charged an administration fee to look at your records so it is best to check this beforehand. The only time that your request will be refused is if they believe that serious harm to you or someone else will arise from you seeing the information contained in them.

It is your right to complain if you feel that your information has been handled inappropriately. The first thing that you should do is ask your GP surgery or Hospital Trust, as appropriate, what their complaints procedure is. You should then raise the matter with the healthcare professional concerned or the complaints manager. You can do this verbally or in writing.

The NHS has to investigate your complaint fully and give you a full and prompt reply.

If you are not happy with the response you receive, you can contact the Parliamentary and Health Service Ombudsman which is an independent body that investigates complaints about the NHS. Most complaints should be resolved before they get to that stage.

If you do make a complaint, this should not make a difference to your treatment or care, and you should not be victimised in any way for making your complaint.

You might also want to see if there are any patient groups or HIV support organisations in your area that can help you with your complaint, or support you as you go through the complaints process. For example, all hospitals have a Patient Advice and Liaison Service (PALS) office which offers confidential advice and information to patients. You might also want to get legal advice from an organisation like the Citizens Advice Bureau.

## References

1. For more detailed information about confidentiality in healthcare see our policy report *Confidentiality in healthcare for people living with HIV* which can be downloaded from the NAT website [www.nat.org.uk](http://www.nat.org.uk)
2. For more information about insurance visit the Association of British Insurers website [www.abi.org.uk](http://www.abi.org.uk)
3. The NHS in all nations of the UK have confidentiality codes of practice which explain these principles in more detail; these can be downloaded from government and NHS websites: [www.dh.gov.uk](http://www.dh.gov.uk) for England, [www.scot.nhs.uk](http://www.scot.nhs.uk) for Scotland, [www.wales.nhs.uk](http://www.wales.nhs.uk) for Wales and [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk) for Northern Ireland
4. For more information about employment, benefits and housing for people living with HIV visit the 'Living with HIV' section of the NAT website [www.nat.org.uk](http://www.nat.org.uk); for general information about benefits or housing visit the DirectGov website [www.direct.gov.uk](http://www.direct.gov.uk)
5. For more information about the how public health law and criminal law can apply to confidentiality in healthcare look at the NAT website [www.nat.org.uk](http://www.nat.org.uk)
6. For more information about criminal prosecutions see our leaflet *Criminal prosecutions for HIV transmission: a guide for people living with HIV in England and Wales* which can be downloaded from the NAT website [www.nat.org.uk](http://www.nat.org.uk)
7. For a more detailed summary of the different electronic records in the UK see our policy report *Confidentiality in healthcare for people living with HIV* which can be downloaded from the NAT website [www.nat.org.uk](http://www.nat.org.uk)

## Where can I go for further information?

### For further information about...

...**confidentiality in healthcare and the law** visit the NAT website  
[www.nat.org.uk](http://www.nat.org.uk)

...**confidentiality rights and data protection** visit the Information  
Commissioner's Office website [www.ico.gov.uk](http://www.ico.gov.uk)

...**how to complain about your healthcare** visit the NHS Choices  
website [www.nhs.uk](http://www.nhs.uk)

...**how to request a change to your medical records** visit the  
National Information Governance Board website [www.nigb.nhs.uk](http://www.nigb.nhs.uk)

...**local HIV support organisations** visit the NAM website  
[www.aidsmap.com](http://www.aidsmap.com)

...**Patient Advice and Liaison Services (PALS)** visit the PALS  
website [www.pals.nhs.uk](http://www.pals.nhs.uk)

...**the Parliamentary and Health Service Ombudsman (PHSO)**  
visit the PHSO website [www.ombudsman.org.uk](http://www.ombudsman.org.uk)

...**your nearest Citizens Advice Bureau (CAB)** visit the CAB  
website [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)





## About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.

**SHAPING ATTITUDES.  
CHALLENGING INJUSTICE.  
CHANGING LIVES.**

All NAT's work is focused on achieving four strategic goals:

- Effective HIV prevention in order to halt the spread of HIV
- Early diagnosis of HIV through ethical, accessible and appropriate testing
- Equitable access to treatment, care and support for people living with HIV
- Eradication of HIV-related stigma and discrimination

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