

June 2014

TRANSFORMING
THE UK'S
RESPONSE
TO HIV



Confidentiality in the NHS: Your Information, Your Rights

A guide on how personal confidential information on HIV is stored, used and shared within the NHS in England

British HIV Association
BHIVA



Contents

A.	About this guide	3
B.	Confidentiality in the NHS	4
C.	Your patient records and your HIV status	7
D.	'Third Party requests' to your GP for information - insurance, employers, benefits and solicitors	9
E.	Sharing your information 'in the public interest'	11
F.	The Summary Care Record	12
G.	Using your information for public health and research purposes	14
H.	Making a complaint	17
I.	Further information and support	19

Acknowledgements

We would like to thank BHIVA (the British HIV Association) for their support, both contributing to the funding of this guide and bringing together an advisory group of clinicians to share their expertise.

We would also like to thank Gilead Sciences Ltd who also contributed to the funding of this guide.

In addition, we would like to extend our gratitude to everyone else who has contributed invaluable advice and feedback, and especially people living with HIV.

A. About this guide

This is a guide for people living with HIV about confidentiality in the NHS in England. We hope this guide will help improve your understanding of how your personal confidential information on HIV is stored, used and shared within the NHS, as well as addressing worries or concerns.

The guide is set out in a question and answer format and will provide information on:

- What your rights and choices are around confidentiality and what you should expect from a safe and confidential NHS service.
- How your information, including your HIV status, is recorded, used and shared.
- How to address any concerns or worries.
- What to do if your confidentiality has been breached or you feel that you have been treated unfairly upon disclosing your HIV status.

It is important to note that this guide is not a substitute for legal advice or information that should be provided by a doctor or another medical professional.

If you still have unanswered questions about confidentiality after reading this guide, your HIV doctor or nurse, your GP, or your local NHS organisation should be able to help. The links provided in this guide will also signpost to further information and support.

More information and guidance:

NAT has developed a resource explaining what your rights are and what you should expect from your health and support services:

[My Care My Voice](#)

For more information about HIV and issues that matter to you, where to get help and support, and how to get involved, visit:

[Life with HIV](#)

To order hard copies of this guide, and for other guides and publications by NAT, visit:

[NAT's publications page](#)

B. Confidentiality in the NHS

Q. Is the information about my HIV status kept confidential within the NHS?

A. Yes, your health-related information, including information about your HIV status, is kept confidential within the NHS.

The requirement to keep your information confidential is based in law, in the NHS Constitution and in key NHS rules and procedures. It is also outlined in every NHS employee's contract of employment and in professional standards set by regulatory bodies. All registered healthcare professionals must abide by these standards and if they are found to have breached confidentiality, they can face disciplinary action.

Q. When will a healthcare worker share my confidential information with someone else in the NHS?

A. A healthcare worker will share your confidential information with someone else who is, or is about to, provide you directly with healthcare to make sure you get the best possible treatment. They will only share information which is relevant to your care in that instance. They will only share this information if you consent.

Q. How do I consent to my information being shared with someone else?

A. There are two ways to do so – you can give '**explicit consent**' or you can give '**implied consent**'.

Explicit consent is when you clearly communicate to a healthcare worker, verbally or in writing or in some other way, that relevant confidential information can be shared.

Implied consent, on the other hand, means that your consent to share personal confidential information is assumed. The healthcare worker will not ask you before sharing your information and you will not have to provide your explicit permission.

When personal confidential information is shared between healthcare workers providing you with direct care, your consent is taken as implied (in other words, it is assumed you agree to your information being shared). One example is when doctors and nurses hand over care between shifts in

a hospital. Another example is when a GP refers you to a hospital for some further tests or treatment.

If you do not want a healthcare worker to share an aspect of your confidential health information with someone else giving you care, you need to make this clear and discuss the matter as soon as possible.

You do have a right in most situations to refuse permission for your health information to be shared with another healthcare professional, even one giving you care – but you will be advised as necessary about the dangers of this course of action.

Your HIV doctor and your GP will usually think that your HIV status, and any HIV medication you are taking, is relevant information to share with another healthcare worker about to give you care.

Q. Why is it important for healthcare workers to know about my HIV status and treatment?

A. HIV is a serious long-term condition which can affect almost all parts of the body – knowing you have HIV will help a healthcare worker decide what treatment and care is best for you if you become unwell. If you are taking HIV medication it is especially important that anyone providing you with healthcare knows about it. Some drugs interact badly with HIV medication. If the healthcare worker knows about your HIV medication they can prescribe drugs which can be taken safely with them.

Q. What about administrative staff in the NHS?

A. The NHS relies on administrative staff who play a vital role in supporting the delivery of your care. For example, reception staff and medical secretaries. All administrative staff receive training on confidentiality and the same strict expectations of confidentiality apply to them as they do to other healthcare workers.

Depending on what their role is, they may well be considered part of the direct care team and so will also be able to see patient records. It may be necessary for them to see your patient record, or at least some part of your patient record, for your care to be organised and provided to a high standard.

If you want to know which administrative staff have access to your patient record in a particular clinic or practice, you can ask your doctor.

“ The requirement to keep your information confidential is based in law, in the NHS Constitution and in key NHS rules and procedures.

It is also outlined in every NHS employee’s contract of employment and in professional standards set by regulatory bodies. ”



C. Your patient records and your HIV status

Q. When I am diagnosed with HIV where is that information recorded?

A. Your HIV clinic will create a patient record for you which will include your key personal details, your HIV positive status, results of tests, and details of medication and of your clinic appointments.

Q. What should my patient record contain?

A. A healthcare worker is required to make patient records which are clear, complete and accurate. Your record should include clinical findings, decisions taken about your care, drugs prescribed, investigations made, treatment provided, and the information you are given.

Q. Is my HIV status included on the records system of the hospital where my clinic is based?

A. This varies from place to place, and if you would like to know, you need to ask your HIV clinic.

Some HIV clinics still have a records system completely separate from the rest of their hospital. But an increasing number of HIV clinics include at least some of the HIV clinic information and in particular your HIV diagnosis, on the hospital-wide patient record when you are diagnosed. This means that if you go to another part of the hospital for healthcare, the staff directly providing you with care will see your HIV positive status in your record.

Q. Will my GP automatically be told about my HIV diagnosis by the HIV clinic?

A. No, not automatically. The HIV clinic will ask for your explicit consent to inform your GP that you have HIV (this is an exception to the usual process of implied consent). It is strongly recommended that you agree to your GP being told about your HIV diagnosis. GPs are responsible for managing and coordinating your overall healthcare and can only do so safely and appropriately if they know about your HIV status.

The GP will enter the fact you have HIV on your GP record along with any HIV medications you are taking and other significant information communicated from the HIV clinic. Once your GP knows about your HIV diagnosis there should be communication between your HIV clinic and your GP at least once a year with information about your health.

Q. When would a hospital record contain the information that I have HIV?

A. Sometimes, as we have described above, the hospital in which your HIV clinic is based will already have a record of your HIV status on the hospital-wide system. But otherwise, for example at another hospital not linked to your HIV clinic, the hospital record will only contain the fact you have HIV if you tell them or if another healthcare worker tells them. If you are referred to a hospital for care, most often by your GP, it is very likely (unless you object) that your HIV status will be included in the information sent to the hospital. So from then on, that hospital record will include the fact you have HIV and this will be seen by a healthcare worker at that hospital who is providing you directly with care.

Q. Can I see my patient records?

A. Yes, you have a right of access under the Data Protection Act 1998 to see your patient records and to have any factual inaccuracies corrected. This is known as making a 'subject access request'. You can find information on how to do this, on the Information Commissioner's Office website (see link below).

Q. Which healthcare workers can see my patient records?

A. Healthcare workers can only look at your confidential healthcare record if they are part of the healthcare team directly providing you with care. They must also have a specific and legitimate reason for looking at your record on every occasion. It is a serious disciplinary offence for a healthcare worker to look at someone's patient record if they are not part of the direct healthcare team.

A healthcare worker accesses an electronic patient record system with a swipe card and password so it is known which healthcare workers have looked at a patient's record. They should never give their swipe card or password to another nor leave a computer screen with a patient record on it (or a paper-based patient record) unattended or open to public view.

For more information on how to access your healthcare records:

[Information Commissioner's Office webpage](#)

D. 'Third Party requests' to your GP for information - insurance, employers, benefits and solicitors

Q. Who else apart from healthcare workers might approach my GP asking for information from my patient records?

A. Requests from outside the healthcare system (often known as 'third party requests') are most often from insurance companies, employers, benefits agencies and solicitors.

Q. Do I have a say in whether the GP responds to requests from insurance companies, employers and benefit agencies?

A. Yes you do. They should only provide the information if you have explicitly consented, though of course if you do not consent this may affect your ability to get insurance cover, be offered employment or receive benefits. For insurance requests, the insurance company should send the GP a consent form you have signed. For employer requests, the GP is also expected to make sure you understand what is involved in the disclosure and have consented to the disclosure.

For benefit requests from a government department or agency, the GP can assume that you have already explicitly consented for the GP to send your information.

Q. Can I see what the GP sends to the insurance company/employer/benefit agency?

A. Yes you can. An insurance company will tell the GP if you have asked to see the GP's reply, and the GP will also offer to show you any information to be sent to other third parties. You can request an amendment of anything you consider inaccurate but the GP is not obliged to agree with your request. If the GP does not agree to change the content as you requested, the GP must append a note to the report about the disputed information.

You can of course refuse to permit the GP to send the information but then you will probably have difficulty with your application/claim.

It is important to note that increasingly, life insurance is available for people living with HIV.

Q. How much of my information should my GP disclose?

A. The GP must disclose information which they consider to be relevant to the request. The GP must not disclose information which is not relevant to the request. Only rarely will it be necessary to send the whole of your patient record - it can be needed for certain benefits requests and for some solicitors' requests.

For more information on third party access to your healthcare records:

[GMC \(2013\) 'Confidentiality: disclosing information for insurance, employment and similar purposes'](#)

“

HIV is a serious long-term condition which can affect almost all parts of the body – knowing you have HIV will help a healthcare worker decide what treatment and care is best for you if you become unwell. ”



E. Sharing your information 'in the public interest'

Q. Are there times when a healthcare worker can share my personal information without my consent?

A. Yes, there are a few limited instances when a healthcare worker can share your personal information without your consent if it is in the public interest. These instances are set out in guidance from the General Medical Council which is the regulatory body for doctors.

Sometimes the healthcare worker has to provide the information - if required by law or in response to a court order. Sometimes the healthcare worker may provide the information, but does not have to, for example -

Telling past or current sexual partners

When you are diagnosed with HIV a health advisor at the clinic will have a discussion with you about contacting your current and past sexual partners who may be at risk of having undiagnosed HIV and may need an HIV test.

If you are uncomfortable about contacting sexual partners yourself, the clinic can do it for you and they don't even have to mention your name – but of course sometimes the person will be able to work out that it is you who has received an HIV positive diagnosis.

Usually this process is voluntary and the clinic will not breach your confidentiality without your consent. But if you have a current or past sexual partner who is at risk of having or getting HIV and you refuse to consent to them being contacted, then the healthcare worker may decide to tell them anyway even if you don't consent.

This is permitted under General Medical Council guidance. They will first try to secure your agreement and will normally tell you if they decide to notify the person of the risk without your consent.

Criminal investigations

It is also permitted for a doctor to breach confidentiality for the purposes of the prevention, detection and prosecution of serious crime.

For more information on sharing your healthcare information in the public interest:

[GMC guidance on confidentiality](#)

F. The Summary Care Record

Q. What is the Summary Care Record (SCR)?

A. The Summary Care Record (SCR) is a brief electronic record accessible to NHS staff which gives information about any medications/drugs you are prescribed, any allergies you have and any bad reactions to particular medicines.

Q. Why is the SCR useful?

A. It is very important that you don't receive medical care which harms you, for example because it reacts badly to drugs you are already taking or because you have an allergy. Sometimes people need care when they are unconscious, confused or otherwise unable to give clear information to the healthcare worker about their current health status. The SCR enables the healthcare worker to treat you safely.

Q. How is the SCR put together?

A. Your SCR is put together through an automatic data gathering process using your GP record. You should be told when this is about to happen. You can tell your GP you want to opt out, in other words not have an SCR. If you say nothing, your SCR will be created.

Q. Who has access to your SCR?

A. Any healthcare worker in the NHS can access your SCR if they are providing you with direct care and you give them your explicit consent to do so. If, however, you cannot give such consent (for example because you have been brought into hospital unconscious) then they can, if necessary, look at your SCR to make sure they treat you safely.

Q. Can I change my mind about having an SCR?

A. Yes, you can decide to have one after you have previously opted out. And you can have your SCR deleted if you change your mind and no longer want to have one. If, however, your SCR has already been accessed by a healthcare worker, then instead of being deleted, your SCR will from then on be hidden so it can no longer be viewed by NHS staff.

Q. Can I see my SCR?

A. Yes, ask your GP. If there is anything you don't understand or are uncomfortable about in what you read, you can also discuss this with your GP.

Q. Is my HIV medication included in the SCR?

A. This may depend on where your HIV medication has been entered in your GP record. **We recommend you check with your GP that your HIV drugs are included in the SCR. If you have an SCR, we strongly recommend that you ensure your HIV drugs are mentioned to avoid harmful interactions between different drugs.**

If they are not currently in the SCR, you can agree with your GP to add that information. You can also add other information which you agree with your GP is useful to include. For example, if some close family members do not know about your HIV positive status, you may want to include that in the SCR.

For more information on the Summary Care Record:

[NHS Care Records](#)

G. Using your information for public health and research purposes

Q. Does my HIV clinic report any information about me for public health purposes?

A. Yes. Public Health England undertake surveillance of HIV in England and this is essential to understand populations affected by HIV and also to ensure that everyone is receiving the best possible care.

Your HIV clinic provides basic information on all their patients to Public Health England on a regular basis. You cannot be identified as an individual from the information sent and Public Health England do not share patient information externally so you should not be concerned about any breach of confidentiality.

You do have the right to opt out of this reporting process (your HIV clinic can explain more) but you are strongly advised not to since this reporting is very important to understand more about HIV in the population, improve standards of care, and prevent HIV.

Q. Is my medical information used for research purposes?

A. Yes it is, if you consent. Consent will usually be assumed unless you opt out. The Health and Social Care Information Centre (HSCIC) extracts a range of identifiable data (your NHS number, gender, date of birth and full post code, but not your name or full address) from GP and hospital records and links them together in a secure and confidential way in order to get information which can improve the quality of NHS care.

The HSCIC is a public body which operates according to extremely strict confidentiality protocols. This programme of data collection and linkage is known as 'care.data' and is being rolled out from Autumn 2014 to cover a wider range of health settings.

Linking NHS records in this way helps the NHS prevent, treat and manage illness, improve standards of care, get a better sense of the outcomes of care, and use NHS resources more effectively. The information collected through care.data will not be used in your direct care by healthcare workers.

The NHS leaflet 'Better information means better care' explains in more detail the benefits to the NHS of collecting, linking and using this data.

The HSCIC, after it has linked data together, produces a new record

which does not contain any personal identifiable information. Any previous identifiable information is erased. This new record will be shared with certain approved research bodies on the basis of a legal contract which requires strict confidentiality processes to be in place and lays down penalties for misuse of data. There are a few situations where identifiable information is needed for research purposes but this would only be provided with your explicit consent or under specifically approved legal powers – and again, the research body would operate under the strictest confidentiality protocols.

No information will be made public by the HSCIC or any research body which can identify or potentially identify any individual.

For the first phase of care.data, information on HIV and some other sensitive issues will not be taken by the HSCIC from GP records. Information on medication, however, will be, and this may include the HIV drugs you are taking.

Q. What should I do if I do not wish my data to be used for research purposes?

A. You should tell your GP you want to opt out of care.data. More detail of how to do this should be available on your GP practice website, or you can ring your GP practice to find out more. If you do not opt out, your data will be shared automatically. You can opt out at any time. You can also change your mind at any time. However, changing your mind will only affect future data sharing. If you want to exclude entirely your data from being shared, you must do so before the first phase of data collection.

Your choice will not affect the care you receive.

When thinking about whether or not to opt out, there are two choices to make. You can decide to opt out of sharing your GP records with the HSCIC. This means the HSCIC will not get any information about your GP care and will not therefore be able to share it with other bodies.

You can also decide to opt out of your hospital records (and your other NHS records) being shared by the HSCIC in identifiable form with other bodies.

For more detailed information about care.data go to the care.data page of the NHS Choices website or ring the care.data patient information line (see overleaf).

Q. What is the NHS number and why will my HIV clinic ask if they can use it?

A. Everyone who uses the NHS has a unique NHS number for identification, consisting of 10 digits. It is used on your patient records and in any NHS communications about your care to ensure that accurate records are kept and that you are not mistaken for anybody else.

In every part of the NHS, use of the NHS number is automatic – apart from the sexual health clinic and the HIV clinic. Your HIV clinic will ask you to agree that they can use the NHS number for your HIV clinic records.

They will ask to use it because this will mean your HIV clinic data can be included in the data extracted by the Health and Social Care Information Centre for care.data and in any other research you consent to – this will help us get a better picture of the quality of treatment and care for people with HIV across the country and identify areas for improvement.

For more information on how your information is used for public health and research purposes:

[NHS leaflet on care.data: 'Better information means better care'](#)

[NHS Choices](#)

[The Health and Social Care Information Centre \(HSCIC\)](#)

Care.data patient information line: [0300 456 3531](tel:03004563531)

H. Making a complaint

Q. Can I complain if I think my confidential information has not been stored, used or shared correctly?

A. Yes you have a right to complain under the NHS Constitution, for that complaint to be efficiently and properly investigated, and to know the outcome of any investigation of your complaint.

You should not be victimised in any way if you complain about NHS services (in other words, complaining should not harm the quality of the NHS care you receive).

Q. How do I complain if I think my confidentiality has been breached by a healthcare worker?

A. You should first direct your complaint to the NHS organisation where you believe the breach took place, for example, the hospital or GP practice. Every NHS organisation has a complaints procedure and complaints manager and you should be able to find out more from their website or by telephoning them. You should complain as soon as possible after the relevant incident.

As an alternative to complaining directly to the local NHS organisation, you can complain to the body which commissions that NHS service. For a hospital it will usually be your local clinical commissioning group (CCG). For a GP practice it will be NHS England.

Q. What should I do if I do not think my complaint has been appropriately investigated by the local NHS body/commissioner?

A. If you are dissatisfied with the outcome of the local investigation of your complaint, you can complain to the Information Commissioner's Office (ICO) about a breach of confidentiality. You should raise the matter with the ICO within three months of your last meaningful contact with the local NHS organisation/commissioner you complained to.

Sometimes a complaint involves both confidentiality issues and also other aspects of care. For example, you may want to complain about the way a healthcare worker reacted to the fact that you have HIV, if they said something stigmatising, or discriminated against you by providing you with different or worse care than you would have otherwise received.

If you are unhappy with the local decision on your complaint, the Information Commissioner's Office can only look at confidentiality issues. Other matters need to be taken to the Parliamentary and Health Service Ombudsman. The Ombudsman can also look at a confidentiality complaint if the ICO decides not to investigate it.

Q. Can I get any help in making my complaint?

A. Yes, help is available. Every local council has to commission an independent NHS Complaints Advocacy Service who can help you make a complaint (whether in relation to hospital care, GPs, dentists or any other part of the NHS). Ring your local council's Customer Services Department to find out who your local NHS Complaints Advocacy Service is, or ask your local Patient Advisory and Liaison Service (PALS) for the information (see below). Every hospital also has a PALS. They offer confidential help, advice and support for hospital patients, including around hospital complaints. Your hospital website will have information on how to contact your local PALS and you can also search for them via the NHS Choices website (see for more information).

The NHS Choices website has useful information on 'Making a complaint - The NHS complaints procedure' and the website of the Information Commissioner's Office has a section on 'Raising a concern with an organisation' with very useful tips on how to complain appropriately and effectively.

For more information on how to complain:

[NHS Choices](#) on how to complain (includes contact details for CCGs, PALS and the Parliamentary and Health Service Ombudsman)

Contact details for [NHS England](#)

[Information Commissioner's Office](#) for advice on 'Raising a concern with an organisation'

I. Further information and support

For further support and advice about confidentiality and any other concerns you may have, you may want to contact your local HIV organisation. You can find your local HIV organisation [here](#).

If you want to find out more about any of the issues in this guide, you may find these resources useful:

[Life with HIV](#)

NAT (National AIDS Trust) 2014 [‘HIV Patient Information and NHS Confidentiality’](#)

Health and Social Care Information Centre (HSCIC) 2013 [‘A guide to confidentiality in health and social care’](#)

To order hard copies of this guide, please visit:

[NAT's publications page](#)

“

You have a right to complain under the NHS Constitution, for your complaint to be efficiently and properly investigated, and to know the outcome of any investigation of your complaint. You should not be victimised in any way if you complain about NHS services ”



TRANSFORMING
THE UK'S
RESPONSE
TO HIV



NAT is the UK's leading charity dedicated to transforming society's response to HIV.

We provide fresh thinking, expertise and practical resources.

We champion the rights of people living with HIV and campaign for change.

www.nat.org.uk

British HIV Association
BHIVA

BHIVA (British HIV Association) is the leading UK association representing professionals in HIV care.

www.bhiva.org

New City Cloisters, 196 Old Street, London EC1V 9FR

T: +44 (0)20 7814 6767 F: +44 (0)20 7216 0111 E: info@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