

A policy report
January 2014



HIV Patient Information and NHS Confidentiality in England

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A Introduction

We are living through a time of immense change in how healthcare is organised and delivered. This is as true for how our medical information is handled as it is for commissioning arrangements and healthcare delivery. There is a renewed emphasis on the effective sharing of our medical information between different professionals responsible for our care, to ensure the care is as integrated and as safe as possible. There is also great interest in the potential our medical information holds for researchers, epidemiologists and commissioners. It can help them better understand health issues affecting the whole nation and particular parts of the country, the quality of health outcomes and care pathways, the impacts of specific drugs and the spread of disease. The increasing computerisation of records and the possibilities of information technology only add further momentum to this agenda.

At the same time as this emphasis on data sharing in healthcare, there is an equally strong focus on confidentiality within the NHS. There has always been a particular attention to confidentiality within sexual health services, but in recent years the wider NHS has also developed strong confidentiality systems, rules, principles and protocols, bolstered by legislation (for example the Data Protection Act 1998 and the Human Rights Act 1998).

How do we maintain a balance between the importance of sharing medical information and the importance of keeping it confidential? HIV status brings this question into particularly sharp relief. HIV remains unfortunately a stigmatised condition and one which understandably many people living with HIV are very wary and sensitive about sharing or disclosing widely. But with effective treatment now available people with HIV can live a normal lifespan and, especially as they get older, will need to access a wide range of services within the NHS, both GPs and hospital specialists, just like everyone else. Their HIV status and the medication they are taking will be relevant information which needs to be shared.

Background

A number of factors prompted NAT to undertake this project looking at 'HIV Patient Information and NHS Confidentiality'. There was of course the context described above which suggested a fresh look was needed at the issue. The Health and Social Care Act 2012 introduced new arrangements around the handling of personal confidential information in the NHS, and in particular the establishment of a new body, the Health and Social Care Information Centre (HSCIC). Also in 2012 the Government asked Dame Fiona Caldicott to chair an Information Governance Review, which looked at all aspects of handling confidential information in health and social care, which reported in March 2013. Another outcome of the Health and Social Care Act was that it brought an end to 'the VD Regulations', as they were known. These Regulations placed particularly stringent confidentiality requirements on sexual health services. In their absence, what, if any, additional protections should there be in the NHS for sexual health information?

One further key motive to investigate this issue was the consultation on the draft BHIVA (British


HIV Association) Standards of Care for People Living with HIV. In the consultation document, in relation to Standard 12 on 'Information for public health surveillance, commissioning, audit and research' was a proposal for the routine request to patients by HIV clinics for the use of their NHS number for the linking of data for secondary purposes such as research and commissioning. NAT raised concerns about the inclusion of this recommendation, not because we were necessarily opposed to the idea but because there was little knowledge amongst people with HIV and HIV organisations, including NAT, as to what the implications might be of the use of the NHS number in this way. We proposed instead a further and separate process to look into the issue, and to feed into any further revisions of the Standards in due course. In the final published

Methodology

NAT's project on 'HIV Patient Information and NHS Confidentiality' has been supported by BHIVA, both with a funding contribution and with a small group of HIV clinicians and researchers being brought together to advise on the project (see Annex). There are two outputs to emerge from the project - this policy report which reviews the relevant issues and makes recommendations, and also a resource for people living with HIV, endorsed by BHIVA, explaining how their personal confidential information is handled within the NHS.

The development of the policy report involved desk-based research and discussions with a wide range of healthcare professionals and experts. An initial briefing paper was drafted which formed the basis of discussions at an expert roundtable held in July 2013 (for participants see Annex). The roundtable discussion clarified some of the key themes and conclusions of this report. It also provided useful background for the next stage of the project, which was to gather views and experiences from people living with HIV.

An online survey was open for about four weeks for people living with HIV in England to complete and there were 245 respondents. We do not of course claim that survey respondents were necessarily representative of all people with HIV in their understanding and opinions - it is likely that the survey over-sampled people who had pre-existing views and concerns. Nevertheless it is precisely such concerns which an appropriate confidentiality system needs to address. Both the quantitative and qualitative data from the survey provide a useful insight into the range of opinion and experience amongst people living with HIV.



We also held two consultation meetings with people living with HIV, one in partnership with George House Trust in Manchester and one in partnership with Positively UK in London. In total 27 people attended and there was diversity in gender, ethnicity, sexuality and recency of diagnosis. In an attempt to compensate for the inevitable bias of the online survey's sampling, volunteers were invited to join the consultation meetings simply to assist NAT in a policy project, without initial information that it was about confidentiality issues.

There are a number of important issues around 'HIV Patient Information and NHS Confidentiality' which were beyond the scope of this particular project. This report looks only at England. The handling of patient information can only be understood within the specific legal and healthcare arrangements of a national system. The system in England is significantly different in a number of respects from those in Scotland, Wales and Northern Ireland. It would have been too complicated to attempt to cover all four different national systems in one project. We do, however, hope that key conclusions from this project can be applied more widely in the UK and we will look for opportunities to do so in the coming months.

There is now a welcome concern to improve integration of health and social care services. Both the Information Governance Review and the statutory functions of the HSCIC cover both health and social care. We do not, however, in this project look at HIV information and social care services. We know of significant concerns amongst many people with HIV about how their personal information is handled within social care¹ and do not believe standards are as yet comparable to those in the NHS. A separate and further piece of work is needed to look in detail at the handling of personal confidential medical information by social care services.

We do not in this report look at issues relating to carer or family access to someone's personal confidential information, or to issues relating to information about someone deceased.

This project only looks at personal confidential information on adults living with HIV. There are additional confidentiality issues relating to children and younger people which we could not in the time available bring within the scope of this project. Again, the issue is an important one and we trust further work will be done on it in the future.

¹ See NAT 'The impact of social care support for people living with HIV: the results of NAT's snapshot survey of healthcare professionals' June 2011 <http://www.nat.org.uk/media/Files/Publications/June-2011-The-impact-of-social-care-support-for-PLHIV.pdf>

B Patient Information And The NHS - The Basic Architecture

In this section we will describe some of the key elements in the 'architecture' of NHS confidentiality and data handling provisions. It is not meant to be an exhaustive account and readers are recommended to go to the website of the Health and Social Care Information Centre (HSCIC) for comprehensive and up-to-date information on these issues at www.hscic.gov.uk. There are a wide range of relevant documents around NHS confidentiality but the HSCIC is aiming in its recent and forthcoming key confidentiality documents to bring together all relevant information and be the first port of call for those who need to know how personal confidential information is handled in the NHS. For that reason, we have thought it best as far as possible to refer to HSCIC documents in this report.

The requirement to keep accurate records

All healthcare professionals have a duty to keep accurate medical records. For example, in 'Good Medical Practice' the General Medical Council tells doctors that 'Documents you make (including clinical records) to formally record your work must be clear, accurate and legible'. Clinical records should include:

- relevant clinical findings
- the decisions made and actions agreed, and who is making the decisions and agreeing the actions
- the information given to patients
- any drugs prescribed or other investigation or treatment
- who is making the record and when.²

The HSCIC states that 'A key part of the trust relationship is ensuring that the care record ... is complete, accurate and fit for purpose. Information is not safe if it is not accurate. It is the responsibility of each member of the team to ensure this'.³

This is an important principle to understand in relation to the recording of HIV status, treatment and medication in patient records. What is recorded in patient records is not for the patient to dictate or determine. The healthcare worker has professional and ethical responsibilities to record relevant information fully and accurately, above all for the benefit of the patient, but also to satisfy any possible further review that they acted appropriately in their clinical care.

²GMC 'Good Medical Practice' 2013 paras.19-21

³HSCIC 'A guide to confidentiality in health and Social Care' 2013 p.11. See also NHS 'Confidentiality: NHS Code of Practice' Nov 2003 Annex A

Patients' right to access their health records

The patient does, however, have a legal right to see their own healthcare records. This right has as its current legal basis the Data Protection Act 1998 (Part II Rights of data subjects and others) and is summarised in the NHS Constitution - 'You have the right of access to your own care records and to have any factual inaccuracies corrected'.⁴ So the patient can see and challenge records if they are thought to be inaccurate. Speaking to healthcare workers it also became clear that if a patient objects to the wording of a particular entry i.e. how something is phrased or put across, especially in relation to a sensitive condition such as HIV, most healthcare workers would make an effort to agree wording which whilst accurate was also something the patient was comfortable with.

The Information Governance Review called for less bureaucratic processes to facilitate access to one's own records, and an end to the charging of fees to see one's records. The Government has committed to provide patients with electronic access to their GP records by 2015, followed soon after by other healthcare records.⁵ In its response to the Information Governance Review, the Government re-stated this commitment.⁶

Electronic patient records allow sight not only of the content of patient records but also of the identities of all who have accessed them, because access for NHS staff to patient records is by a combination of personal swipecard and password. (Of course this would not include people who 'borrow' someone else's swipecard and password to access a record, or where a screen is not closed down or shielded properly and others see its contents - both of which are a breach of confidentiality rules). The Information Governance Review recommended that details should be made available to the patient of 'anyone and everyone who has accessed an individual's electronic personal confidential information'.⁷ The Government in its response to the review agreed with the general need for patients to have confidence in the safety and security of their records but fell short of agreeing with this specific recommendation, stating that an 'options analysis' would be commissioned to determine the best approach by April 2014.⁸

Looking forward, there is increasing interest in the use of personal health records 'owned' by patients themselves.

⁴NHS Constitution 2013

⁵See Information Governance Review March 2013 Chapter 2 'People's right to access information about themselves'

⁶Information: To Share or not to Share - Government response to the Caldicott Review' Sept 2013 para 2.3

⁷Information Governance Review March 2013 section 2.4

⁸Information: To Share or not to Share - Government response to the Caldicott Review' Sept 2013 para 2.5

Confidentiality of personal medical information - the legal and policy basis

There is a long-standing common law⁹ duty of confidentiality in relation to personal medical information, which can be summarised as follows: that information provided in confidence should be treated as such and not divulged to third parties. This fundamental principle has been extended and deepened through statute law, through regulatory requirements and through NHS policy and practice.

In addition to the common law duty itself, three key benchmarks are:

- the Data Protection Act 1998, including the Data Protection Principles, as found in Schedule 1 of the Act, further explained in a Guide from the Information Commissioner's Office;¹⁰
- the Caldicott Principles, as set out in 1997 in the first Caldicott Review¹¹ and then added to with a further final principle as a result of the more recent Information Governance Review;¹²
- and the five Confidentiality Rules set out by the HSCIC in 'A guide to confidentiality in health and social care.'¹³ The HSCIC is also currently preparing a Code on Confidentiality. Both the published HSCIC Guide and the forthcoming Code have legal force in that the Health and Social Care Act 2012 requires health and social care bodies to have regard to the Guide and the Code.

The Caldicott Principles have since 1997 been an important driver of increased NHS sensitivity to confidentiality considerations. Every NHS organisation, including individual GP practices, must have a Caldicott Guardian or Caldicott Lead to ensure compliance with the Caldicott Principles.

Healthcare professionals are required to uphold certain standards of confidentiality as part of their regulatory requirements. The HSCIC provides a full list of such regulatory bodies, but examples include the General Medical Council for doctors and the Nursing and Midwifery Council for nurses and midwives.¹⁴ These professional confidentiality standards are consistent with the requirements of the NHS and the HSCIC, and may in some instances make additional confidentiality requirements. If these standards are not met the healthcare professional risks being disciplined and struck off their professional register. This would mean they can no longer practice. Non-regulated administrative and managerial staff in healthcare bodies have equivalent confidentiality obligations as part of their NHS contracts of employment (and indeed contracts for regulated NHS staff also contain these confidentiality requirements).

Other important components of NHS confidentiality requirements to mention briefly include - the Human Rights Act 1998, and Article 8 of the European Convention of Human Rights. Both the Act and the Convention provide a qualified right to a private life; administrative law which requires public bodies to handle information in accordance with the purpose for which they have been created; and the NHS Constitution, revised in 2013, which contains rights and pledges relating to 'Respect, consent and confidentiality', and which all NHS bodies are required by law to take account of.¹⁵

Confidentiality of personal medical information - some key concepts

In this section we highlight some aspects of confidentiality which are particularly relevant to the HIV-specific issues we will go on to address later in this report. Readers are referred to the websites of the HSCIC and the Information Commissioner's Office for more detailed and comprehensive information.

Use confidential information only when there is a specific and lawful reason to do so

The first Caldicott Principle is 'Justify the purpose' - any use of confidential information 'should be clearly defined, scrutinised and documented'. The second Data Protection Principle of the 1998 Act states that 'Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or purposes'.

Use confidential information only when it is necessary to do so

Only use confidential information if the purpose cannot be achieved by anonymising or aggregating the information so as to hide the identity of the individual concerned. The second Caldicott Principle states 'Don't use personal confidential data unless it is absolutely necessary' and the third Principle states 'Use the minimum necessary personal confidential data. The fourth principle states 'Access to personal confidential data should be on a strict need-to-know basis'. All three Principles underline the absolute requirement of necessity for any use and sharing of, or access to, confidential health information.

Consent of the patient is necessary for the use and handling of their personal confidential information – explicit consent or implied consent

When a patient shares their personal health information with a healthcare professional this is done under an expectation that the information is kept confidential and not shared with anyone else. Of course this duty of confidentiality can be overridden when the patient consents to the healthcare professional sharing that information with others.

There are two sorts of consent - explicit consent and implied consent. The HSCIC defines consent as “the approval or agreement for something to happen after consideration”.¹⁶ They go on to state, ‘Explicit consent is unmistakable. It can be given in writing or verbally, or conveyed through another form of communication such as signing’.

The HSCIC explains that ‘Implied consent is applicable only within the context of direct care of individuals. It refers to instances where the consent of the individual patient can be implied without having to make any positive action, such as giving their verbal agreement for a specific aspect of sharing information to proceed. Examples of the use of implied consent include doctors and nurses sharing personal confidential information data during handovers without asking for the patient’s consent’.¹⁷

The concept of implied consent has proved to be an important one when we discussed confidentiality issues with people living with HIV. It is assumed that the patient is happy for their relevant personal confidential information to be shared amongst those who are part of the team or teams providing the patient with direct care. This includes both sharing within a care team and also between care teams (for example, when a referral is made).

Sharing with the direct care team

Implied consent is assumed for the sharing of personal confidential information amongst those in the team providing direct care to the patient. This is not only sharing information within a particular team (e.g in the HIV clinic) but also across different teams, for example when a referral is made from an HIV clinic or GP to a hospital specialty. Administrative staff who are members of a direct care team are amongst those for whom implied consent is assumed (see further below). The rationale for this approach is neatly summed up by the HSCIC, ‘Confidential information about an individual must not leak outside the care team, but it must be shared within it in order to provide a seamless, integrated service’.

Right to refuse consent to sharing of information with those providing care

Whilst implied consent is assumed for sharing of personal confidential information within the direct care team, individuals should generally ‘be informed about who will see their confidential information. Without such advice they may not be aware of the wide range of staff who are part of the direct care team’.¹⁸ The individual can explicitly refuse consent to the sharing of their information with someone providing them with direct care and this decision ‘should be

¹⁶HSCIC ‘A guide to confidentiality in health and social care: references’ September 2013 Section 2 p.7

¹⁷ibid. pp.7-8

¹⁸HSCIC ‘A guide to confidentiality in health and social care’ 2013 p.13

respected'.¹⁹ In some instances staff may believe that the item of confidential information is essential for the safe provision of direct care. In such cases 'staff should explain that failure to disclose that information may compromise the individual's care'. The HSCIC does go on to say that 'In some exceptional cases, an individual's request not to share confidential information within the care team may effectively mean that care cannot be provided. The individual's choice to refuse to share confidential information about them in this way is tantamount to refusal of care'.²⁰

Patients should know how their personal confidential information is used

You cannot consent to the use of information you know nothing about. The HSCIC Guide on confidentiality provides a helpful and extended definition of consent:

'Consent is the approval or agreement for something to happen after consideration. For consent to be legally valid, the individual must be informed, must have the capacity to make the decision in question and must give consent voluntarily. This means individuals should know and understand how their information is to be used and shared (there should be 'no surprises') and they should understand the implications of their decision, particularly where refusing to allow information to be shared is likely to affect the care they receive. This applies to both explicit and implied consent.'²¹

It states:

'Unless those patients and service users understand how confidential information about them will be used and who will get to see it, they cannot be considered to be fully informed when they consent to treatment and care.'²²

¹⁹ibid. p.13

²⁰ibid. p.14

²¹HSCIC 'A guide to confidentiality in health and social care: references' September 2013 Section 2

²²HSCIC 'A guide to confidentiality in health and social care' 2013 pp. 7-8 ²¹HSCIC 'A guide to confidentiality in health and social care: references' September 2013 Section 2

Third party requests to GPs - insurance, employers, benefits and solicitors

Insurance reports or reports to employers are the main outflow of information from GPs to non-NHS third parties.²³ An insurance company will send to the GP a signed consent form from the patient agreeing to the release of the information (the GP practice should have a record of the patient's signature). The request for information will also say whether the patient wishes to see the information before it is sent out (we were told this is very rare) plus further guidance (for example not including negative HIV tests). Similarly for employers' requests for information, it is expected that the GP will satisfy themselves that the patient understands what is involved in the disclosure, has consented to the disclosure and will offer to show the patient, or give them a copy of, any report they write about them.²⁴

If a patient refuses consent the information should not be sent (apart from where disclosure is required by law or can be justified in the public interest - see below).

Whilst in the past the doctor would write a letter and include relevant information, the advent of the summary record means it is now often easier to send that - which may well mean that processes have become laxer and more information than is strictly necessary may be communicated. Issues around the sending of 'whole records' are picked up in the Information Governance Review. Guidance from the General Medical Council makes clear that only information relevant to the request should be disclosed 'so you should not usually disclose the whole record'.²⁵ Exceptions to this are some benefits claims and litigation where solicitors may sometimes ask for, and have the right to, the whole record of someone in, for example, negligence or compensation claims.

Just as the GP should not include irrelevant information, she or he should not leave out information which is relevant.

²³See 'Medical Information and Insurance' Joint Guidelines from the British Medical Association and the Association of British Insurers March 2010, and 'Confidentiality: disclosing information for insurance, employment and similar purposes' General Medical Council Sept 2009

²⁴General Medical Council 'Confidentiality: disclosing information for insurance, employment and similar purposes' September 2009

²⁵ibid.

Justification for non-consensual disclosure

There are circumstances where disclosure of personal confidential information is required or is permissible even without patient consent. This may involve a legal obligation to disclose, for example in response to a court order or on the basis of legislation such as that requiring the notification of certain infectious diseases (HIV is not a statutorily notifiable infectious disease).

It can also involve a permission to disclose without consent when the clinician believes there is an overriding public interest to do so which trumps the common law duty of confidentiality. The General Medical Council provides detailed advice in this area.²⁶ Such cases are expected to be exceptional and in most instances there should still first be an attempt to secure patient consent. Common public interest considerations include the prevention, detection or prosecution of serious crime, or to prevent the spread or reduce risk from serious communicable disease.

For people living with HIV it is this latter context which may be most relevant since guidance does allow the clinician to disclose, without patient consent, to a current or former sexual partner of someone diagnosed with HIV that they may be at risk.²⁷ It is important to note this is permissive, not mandatory - in other words the clinician can override consent but is not obliged to do so. It is possible that the clinician deems the risk of harm to the patient, or to confidence in the confidentiality of the clinic, to be more significant than concerns about sexual partners. It would also be expected that such non-consensual partner notification would be a last resort after extended and intensive efforts to secure the patient's consent.

²⁶General Medical Council 'Confidentiality' 2009 paras.36-56

²⁷General Medical Council 'Confidentiality: disclosing information about serious communicable diseases' September 2009

C HIV Patient Information and NHS Confidentiality

In this section we discuss some of the main issues which have emerged in discussion with experts, both one-to-one and at our roundtable, and with people living with HIV in our two consultation meetings and via our online survey.

The NAT Online Survey – characteristics of respondents

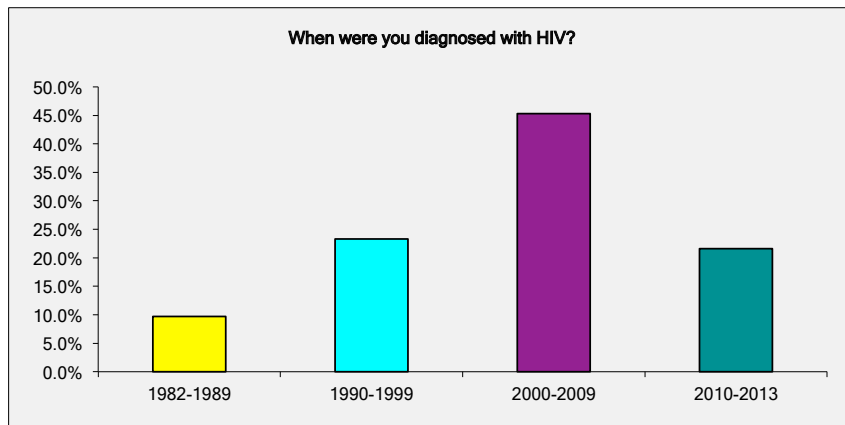
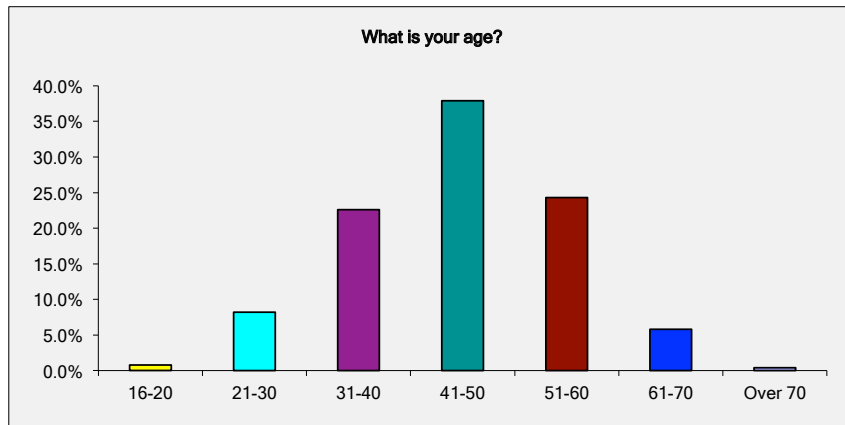
We received 245 responses to our online survey. Please note that percentages may not add up to 100% due to rounding and missing data.

71% of respondents were male and 28% female. 34% identified as straight, 59% as gay, 4% as bisexual and the remainder either as 'Other' or preferred not to say.

Most respondents were aged between 31 and 60, with 23% between 31 and 40, 38% between 41 and 50, and 24% between 51 and 60.

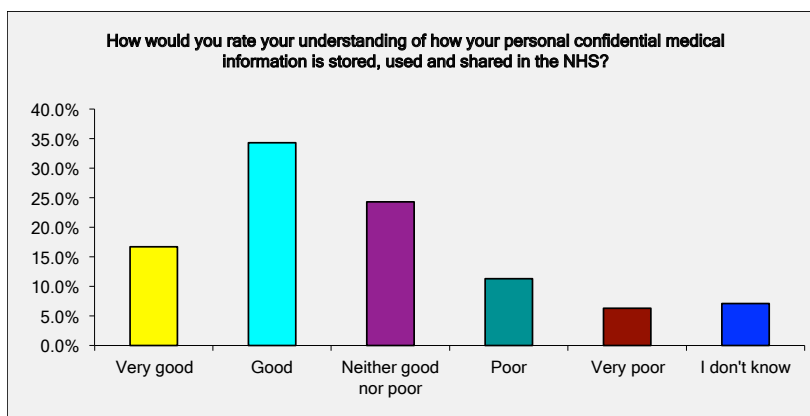
70% said they were white, 17% black African, 2.5% black Caribbean, 1% Asian and the remainder identified as mixed ethnicity's, 'other' or 'preferred not to say'.

There was a good spread in response to the question of when the respondent was diagnosed. 69% of respondents had been diagnosed since 2000.



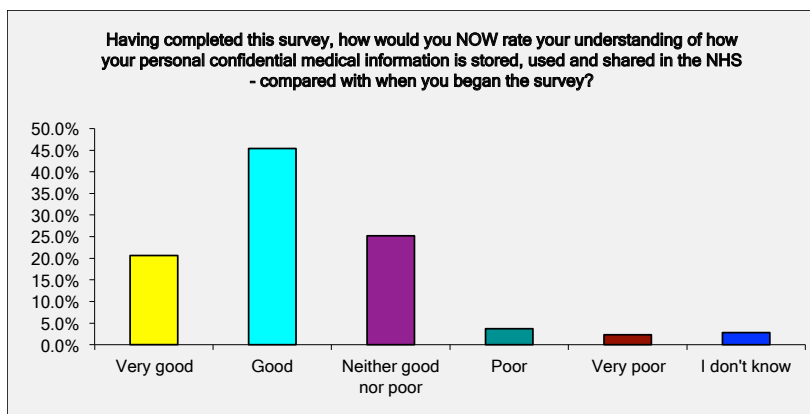
67% said they lived in a city, 24% in a town and 7% in a rural area. 98% were being seen by an HIV clinic for care, and 90% were currently on anti-retroviral medication. 99% of respondents were registered with a GP and 91% had disclosed their HIV status to their GP (only 20 respondents had not done so). This last statistic is interesting - if we take disclosure of HIV status to one's GP as a proxy for a degree of comfort in sharing personal confidential information, it suggests that the survey did not disproportionately recruit people who were especially averse to sharing their HIV status with healthcare professionals outside the HIV clinic.

We should note, however, that survey respondents were not in some important aspects representative of the demographic diversity of people living with HIV. For example, we know that 34% of people being seen for HIV care are of black African ethnicity, as opposed to the 17% in our survey.



The first question in the survey was 'How would you rate your understanding of how your personal confidential medical information is stored, used and shared in the NHS?'. The second question was 'Having completed this survey, how would you NOW rate your understanding of how your personal confidential medical information is stored, used and shared in the NHS - compared with when you began the survey?'

17% said their understanding was very good, 34% said it was good, 24% said it was neither good nor poor, 11% poor, 6% very poor and 7% said they didn't know.



The HIV clinic patient record

Much of the survey involved providing the respondent with information about how NHS confidentiality works and asking whether the respondent was aware of the relevant fact before answering the survey. At the end of the survey we asked how they would now rate their understanding, and as the results demonstrate below, there was significant improvement. 21% said their understanding was now very good, 45% said good, 25% said it was neither good nor poor, 4% poor, 2% very poor and 3% didn't know.


Some respondents added comments showing their appreciation for the way the survey was also an educative tool for those participating.

The HIV clinic's patient record is of course at the heart of any discussion as to how the personal confidential information of someone living with HIV is handled and shared. Once you have been diagnosed with HIV and begin receiving HIV treatment and care at a specialist clinic, a record of that care will be created. Who has access to that record and with whom is it routinely shared outside the HIV clinic?

The answer is not straightforward, and reflects the particular history of HIV care in the UK and the fact that we are currently in a time of transition in how such data is stored and handled in the NHS.

Most HIV treatment and care has historically been provided within the Genito-Urinary (GU) specialty. Sexual health clinics, in which GU medicine is delivered, has some of the most longstanding confidentiality provisions in the NHS, under what are commonly known as the 'VD Regs' ('Venereal Disease Regulations'). More accurately they are, in their most recent incarnations, The National Health Service (Venereal Disease) Regulations 1974 and The NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000. There has been debate as to what these Regulations actually required and whether they have been interpreted correctly over the years. But in practice the impact of the VD Regs has been that sexual health clinic records have been kept separate from the rest of the NHS records system, including, for example, from the record of the wider hospital trust to which the sexual health clinic belongs. This is significant, as most hospital records are now incorporated into trust-wide records. The VD Regs have also meant that the explicit consent of the patient is required before the sharing of any information from the sexual health clinic record with anyone else, including any other healthcare worker outside the sexual health clinic (putting aside non-consensual disclosure in the public interest).

The VD Regs lapsed in 2013 and we will discuss below the future of sexual health clinic records



and the need for ongoing additional protections for such sensitive information. It is important to understand that HIV care has historically sat within the GU specialty, and therefore delivered within the sexual health clinic, to understand how it is still sometimes the case that HIV care records are kept separate from the general records system of the hospital trust. One HIV doctor told us that his clinic had not gone down the road of records integration with their trust because the current system works well, as importantly it facilitates GU/HIV integration. The doctor also said that they would not want to integrate with the hospital-wide records system without extensive patient consultation. Most patients, he said, are happy to disclose their HIV status to their GP which ensures drug-drug interactions are avoided.

More frequently doctors told us that a process was underway, or had already taken place, to integrate the HIV patient record with that of the wider hospital trust. Quite what integration involves may vary. One expert said that historical confidentiality concerns may not be the main reason for continuing separate records, 'it is about having a tailored, clinically appropriate database that records HIV-specific information in a meaningful way and can be easily queried, e.g to produce SOPHID/HARS returns or a list of patients with detectable viral load. Hospitals have specific patient databases for many other conditions for the same reason, i.e clinical relevance'. Some HIV clinics will effectively create a hospital trust-wide record of the patient's HIV status as soon as they request an investigation from another part of the hospital and include the HIV status in the note.

Others will with the patient's permission proactively create a hospital-wide record in addition to the more detailed clinic record. Two HIV clinicians told us that whilst their clinic record remained separate from the hospital records system, when a patient agreed to a letter going to their GP informing the GP of the patient's HIV status, a letter was also generated for the hospital record to ensure the hospital record also included the fact the patient had HIV, rather like a local summary care record (see below). This would mean that were, for example, the individual to attend A&E unconscious or incoherent, accurate diagnosis can be supported and drug-drug interactions avoided.

There may also be systems where HIV clinic information is fully integrated into the hospital records. Whilst most HIV care is provided from within the GU specialty, in some parts of the country there is a tradition of HIV treatment and care being provided by Infectious Disease (ID) specialists. A number of ID clinicians told us that HIV clinic records were routinely integrated within the wider hospital records system.

Conclusion

There is inconsistent practice across the country on the degree and nature of integration of HIV clinic records with that of the wider hospital trust. The trend seems to be towards such integration – which means most patients with HIV should expect the hospital trust within which their HIV clinic is based also to have a record of their HIV positive status, simply as a result of their receiving care at that HIV clinic.

A number of people at our roundtable argued for a consistent approach from all HIV clinics on records integration.


It should be stressed that one's HIV positive status being on the hospital record system should not mean anyone inappropriately accessing that information. A healthcare worker should only look up your patient record if they have a legitimate reason to do so as someone providing you with direct care.

Survey respondents were asked 'Are your HIV patient records separate from the other patient records of the hospital where your HIV clinic is based?' 39% thought they were separate, 12% thought they were part of the hospital records system, and 49% said they did not know. These answers do not necessarily, of course, represent the actual state of affairs but rather the understanding of patients.

Recommendation: HIV clinics should inform patients of how information on their HIV status is stored within clinic and trust records systems, providing assurance around confidentiality protocols and protections.

The NHS number and the patient record

If the HIV clinic record is linked to the wider records system of its hospital trust then the patient will also have their NHS number linked to that hospital-wide record. The NHS number is the one unique patient identifier within the NHS, and consists of ten digits. It is used on all NHS records routinely, apart currently from GU/HIV clinics, and is considered an essential safeguard in matching patients accurately to their records and in ensuring communications between settings



and providers are referring to the same patient (something not certain from the use of other identifiers such as name or date of birth). It is thus also an element in patient safety when it comes to contra-indications in prescribing, allergies and medical history.

The NHS number is one of the pieces of information held nationally on the Personal Demographics Service (PDS) along with other data including name, date and place of birth, address, and GP.²⁸ Most healthcare workers have access to the PDS and thus knowing someone's NHS number will enable the healthcare worker to know this linked information on the PDS and thus the individual's identity. Of course access to the PDS has to be justifiable. There was some variance at the roundtable as to what proportion of healthcare workers in different clinics were thought to have access to the PDS.

Whenever a GP communicates with a hospital about a patient with HIV the NHS number will be used as an identifier. The hospital will generate a record about the patient – either creating a new record for the hospital trust system if the patient has never received care there before, or adding further detail to the currently existing record. The same of course is true when an HIV clinic communicates with another part of the NHS – the HIV clinic may not use the NHS number, but the new record created about the patient by the hospital will do so.

One GP told us – ‘once information gets ‘out there’ in the NHS it does tend to become pervasive in the records system’. Once, for example, you have had a referral to a particular hospital trust and your HIV status has been included in the referral information, your HIV status will then be permanently on that hospital trust record system, linked to your NHS number. Anyone providing you with care (for example in A&E) at that trust in the future will open your record and see the information about your HIV positive status, whether or not you or your doctor have disclosed that information for this new presentation/referral. This brings many benefits, above all that you can receive the most appropriate care and medication. But patients may not be aware of how their HIV status is held at a trust level permanently once a referral is made to a particular specialty or clinic.

There were comments at our expert roundtable about the trend towards amalgamation of hospital trusts, as well as of GU and CASH (contraception and sexual health) services. Records systems are also combined and integrated as a result. So the record with one's HIV status is on a system accessible by a large number of healthcare professionals.

One risk with use of the NHS number is communications occurring because they are routine

practice but which are not consented to by the patient with HIV. In the course of this project we have heard of two occasions where laboratories have informed a patient's GP of a result where the patient had not disclosed their status to their GP, and of the same happening to people referred from their HIV clinic to another secondary care specialty.

The continuing separation of GU clinic records and the patient with HIV

As mentioned above, the VD Regs lapsed in 2013 as a result of the NHS reforms brought in by the Health and Social Care Act 2012. There are no plans by the Government to bring in identical legal requirements for the new healthcare organisations which have been created. BASHH (the British Association of Sexual Health and HIV), the clinical professional body for GU clinicians, has made clear how important it is for there to be a continuing requirement that GU records are kept confidential and separate from other NHS records.

This position was overwhelmingly supported in a survey BASHH undertook of their GU patients (4,627 respondents). Without such a mandatory requirement, hospital trusts, it is feared, will be unwilling to continue to invest in the additional resources necessary to maintain a separate GU records system. In a letter to the Department of Health of 19 September 2013, BASHH states, 'The current regulations and Directions provide GUM clinics, over and above the NHS Code of Practice on Confidentiality and Information Governance, with a guarantee of anonymity rather than simply confidentiality'. To end such additional protections would be to deter people from accessing sexual health clinic services. Amongst other things, this would seriously harm access to HIV testing and thus undermine attempts to reduce the high rates of late HIV diagnosis in the UK.

Recommendation: NAT strongly supports an ongoing mandatory requirement for GU records to be kept separate from the rest of the NHS records system and for people to be able to access GU services anonymously if they wish to.

It seems that an alternative solution to new legal regulations has been found to achieve this – it is proposed that the forthcoming Health and Social Care Centre Code on Confidentiality include distinct and additional provisions around sexual health information and sexual health clinics. This Code is drawn up under section 263 of the Health and Social Care Act 2012 and thus has legal force – any body or person providing health or adult social care services must 'have regard to the code' when exercising their relevant functions. This seems to be an acceptable way to continue to provide legal underpinning for a separate GU records system.

BASHH in its letter to the Department of Health made clear that it contrasted sexual health clinic

records with the care records of people living with HIV - 'a chronic life-long condition', where a number of doctors are often involved in their care and there can be a risk of harmful drug interactions. 'Consequently, BASHH is in complete agreement with the principle that people living with HIV should have all their care provision, and investigations performed, using their name and NHS number'.

This seems a clinically sensible position to take to ensure the safety and high quality of care of the patient with HIV. But some further points should be made. First, the GU clinic will have an ongoing responsibility for the sexual health of the patient living with HIV. BHIVA Guidelines recommend the annual offer of sexual health screen to all patients with HIV (and additional screens or tests dependent on risk or symptoms).²⁹ The HIV clinic will want to have an audit trail in its records of the offer and uptake of sexual health screening as recommended by BHIVA and good clinical practice.

Recommendation: The patient with HIV has the same right as any other patient for the outcome of his or her sexual health screen or test, and any consultation, treatment and care received for STIs at a sexual health clinic, to be kept separate from their other NHS records. That information should be on the patient's GU record but not on the HIV clinic's record of their HIV treatment and care. The HIV clinic record should only include whether appropriate sexual health screens and tests were offered and taken up.

At our expert roundtable on this issue there seemed consensus that keeping the GU records of the HIV positive patient separate from their HIV clinic records was usual practice.

Recommendation: It would be useful for BASHH to make clear and explicit that the GU records of patients with HIV should be kept separate from their HIV clinic record, and ensure via survey or audit that this is in fact the case consistently across the country.

Secondly, whilst there is a strong case, once someone is diagnosed with HIV, for their HIV treatment and care not to enjoy the same additional confidentiality protections in law as other GU information, this should not blind us to the real sensitivity of HIV positive status and the fact that stigma and discrimination still exist. Indeed it is in healthcare settings that discrimination is most frequently reported.³⁰ The vast majority of people with HIV in the UK acquired their HIV sexually - and thus their HIV status is in that sense sexual health information. The HSCIC reminds us that 'it

²⁹BHIVA 'Guidelines for the routine investigation and monitoring of adult HIV-1 infected individuals' 2011

³¹HSCIC 'A guide to confidentiality in health and social care' 2013 p.15

³⁰Elford J et al 'HIV-Related Discrimination Reported by People Living with HIV in London, UK' AIDS and Behavior 2008 12:255-264

is likely that individuals will regard matters relating to their mental and sexual health as particularly sensitive'.³¹ The sensitivity of GU 'culture' around HIV status must apply also in the HIV clinic. And it does appear to do so – HIV clinics do seem routinely to ask for explicit consent for the HIV diagnosis to be communicated to the patient's GP for example, and respect the wishes of those who refuse consent.

Given the sensitivity of HIV positive status, the HIV clinic seems the appropriate place to provide the patient with a clear explanation about the use of personal confidential information and how confidentiality works in the NHS. With 50% of our survey respondents unclear as to whether or not their HIV clinic record is separate from that of the hospital trust, this is clearly not happening at the moment as it should.

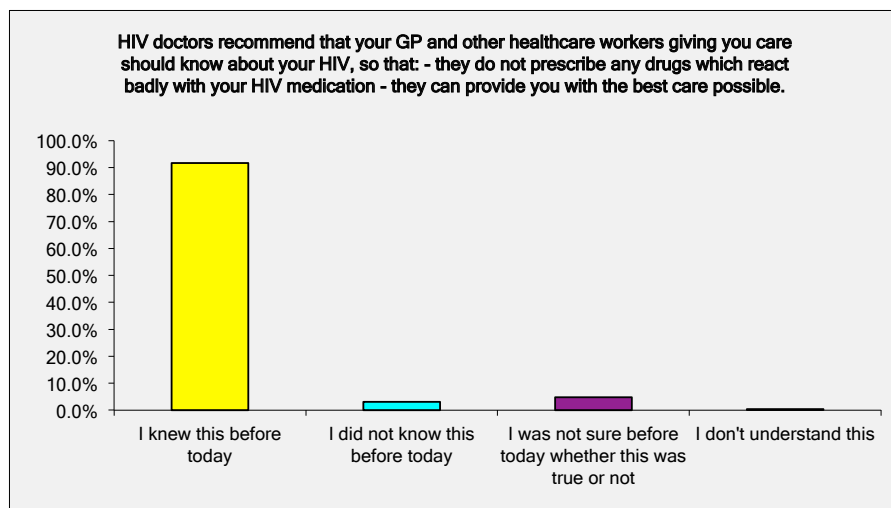
Recommendation: BHIVA should revise the 'Standards of Care for People Living with HIV' to include a Quality Statement which states that all HIV clinics must ensure that the patient is aware of how their information is stored, handled and shared. There should be constant attention to make sure there are 'no surprises' for the patient living with HIV as to how their personal confidential information is used, and that there is genuine consent to that use.

Sharing information on HIV status to support high quality care

The Information Governance Review added one further principle to the Caldicott Principles which underpin how the NHS handles confidential information: 'The duty to share information can be as important as the duty to protect confidentiality'. The Review emphasises that confidentiality provisions are not meant to undermine appropriate sharing of information to ensure good clinical care. There has been a similar rebalancing of emphasis recently from within the HIV sector with much more emphasis on the importance of GPs and other healthcare professionals knowing that the patient has HIV to ensure the best possible care and avoid drug-drug interactions.

This emphasis seems to be getting through to patients. NAT's survey asked whether people knew that 'HIV doctors recommend that your GP and other healthcare workers giving you care should know about your HIV - so that they do not prescribe any drugs which react badly with

your medication – they can provide you with the best care possible’. 92% of respondents knew this.



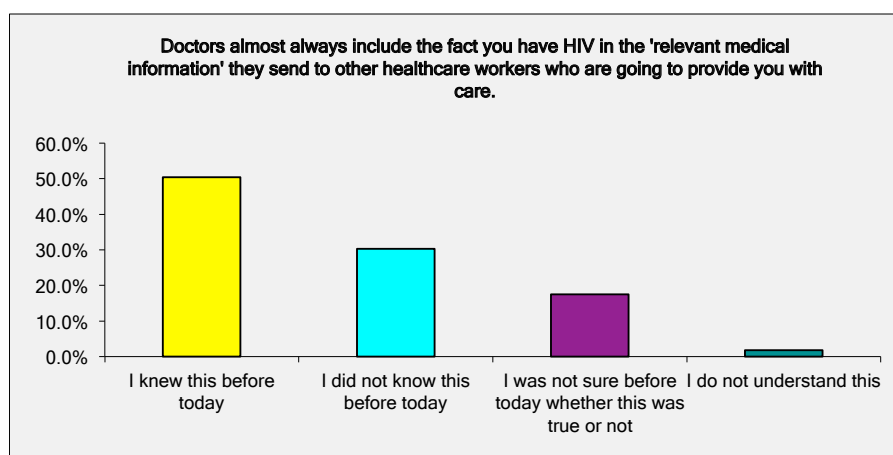
However, patients may not appreciate the extent to which doctors think that their HIV positive status should be shared with other healthcare workers giving them care. In discussions with clinicians it was clear that HIV would almost always be considered relevant information to share with another healthcare worker. This was because of possible drug interactions with antiretrovirals and also to ensure the best diagnosis and treatment for any condition or ailment. In effect almost any referral or other sharing of information in the NHS about the direct care of an HIV positive patient would include the fact that the patient had HIV and any HIV medication they are taking.

Whilst a majority of survey respondents were aware that their HIV status would almost always be considered relevant information to share, it was a significantly smaller percentage than those who knew that HIV doctors recommend the sharing of HIV status with GPs and other healthcare workers providing care. Only just over 50% of respondents knew that doctors would almost

always include HIV as relevant medical information to share, 30% did not know this, and 18% were unsure whether or not this was the case.

Conclusion

Whilst the theory of greater sharing of HIV status in healthcare seems to be known by most patients, the implications and extent of that sharing seem to be less widely understood.

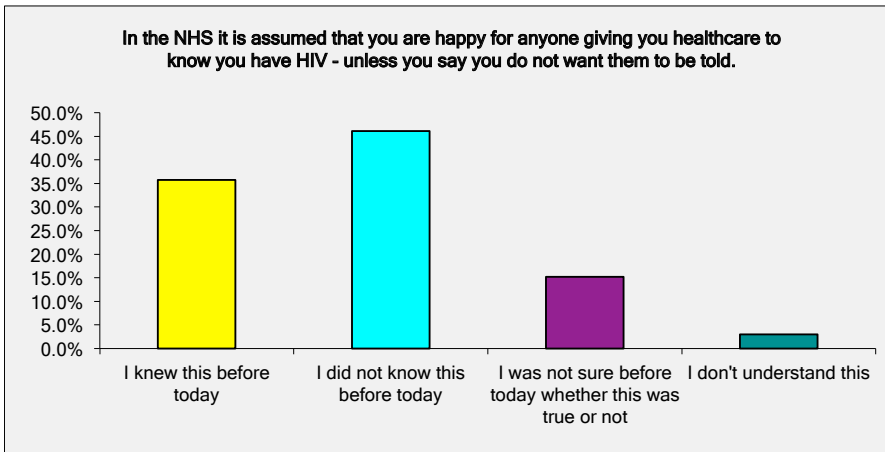


Implied consent

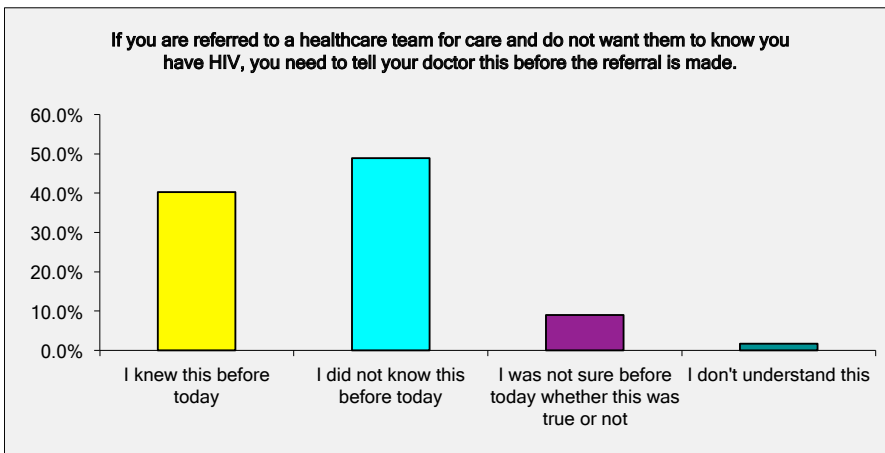
If HIV is considered relevant information for someone providing direct care to know, according to the principle of implied consent outlined previously, the clinician (for example a GP) would simply assume the patient was happy for HIV to be mentioned in the referral without asking for explicit agreement from the patient. 46% were unaware of the principle of implied consent, 36% were aware, and 15% were not sure.

Similarly large numbers (49%) were unaware that they needed to explicitly tell their doctor not to mention HIV in a referral if they did not want that healthcare team to know they had HIV, whilst 40% were aware, and 9% were not sure:

This was echoed in our two consultation group meetings where most people were unaware of the statements in the bar graphs below, and many were surprised. One participant said that they assumed all the NHS operated in the same way as the HIV clinic, always asking for explicit consent before sharing information with anywhere else in the NHS.



It is unclear the extent to which GPs and other clinicians rely on implied consent when sharing the HIV status of their patients with other healthcare workers who are to provide direct care, and the extent to which, given patient sensitivities, they check first or agree a process with their patients. We have heard of different practice and it no doubt varies not only by clinician but in relation to the different patients they see.



What is clear from our evidence is that only a minority of patients with HIV understand the concept of implied consent. Implied consent cannot exist if the concept is not understood. We do not know how often in the NHS implied consent is relied on in the absence

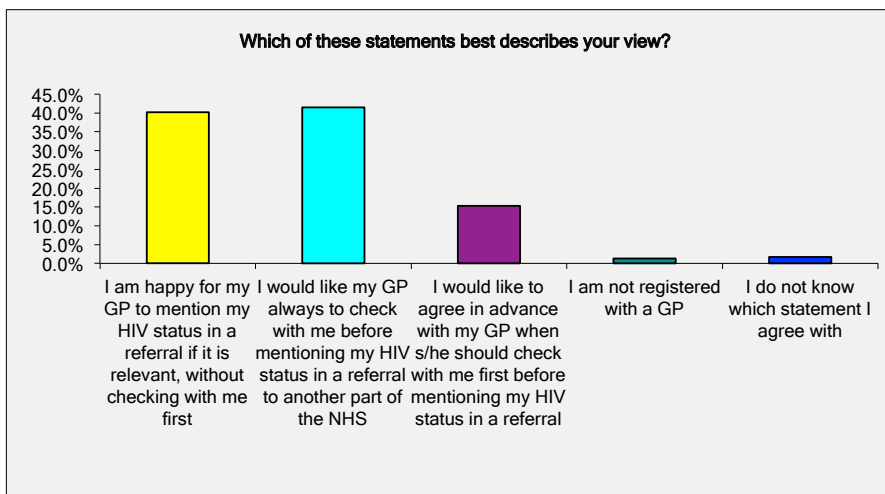
of genuine patient understanding, to share HIV status between different direct care teams – but the evidence suggests it may well happen frequently.

Of course where the HIV clinic itself makes a referral, the patient may well assume that their HIV status is included in the information shared – it will in any event be obvious given the source of the referral. It is not the same situation for GP referrals. In the survey, patients were asked a number of different statements about the GP referral process and consent and asked to state which statement best described their view.

I am happy for my GP to mention my HIV status in a referral if it is relevant, without checking with me first	40.17% 92
I would like my GP always to check with me before mentioning my HIV status in a referral to another part of the NHS	41.48% 95
I would like to agree in advance with my GP when s/he should check with me first before mentioning my HIV status in a referral	15.28% 35
I am not registered with a GP	1.31% 3
I do not know which statement I agree with	1.75% 4

Survey respondents were almost equally split between 40% who were happy for the GP to mention HIV in a referral without asking for consent and 41% who wanted the GP always to check with them before mentioning their HIV status in a referral. A further 15% wanted to agree some 'ground rules' with their GP as to when the GP should check and when they could simply go ahead and include HIV in their notes.

We heard from one or two clinicians the concern that ‘stoking’ patients’ concerns around confidentiality, and offering to check for their consent for every referral, would be unhelpful and burdensome, and not contribute to patient care. Whilst these concerns should be acknowledged, a paternalistic view that ‘the doctor knows best’, and that the patient



need not worry themselves, is not the way to meet those concerns. There are clear rights and expectations around explanation to patients about the use of their data, and when the purpose and value of sharing such information is talked through well, in almost all cases sensible arrangements can be agreed between doctor and patient. We suspect over time many of those who currently would like to be asked for consent for every referral will, as they experience the benefits of sharing such information, modify their expectations.

Recommendation: Both HIV clinicians and GPs need to have explicit discussions with their patients living with HIV on when their HIV status would be shared with other healthcare professionals, the benefits of doing so, how implied consent works, and any preferences as to how to involve the patient in that process.

Refusal of consent to share information in direct care

As has been stated previously, the patient retains a right to refuse consent to the sharing of information in direct care. It is important that the risks to the patient's safety are clearly explained, but if the patient continues to insist, then in almost all circumstances the patient's wishes must be respected. There could, however, be circumstances where the refusal for key information to be shared in effect constitutes a refusal of treatment. This was discussed at the expert roundtable. Whilst there was a consensus in favour of the position as outlined above and in official publications from the HSCIC, there was also some disquiet.

One concern raised was around risks to the healthcare worker undertaking 'exposure prone procedures' e.g certain surgical procedures. This echoed what one consultation group participant reported, that they had been told by an HIV consultant that if they refused consent to disclose to a surgeon there could be criminal charges (it was unclear who would be charged and with what). This is not in fact the case, but shows the confusion that exists around the law, confidentiality and risks of HIV transmission to healthcare workers.

Recommendation: Universal precautions are expected of all NHS staff and patients with HIV should not be pressurised inappropriately into sharing their HIV status on the basis of supposed risk of transmission to healthcare workers or inaccurate claims around legal liability.

It is also the case that in creating a health record where records are integrated in a trust-wide system, there is an inherent sharing of HIV status, even in the absence of a referral, with other healthcare workers in the trust who in the future provide care to that patient for other illnesses or conditions.

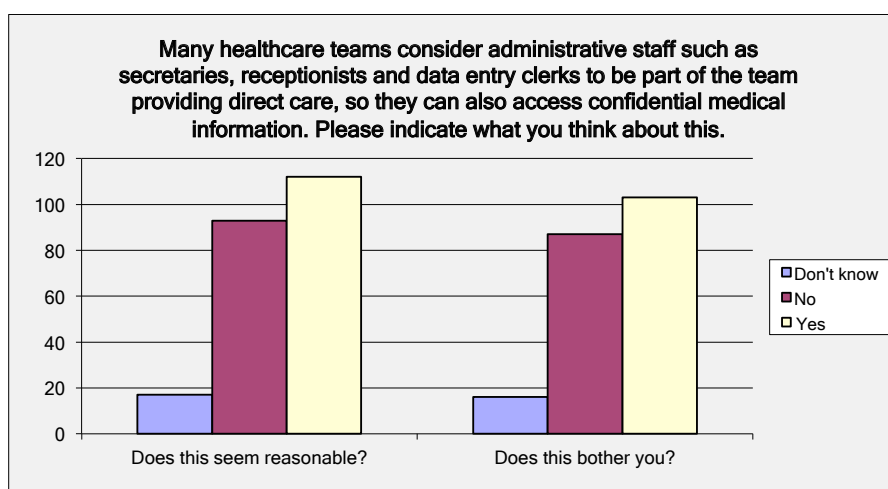
Conclusion

The consensus in discussion was that the right to refuse the sharing of information in direct care did not extend to a right to insist that a separate records system be established for an individual patient.


Administrative staff

One issue around the sharing of personal confidential information relates to the role of administrative staff (often termed ‘non-regulated staff’) and the access they have to such data. Such staff are not regulated professionals in the way that, for example, doctors and nurses are, but they are subject to the same contractual requirements around confidentiality as all other NHS staff.

In our survey we said, ‘Many healthcare teams consider administrative staff such as secretaries, receptionists and data entry clerks to be part of the team providing direct care, so they can also access confidential medical information’. Respondents were almost equally divided as to whether this seemed reasonable (50% yes / 42% no) and whether they were bothered by this fact (52% bothered / 42% not).



In the survey response comments there was quite a lot of disquiet about administrative staff access to personal confidential information. Twenty one separate comments questioned why such staff needed the access at all given they were not providing care directly to the patient. There were a number of concerns raised by respondents who lived in small towns or rural communities – ‘Since I live in a small town and my GP’s practice manager lives a few doors away from me, I do not wish non-medical staff at my GP practice to see my HIV status’. Some respondents also felt that administrative staff tended to be less professional, especially on confidentiality matters, and not trained to the same standard on the issue as regulated healthcare staff.



There were complaints both in our survey and at our consultation meetings of instances where there had been casual attitudes to confidentiality, for example receptionists had opened envelopes containing confidential medical reports at their desks or discussing HIV status in a public area.

At our consultation meetings most participants understood the need for some administrative staff to see patient records if they are part of the direct care team. One survey respondent said, 'there is no alternative. You cannot expect the healthcare team to do all the voluminous admin required'.

This last view was echoed at our expert roundtable and in discussion with individual clinicians where the consensus view was that NHS care could not function without such administrative staff accessing personal confidential information. For example, GP practices need data entry clerks to input letters about patients into electronic patient records.

Two important issues raised were the availability of sanctions against administrative staff who breach confidentiality; and the need to distinguish amongst different kinds of administrative staff when deciding whether access to personal confidential information should be permitted.

Some survey respondents in qualitative answers said that since administrative staff were not bound by professional ethics, repercussions for them, of confidentiality breaches were less serious. There is not the prospect of permanent disbarring from the profession you have trained for and worked in. At a consultation meeting someone said that dismissal seemed the only possible option. One point made was that whilst administrative staff had contractual obligations whilst employed by the NHS they took personal confidential information with them when they left an employer 'in their head'. Gossip after leaving an employer might in theory be a breach of the common law duty of confidentiality but the possibility of mounting a successful legal case would be slim.

Some people said that whilst they could understand medical secretaries and data entry clerks having access to personal confidential information, they did not see why hospital porters should know their HIV status (there were a couple of examples given where this had been the case, and NAT has come across others). The same question was raised about receptionists.

We investigated the potential of electronic records systems to limit what parts of a patient's record administrative staff could access, for example via 'sealed envelopes'. There seemed some use of differentiated records access - not so much in terms of what can be seen but more in terms of what can be done - for example, the record would not allow administrative staff to write a new prescription. Beyond that, we were told by a number of clinicians we spoke to that such envelopes did not function well and in any event were undesirable because it was necessary for administrative staff to see all of a patient record to ensure good quality care.

It is clear that the consensus view has moved on from even a few years ago and that the emphasis now from the NHS is on accepting that administrative staff are part of the direct care team, and may have full access to the patient's record, explaining this to patients, and ensuring confidentiality is maintained via NHS contracts, training and appropriate disciplining of staff who breach confidentiality requirements.

The Information Governance Review looked at the issue in some detail and found evidence 'that patients and the public did not always appreciate how many non-registered staff could be part of a person's healthcare team'.³² It made recommendations on the necessary conditions for such access which have since been adopted by the HSCIC and included in their Guide on Confidentiality. In all instances the non-regulated member of staff must be part of the direct care team and have in their terms and contractual obligations of employment 'an explicit duty of confidentiality as part of the contract with sanctions'. In addition the review set out a range of conditions any or all of which need to be met, such as management or supervision by a regulated appropriate professional, or patient consent.

In particular the Information Governance Review stated that such staff should be able to access '**a proportion** [our emphasis] of a patient or service user's personal and confidential data'. The HSCIC in its Guide on confidentiality stresses that rules on confidentiality and privacy still apply so 'only those who have a clear 'need to know' should have access to the relevant confidential information',³³ that 'only information that is relevant, necessary and proportionate should be shared' and that 'the extent of the information sharing is kept as limited as possible, consistent with achieving the clear purpose'.³⁴ They go on to say it is not acceptable to share non-relevant information from a care record within the direct care team 'where confidential information is stored in a way that makes it practicable to separate pieces of confidential information'.³⁵

³²Information Governance Review March 2013 para.3.7

³³HSCIC 'A guide to confidentiality in health and social care' p. 13

³⁴HSCIC 'A guide to confidentiality in health and social care' p. 14

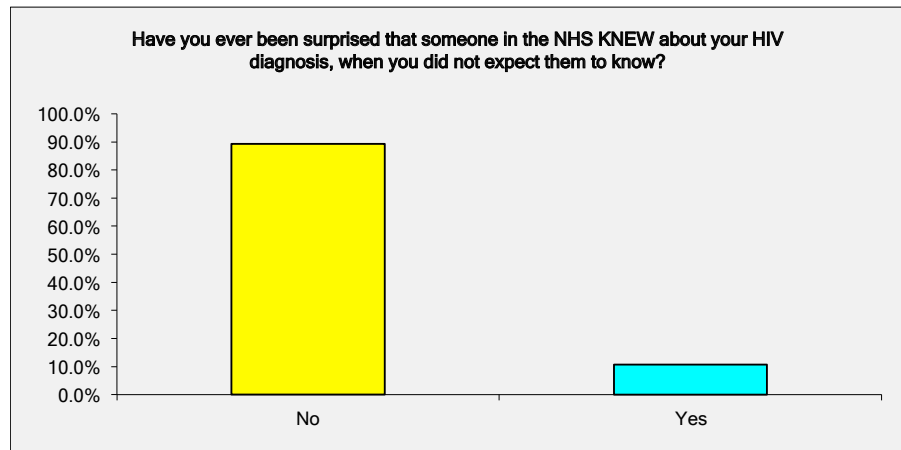
³⁵HSCIC 'A guide to confidentiality in health and social care' p. 15

Our project has unearthed considerable disquiet at the sharing of personal confidential information with administrative staff. This has on the whole not been an absolute refusal to countenance it - most people understand it may be necessary. But there is a view that not all administrative staff need access to such personal confidential data and those who do may not need to see all of a person's record. This is supported by official advice. It does not, however, seem to be supported by information technology, or if it could be this is not known about, nor in current practice.

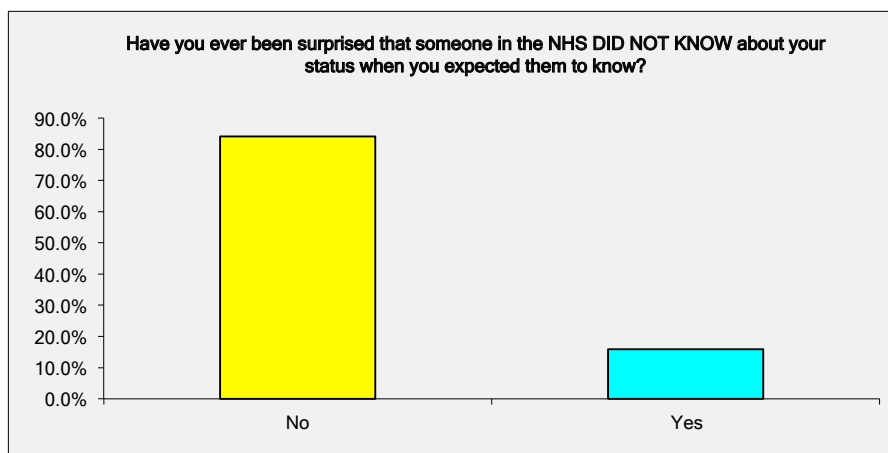
Recommendation: The HSCIC should commission more research on the current use and potential of sealed envelopes and other technologies to allow differentiated access to patient records, and provide advice on their website on relevant technologies and how to use them effectively. Further advice would be useful on practical ways to distinguish levels of access between different administrative staff so as to maintain confidentiality without compromising high quality care and appropriate sharing of information.

'No surprises' - informing patients about how their personal confidential information is used and shared

We asked respondents whether they had ever been surprised that someone in the NHS knew their status when they did not expect them to know - only 11% said they had been surprised that someone knew they had HIV:



It was more likely that respondents were surprised someone did not know their HIV status when they expected them to do so - 16% had been surprised that a healthcare worker did not know their HIV status when they expected them to.



In more detailed comments from survey respondents

there were a number of cases recorded of healthcare workers not knowing of the patient's HIV status after referral, sometimes because it appeared not to have been recorded and often because of cursory reading of notes by staff. There was mention of a particular problem with locums and temporary staff. Another problem mentioned a number of times was the failure of healthcare staff to use universal precautions and the patient with HIV feeling they had to disclose their status and remind them of the importance of such precautions. In some cases they were then berated for not having disclosed earlier, with claims that this put the healthcare worker at risk.

This echoes the conversations we had with people with HIV at our consultation meetings where there was an expectation that everyone providing them with healthcare should know they had HIV and frustration at healthcare workers who should have been told about the patient's HIV status but were not or did not look at notes properly. In some cases this had resulted in serious and dangerous failures in care, in others the annoyance of having to 'disclose' their HIV status afresh or repeatedly.

'On my part I am more concerned that it is not always passed on so that my GPs and other specialists are aware without me having to tell them again. I get tired of telling everyone every time I see a new GP or consultant.'

Survey respondent

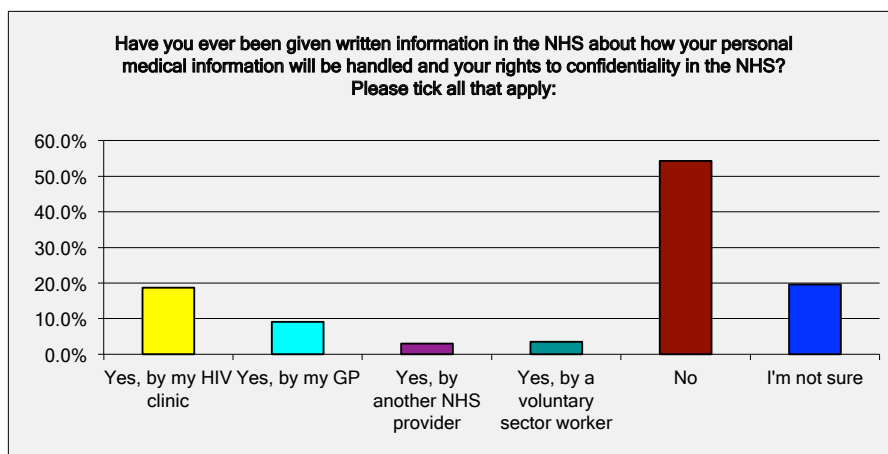
A number of people commented on the fact that disclosure of HIV status can mean better treatment, for example prioritisation.

Conclusion

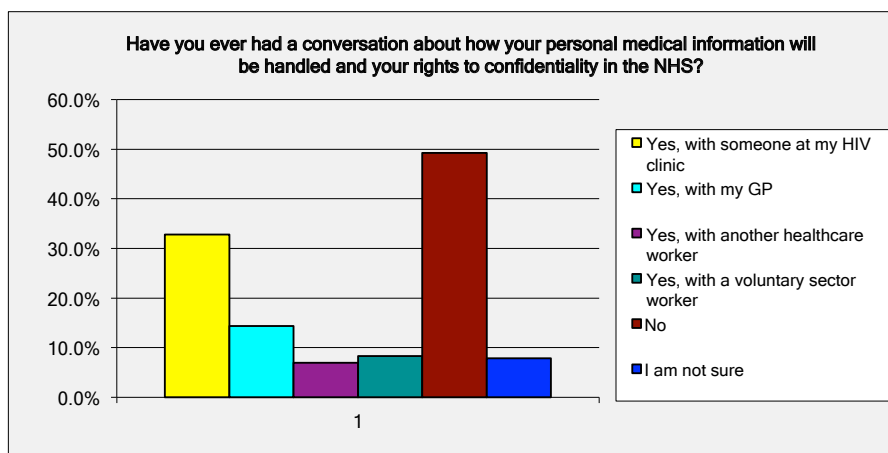
Although more work is needed to reduce further the numbers of people surprised at how their information is or is not shared, the survey results suggest there is not a major issue of distress amongst people with HIV at current confidentiality rules and processes within the NHS.

This is not necessarily because they have been well informed about those confidentiality processes, and in particular their right to consent or refuse consent. It may rather be because confidentiality processes simply reflect their common sense view as to how their information should be shared to ensure high quality treatment and care. That does not, however, meet legal requirements around information to patients as to how their personal confidential information is used.

We asked patients whether they had ever received written information about how their personal confidential information is handled and their confidentiality rights in the NHS. 54% said no and 20% were not sure. 18% had received written information from their HIV clinic. Of those who had received written information, 49% said it did not answer their questions, 29% said it did answer their questions and 21% said it partly answered their questions.



We then asked the same two questions in relation to a conversation on these issues. Again 49% had not had any such conversation, 33% had had a conversation with their HIV clinic and 14% with their GP. When those who had had such conversations were asked whether their questions were answered, 43% said no, 34% said yes and 23% said partly.



Hardly anyone at our consultation meetings had received either verbal or written explanation of how their information is handled in the NHS and their confidentiality rights.

Conclusion

It is clear some explanation of rights to confidentiality in the NHS is happening but not enough, and the explanation that does take place is not consistently meeting the information needs of patients.

There was enthusiasm from people with HIV at our consultation meetings for a resource available both in hard copy and electronically which could be accessed by people with HIV and be provided by clinics to explain the system. There was also a strong view that a published resource was not by itself sufficient but there should also be an opportunity to discuss these issues with an appropriate healthcare professional. Clinic patient forums were mentioned as another useful vehicle to inform people as to how their personal confidential information is handled.

At the expert roundtable there was worry amongst some clinicians that ‘excessive’ information could cause unnecessary disquiet or concern, and that it is not practical to explain all aspects of data sharing to patients. An appropriate degree of explanation is, however, a legal obligation and we believe it can be readily met by a combination of consistent written information supplemented by the offer of verbal explanation.

Recommendation: NAT will publish a written resource explaining how the personal confidential information of people with HIV is handled and shared in the NHS. We would urge all HIV clinics and GP practices to provide this resource, or comparable ones, to all their patients living with HIV and accompany it with verbal explanation and the offer to answer any questions. This is essential for there to be genuine consent to the use of their information.

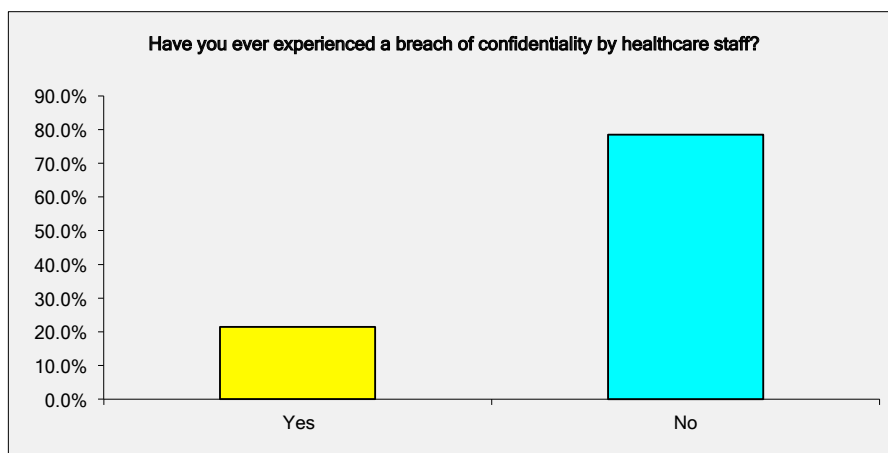
Wider issues of conduct in healthcare - breaches of confidentiality

Hearing from people with HIV, issues raised were less about people in direct care teams seeing their health records, and much more concerns about how particular healthcare workers handle those records or respond to the information that the patient has HIV. In our survey we asked respondents whether they had ever experienced a breach of confidentiality by healthcare staff. 22% said yes and 78% said no.

Conclusion

The great majority of people with HIV do not experience breaches in confidentiality in the NHS - but a minority do and that minority is still far too large.

In both the many additional comments made by survey respondents and at the two consultation meetings it was clear that perceived breaches of confidentiality described were not the agreed processes for sharing of personal confidential information between healthcare workers providing direct care, but rather what anyone would agree to be breaches of the current rules.



‘When I gave birth to my second son ... nurses and carers stood in the corridor talking about my status. Anyone passing could have heard them, as I managed to hear what they said.’

Survey respondent

We asked those who had experienced a breach of confidentiality whether they had complained about it. It is worrying that only 20% of respondents (24 people) who had experienced such a confidentiality breach complained about it. This underlines how difficult people find it to complain in the NHS, especially when living with a stigmatised condition. We also asked those who had complained whether they felt their complaint was taken seriously and whether they were satisfied with the outcome. It is difficult to conclude anything from responses when the absolute number of respondents is so low but we note the ‘mixed picture’ on these two questions - 60% thought their complaint was taken seriously, 31% did not and 12% were not sure; 24% were satisfied with the outcome, 12% were partly satisfied, 44% were not satisfied and 20% were not sure.

There is clearly in many instances a need for greater thoughtfulness and sensitivity as to how HIV-related information is handled and shared in the NHS. One matter raised a number of times was conversations about a patient's HIV status either with the patient or between healthcare workers taking place in public or inadequately private settings - an open ward or reception area, or in a cubicle merely screened off by a flimsy curtain.

A related matter was patient records, with HIV status visible, being in sight of people other than the patient and their healthcare worker. This could be a computer screen visible to others or paper records left open in a publicly accessible area (five survey respondents mentioned specific examples of this happening to them). There was concern at the covers of records or, for example, blood samples being either explicitly labeled with 'HIV' or having some indication of biohazard or 'difference'.

“Hospital outpatient for elective treatment to my back. There was a post-it attached to the front of my medical records folder on the bed that I was sent to saying ‘surely there is somewhere to record this patient is HIV+’. Another patient saw the post-it on my medical notes and made a loud comment about it in the outpatients’ treatment room and again later at a follow-up appointment in the waiting room.”

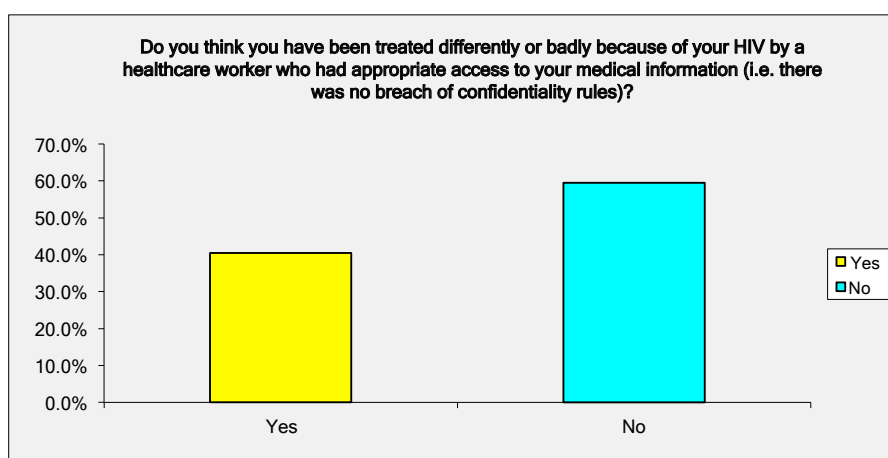
Survey respondent

An interesting example of inadvertent disclosure mentioned independently at both our consultation meetings was doctors coming into a GU reception area and calling for a named patient whilst carrying a thick file, indicating the patient was receiving long-term ongoing care from the clinic - this was felt to make it obvious that the patient was receiving HIV care.

Wider issues of conduct - stigma and discrimination

It is clear, however, that the real concern for people with HIV is less who is seeing their information but how healthcare workers respond. We have known for some time that it is in healthcare settings that people with HIV more frequently experience HIV-related stigma and discrimination.³⁶ Both in our two consultation meetings and in responses to our survey we received numerous examples of inappropriate behaviour and comments from healthcare staff.

We asked survey respondents whether they had been treated differently or badly by a healthcare worker because of their HIV status. 40% of respondents said they had. We cannot of course investigate or assess each respondent's experience but that this is the perception of so many people with HIV must be a serious cause for concern to the NHS.



Examples cited included healthcare workers asking patients how they got HIV, blaming people for becoming HIV positive, inappropriate discussions around lifestyle, being made to feel inferior or different, refusal to operate/provide treatment, treatment being postponed to the end of the day after all other patients were seen, and accusations of posing a health threat to the healthcare worker and colleagues.

³⁶Elford J et al 'HIV-Related Discrimination Reported by People Living with HIV in London, UK' AIDS and Behavior 2008;12:255-264


“Blaming and judging the individual for contracting HIV. I was asked by a paramedic if I was ‘healthy’ and I mentioned my HIV after being reminded by my boyfriend. The paramedic then said ‘So you’re NOT healthy, that’s why I asked!’. She then went on to yell at her colleagues, ‘Gloves on guys, he’s HIV+’.”

Survey respondent

Two people at our consultation meetings spoke of going with an HIV negative partner to help them access PEP (post-exposure prophylaxis) and being made to feel they had done something wrong – one said that in front of her, her boyfriend was asked whether he ‘was OK with that girl’. The other had to sign a declaration that they were liable for any possible criminal charges.

There does seem to be a particular problem around universal precautions and healthcare workers’ fear of infection. We have already mentioned patients reporting the need to remind healthcare workers of universal precautions – a difficult disclosure scenario for a patient – and rebukes once disclosure has happened that it was not done earlier and accusations of putting healthcare workers at risk. Refusals to treat, or treating at the end of the working day are different but related examples of discrimination linked to poor understanding of infection risk and control.

The recent decision to end the ban on HIV positive healthcare workers undertaking exposure prone procedures is an important opportunity for the NHS to remind staff of how unlikely HIV transmission is in a healthcare setting and the impact treatment has in reducing infectiousness. It is predominantly people with undiagnosed HIV (of whom there are about 22,000 in the UK), and especially those recently infected, who possibly pose a limited risk in healthcare settings – precisely those who cannot disclose because they are undiagnosed.



That is why universal precautions are so important. In its Confidentiality Guidance the General Medical Council, whilst acknowledging the possibility of non-consensual disclosure to protect a healthcare worker from risk of infection from a serious communicable disease, states, ‘such situations are likely to be very rare, not least because of the use of universal precautions to protect healthcare workers and patients, particularly during exposure-prone procedures’.³⁷ Recent analysis by NAT of what is taught to medical undergraduates about HIV revealed an unhelpful emphasis on the virus as a risk to healthcare workers, rather than a condition lived with by approximately 100,000 in the UK.

Recommendation: The answer to stigma in the NHS must be a more robust response from all healthcare bodies to root it out, rather than designing a different set of confidentiality guidelines for people with HIV.

Recommendation: All healthcare bodies need to train all their staff on how to avoid HIV-related stigma and discrimination, using the concrete and practical examples of such behaviour, such as those set out in this report, which are repeatedly complained about by people living with HIV.

Recommendation: Healthcare workers should be trained in the importance of universal precautions and that if they are followed there is no need for concern when providing care for those with HIV or another blood borne virus. Additional precautions or expressions of fear or disgust can be considered discriminatory in law. They should also be taught about the impact HIV treatment has on infectiousness.

Recommendation: There should be robust disciplinary procedures for those found to have acted in a stigmatising or discriminatory way.

³⁷General Medical Council ‘Confidentiality: disclosing information about serious communicable diseases’ September 2009 para.8

The Summary Care Record

The NHS in England is creating a national data base of Summary Care Records (SCRs) for patients, containing information on that patient's allergies, bad reactions to medicines and any medication the patient is taking. Over 27 million SCRs have been created to date. Ordinarily a healthcare worker asks consent from the patient to access the SCR. But there can be instances where a patient is unconscious, incoherent or incapacitated in some way and unable either to give consent to such access or to inform a healthcare worker of, for example, medication they are taking which could possibly interact with other medicines prescribed. In these circumstances the healthcare worker can access the SCR to get this key information, which is vital for patient safety.

Information for the SCR is extracted by an automated process from GP records. Patients are informed that it is planned for relevant data to be taken to create an SCR for them - and they have a right to opt out of the process, and thus for no SCR to be created. The SCR will be created unless the patient explicitly objects. A patient can decide at any point after the creation of an SCR to withdraw their consent and the SCR will then be deleted. Patients have a right to see what information is contained on their SCR.

In discussion with NHS representatives it became apparent that it is unclear whether antiretrovirals would automatically be included within the SCR. This is because they are not prescribed by the GP (rather by the HIV clinic). Even though the antiretrovirals will usually be added by the GP to the GP patient record, how and where they are added and whether the different GP electronic record systems allow for extraction of that information for the SCR was not known.

Conclusion

Patients who want an SCR created will need to check with their GP as to whether their antiretrovirals have been included.

It is possible for additional information to be included in the SCR with the agreement of both patient and GP. So even if antiretrovirals are not automatically extracted and included in the SCR, they can then be added. It would also be possible to add, for example, information as to whether relatives know of your HIV status to avoid inadvertent disclosure. In one survey response, someone mentioned the great distress of their HIV status being disclosed to their family, who had not known it, when the respondent was unconscious in hospital.

Recommendation: Both HIV clinics and GPs should explain the benefits of the Summary Care Record to people on ongoing medication for long-term conditions such as HIV.

At the NAT / Positively UK consultation meeting there was general welcome for the SCR and accounts of real difficulty where, without an SCR, a patient was trying to explain medication they were taking and allergies but unable to breathe and speak properly. It is not known what proportion of people with HIV are opting out of the SCR process but there are definite advantages for an SCR to be created for people living with HIV on long-term medication.

Local clinical audit

The use of personal confidential information for local clinical audits, is considered a component of direct care, and therefore implied consent is assumed unless the patient indicates otherwise. The HSCIC make clear that 'local audit / assurance of the quality of care provided' is considered to be part of direct care ... 'It is generally accepted that consent can be implied for activity concerned with the quality assurance of care, but only when the audit is undertaken by those who are part of the direct care team'.³⁸ Such local audit should not be confused with national audits (see Section D below) where explicit consent or another legal basis for sharing identifiable information is required.

It is recommended in the unusual case where a patient objects to their records being looked at for such local audit purposes, 'this should be respected unless there are such strong concerns about the care that has been provided that the public interest must take priority'.³⁹

³⁸HSCIC 'A guide to confidentiality in health and social care: references' September 2013 Section 10

³⁹ibid. Section 10

D 'Secondary Uses' - Surveillance, Research, Audits and Commissioning

A key use of health data is for purposes of communicable disease surveillance, health service management and health-related research, all of which are essential elements in any health system aiming both to improve continuously and meet population-based needs.

Such uses are commonly termed 'secondary uses' or 'indirect care' - they are not 'direct care'.

It is important that this report looks at secondary uses of information since proposals to use the NHS number in the HIV clinic often cite its value for research, audit and commissioning purposes because it will allow linking of identifiable information across providers and settings to get a better picture of clinical pathways and treatment and care outcomes for this group of patients. At our experts roundtable a number of examples were given of how the use of the NHS number could enhance our understanding of HIV treatment and care, and thus equip us to make further improvements. One was a better sense of health outcomes in relation to particular drugs prescribed. Another was knowledge of hospitalisation amongst people living with HIV, when and for what, with a better sense of health outcomes and their relation to the care pathway.


This section of the report aims to give an overview of the confidentiality requirements for secondary uses of personal medical information. Again, much more detail can be found in the various documents referred to and on the HSCIC website.

Key principles for secondary uses of personal information

Anonymised information can be shared...

The basic principle for secondary uses of confidential personal medical information is that wherever practicable it must be anonymised. This principle is reflected in guidance from the Department of Health, the General Medical Council and the Royal Colleges. Most recently Rule 3 of the HSCIC's Guide on confidentiality states: 'Information that is shared for the benefit of the community should be anonymised'. Effectively anonymised information can be used by another organisation and also published without any breach of confidentiality provisions.

... but if identifiable or potentially identifiable information needs to be used, processing must be in controlled environments, either through data sharing agreements or in an accredited safe haven.



Anonymisation is itself a context-dependent concept. The HSCIC has developed a standard covering the steps that should be taken before publishing information.⁴⁰ Publication puts information into an uncontrolled environment so great care has to be taken to prevent it from being used in combination with other information to re-identify individuals.

Pseudonymised data i.e. where identifiers have been replaced with a pseudonym, will generally not be safe for publication but would fall into the category of safe to use within a 'controlled environment'. Such a controlled environment would be an organisation where information controls have been secured through regulations or data sharing agreements, or through contracts with appropriate liabilities and sanctions included.

There are also rare instances where confidential personal medical information must itself be used. But this can only happen:

- if there is explicit consent from the patient, or
- if there is a legal obligation to share the information (for example to notify of a particular infectious disease or in response to a court order), or
- if the law allows the sharing of confidential information for a particular purpose, whether in the public interest (e.g the investigation or punishment of serious crime, or the prevention of serious harm to others) or under legislation.

With the most robust controls the use of information that is normally considered identifiable might be safely used in a controlled environment. For example, the Information Governance Review lists the NHS number as one instance of personal identifying information that might be used to support data linkage where the user has no access to tracing facilities. The Information Governance Review recommended that a process of establishing 'accredited safe havens' be instituted for this purpose, and this process is currently underway. An accredited safe haven is an accredited organisation, or designated part of an organisation, which is contractually and legally bound to process data in ways that prevent the identity of individuals to whom the data relates from being identified.

All data for 'secondary uses' which poses a risk of identification should be processed under such strict data stewardship functions and on a clear legal basis – either, as has been stated above, with explicit patient consent, or under the aegis of an explicit legal gateway. One such legal gateway is the Health and Social Care Act 2012 which grants the HSCIC permission to process personal confidential data. Another is the NHS Act 2006 section 251 which grants the Secretary of State powers to give permission to collect personal confidential data without patient consent for specific purposes (see below). Accredited safe havens are provided with the lawful basis to receive and process personal confidential data under section 251.⁴¹

Section 251 powers

A small number of organisations, for example Public Health England, currently have the power to receive and process identifiable or potentially identifiable information for specified purposes related to public health risks or cancer under the Health Service (Control of Patient Information) Regulations 2002. These powers are known as 'Section 251 powers' since the 2002 Regulations are made under powers found in Section 251 of the NHS Act 2006.

In other cases organisations may seek support under Regulation 5 of the 2002 Regulations by making an application to the Confidentiality Advisory Group (CAG) of the Health Research Authority (HRA). The purposes that may be supported are limited, primarily to research and audit, and applicants must demonstrate that:

- they abide by Data Protection Act requirements,
- the aim of the processing is in the public interest,
- anonymised information could not be used to achieve the required results, and
- it would be impractical both in terms of feasibility and appropriateness, to seek specific consent from each individual affected.

What Section 251 does is waive the requirement to abide by the common law duty of confidentiality.

⁴¹The NHS Act 2006 was a consolidating measure bringing together various legislative provisions. These powers were originally found in section 60 of the Health and Social Care Act 2001 - which explains why the Regulations have a date preceding that of the current 'parent Act'.

Some examples of secondary use

Data Extraction Services

Personal confidential information from medical records is extracted from individual provider records systems and collected by the HSCIC. The two key extraction systems are Hospital Episode Statistics (HES) and the General Practice Extraction Service (GPES).

Public Health England surveillance


There is immense value in collecting data on HIV for surveillance purposes to improve preventive medicine and enhance health protection, as well to support and improve the provision of patient care and treatment. The reporting of such data is made to Public Health England (PHE [formerly the Health Protection Agency])

Unlike many communicable diseases HIV is not a notifiable disease. In other words, there is no statutory/legal requirement for a case of HIV to be reported to PHE (unlike, for example, TB or hepatitis C), in recognition of the stigma that has been historically attached to the condition. Therefore, reporting of HIV-related data is undertaken by clinicians on a voluntary and consensual basis and is processed through the HIV and AIDS Reporting System (HARS).

Information sent to PHE is 'de-identified', also termed 'pseudonymised'. This means that PHE themselves cannot infer the identity of an individual from the data received. Explicit consent is deemed not practicable to secure from every patient with HIV for this reporting process. There is, however, a risk of 'deductive disclosure' from pseudonymised information if linked to other information / datasets and this means in the absence of explicit consent from all patients, the PHE has had to receive approval under Section 251 of the NHS Act 2006 to handle and process this data.

As with other secondary uses, patients do have the opportunity to 'opt-out' of this reporting system to PHE. However, as with any reliance on implied consent, it is only valid if generic information is promoted and patients have a general understanding of how their data is used. PHE has produced a leaflet for patients explaining how their information is used, and this leaflet should be available and provided at every clinic to all patients.⁴²

⁴¹See http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1194947352367




To ensure that HIV data is collected accurately, PHE collects limited patient identifiers, including a 'soundex' code, gender and first initial, date of birth, clinic number and LSOA (lower super output area) of residence. Soundex is a pseudonym which changes an individual's surname into a code to link different data sets - the code is generated by the individual clinic. LSOA is a shortened post code and can be used to identify the locality and cluster of certain communicable disease outbreaks. There is no collection of name, address or NHS number.

In accordance with requirements for Section 251 accreditation, PHE has well-established precautions and processes to protect and safeguard sensitive data. Disaggregated pseudonymised data is only ever accessed on site by Caldicott-trained staff. There are Security Information Officers in each lab as well as Caldicott Guardians for each centre. In addition, PHE staff are contractually obliged to adhere to ethical and professional obligations around confidentiality, as are those whom the data is shared with.

When sharing pseudonymised data with partner agencies, there is a raised risk of re-identification, as it is not always known 'what is out there' with regards to data which could re-identify once it is linked. However, PHE uses a HIV/STI data sharing policy which mitigates this risk.

When data is shared, it is always further anonymised and released in aggregated form. For example data is often shared to support auditing and commissioning, where a unique and consistent patient identifier would enable commissioners to track individual data. Any researcher wanting to use PHE data would receive only aggregated data. Anyone wanting to use disaggregated data would need to get ethics approval first and then would only be able to look at the data on site at PHE after Caldicott training.

There has been discussion between NAT and PHE officials on whether there would be any benefit to PHE collecting the NHS number along with other patient information. This would of course mean that information is potentially identifiable rather than pseudonymised, and would require robust controls as referenced above. It was accepted that the NHS number would certainly facilitate further surveillance and research by PHE. It is possible to link HIV and other datasets using soundex but it is extremely laborious - it was done recently for HIV and TB. The absence of the NHS number means in practice linkages are not made which they would make if the number were available. For example one could link with Hospital Episode Statistics data to understand hospitalisation rates / morbidity for people living with HIV.



On the other hand, there has not to date been any confidentiality breach from the current system or any dissatisfaction expressed. This should be welcomed and mean that any proposal to move to more identifiable data is treated with caution. Furthermore PHE is approached from time to time for information on patients with HIV, whether by the Foreign and Commonwealth Office (FCO), the Home Office or the police. It has been very useful to be able to say that PHE cannot identify particular patients. The Information Standards Board was content for information being collected without the NHS number.

National Clinical Audits


All clinical audits must be conducted in compliance with the Caldicott Principles, the Data Protection Act 1998, the NHS Confidentiality Code of Practice and other legal provisions.

It is important to note that clinical audits are not the same as research. Nothing is 'done' to patients additional to or other than their routine / appropriate clinical care. Therefore, unlike for research, audit projects do not need Research Ethics Committee (REC) approval. But they must still be conducted within a strict ethical framework which abides by essential information governance principles.

We have discussed previously local clinical audits within a single provider where implied consent is assumed, since the local audit is deemed an element of direct care, with the ability of the patient explicitly to opt out should they wish to. Here, however, we are considering clinical audits which cover a number of different providers, so that implied patient consent cannot be assumed.

One of the main arguments for use of the NHS number for patients by the HIV clinic is that this will enable national clinical audits to review care pathways and treatment outcomes across a range of providers and healthcare settings. The NHS number will mean records for the same patient can be readily and confidently linked. It should be noted that where the audit covers more than one NHS organisation, patient identifiable information, such as the NHS number, can only be used either with the explicit consent of the patient or through a 'statutory gateway' such as through the HSCIC or under Section 251 powers.

Patients do have the right to object to their data being used for clinical audit undertaken under



Section 251 powers, but this is based on an 'opt-out' arrangement. In other words, people need explicitly to state they do not wish their personal data to be used for such secondary uses. If they say nothing, it will be assumed they consent to such use.

Commissioning

Commissioners need health-related information on their local population if they are to understand health need, current service outcomes and monitor improvements / changes over time. Do commissioners ever need patient confidential information for people with HIV? NAT were told by PHE that they only provided data to commissioners in anonymised form and were wary about risks of deductive disclosure. There was an HIV/STI data sharing policy at PHE to avoid such disclosure and, as a rule of thumb, data was not disclosed where the denominator was less than 10,000.

At our experts roundtable, commissioners said that patient information was needed for payment purposes to providers and to monitor outcomes and improvements. For example, one commissioner told us, analysis can be done 'identifying patients who may be at greater of risk of hospitalisations or for whom services are not working effectively because you can see there have been multiple A&E attendances / admissions which could have been avoided'. It would 'support more outcomes based commissioning to ensure HIV patients do not have poorer health outcomes than other patients'. One issue with PHE data was that there is a time-lag between data collection and sharing of information from PHE - this means a lack of real-time data which commissioners really need to monitor new diagnoses and outbreaks.

The Information Governance Review has a chapter on 'Commissioning' and found 'a lack of consensus concerning the extent of the need for identifiable data to be used for commissioning purposes'. NHS England and Clinical Commissioning Group representatives told the Review that there would sometimes be no alternative but to use personal confidential information, for example to allow linkage from multiple sources or to access more extensive data, and more rapidly, than they might be able to secure from the HSCIC. They argued that use of such data by commissioners was legitimate as part of a proposed 'consent deal' between the NHS and its service users.

The Review authors disagreed and emphasised the need for any processing of such identifiable

data to have a legal basis in either explicit consent, information drawn from local clinical audit, or data processed in an accredited safe haven. The Review concluded that poor data quality often impeded data linkage and thus increased the demand for identifiable data. Thus, the improvement of data quality was a key recommendation going forward.

The HSCIC has published a Guidance note on 'Approval to flow personal confidential data to support defined commissioning purposes from the HSCIS to commissioning organisations' under Section 251 powers. Data includes, for example, referrals data and Hospital Episode Statistics and will go to commissioning bodies which meet level 2 requirements of the Information Governance Toolkit. It will therefore include some limited identifiable information such as NHS number. This approval lasts currently until October 2014.

However, the NHS number is not currently used for patients living with HIV in these data flows to commissioners (it is for other conditions). Commissioners emphasised to NAT that were they to have access to NHS numbers this would not enable them to access further identifying information such as name and address.

Right to refuse consent for secondary uses

In its Guide on confidentiality the HSCIC states in the Foreword:

'While people are unlikely to object to sharing confidential information within their own care team, there are some who may not want it used for purposes such as research or reshaping the patient pathway in order to achieve safer care in general. These wishes must be respected by everyone who has access to health and social care data. This guide supports the individual's right to object.'⁴³

It should though be noted that where information is fully anonymised there is no right to object to its use - 'once information is effectively anonymised it is no longer confidential'.⁴⁴ The right to object to secondary use relates to information which is identifiable or potentially identifiable, which as we have seen is sometimes used in surveillance and research.

⁴³HSCIC 'A guide to confidentiality in health and social care' 2013 Foreword

⁴⁴HSCIC 'A guide to confidentiality in health and social care: references' September 2013 section 2

Further information on the right to object is found in Section 18 of the accompanying references document of the HSCIC Guide to confidentiality. Where a person has refused consent to their information being shared for such secondary uses, the common law of confidentiality can nevertheless be set aside by the powers under Section 251 of the NHS Act 2006. But 'this has never been invoked and support under the current regulations is generally provided under a condition that objections are respected'. Similarly, whilst the Health and Social Care Act 2012 gives powers to the HSCIC to require the provision of identifiable information as directed or requested by bodies such as NHS England or NICE (National Institute for Health and Care Excellence), 'these bodies have agreed that, in the absence of an emergency of exceptional public interest grounds, they will limit directions and requests only to information where an individual has not raised an objection, thus providing individuals with a means of preventing their data being collected in an identifiable form'.⁴⁵

Recommendation: We note that this right of refusal to secondary use of personal data is not always enshrined in law, for example use by the HSCIC or under section 251 powers. We believe it should be, apart from an overriding public interest test with a high threshold. We would be concerned if a future Government reversed its current agreement always to respect such refusal of consent.

Of course no one can object if they are unaware of the proposed use in the first place. The HSCIC state, 'The right to object to confidential information being shared for purposes beyond an individuals' care and treatment should be followed through by actual processes to ensure individuals fully understand what they can object to and how to initiate the process, otherwise it could be considered unfair processing'.⁴⁶

Recommendation: HIV clinics, GPs and other relevant NHS providers of care must ensure that people living with HIV are aware of planned secondary uses of their personal confidential information, and that they have the right to object should they wish.

⁴⁵ibid. section 18

⁴⁶ibid. section 3

The NHS number and secondary uses

The immediate occasion for this NAT project and report was a proposal from BHIVA that all patients in HIV clinics be asked for consent for their clinic record to use the NHS number – and this was to allow for the kinds of ‘secondary use’ activity – surveillance, national audit, review of clinical pathways and outcomes, outlined in this section.

Our analysis sets out a number of key considerations to decide on this issue.

First, assigning the NHS number to the HIV clinic record does not in and of itself inform anyone outside the HIV clinic of the identity of the patient living with HIV.


Secondly, the patient always has the right to refuse consent to the sharing of his or her information with a GP or any other part of the NHS (albeit this is not advisable for safe and good quality care).

Thirdly, a referral or other communication from the HIV clinic to a GP, hospital clinic or other part of the NHS inevitably involves the use of the NHS number – if the HIV clinic does not itself use it in its initial communication, the ‘receiving’ NHS provider will nevertheless immediately assign the person’s NHS number to the record they create.

Fourthly, many HIV clinics will already be using the NHS number for the patient’s record – they may be ID (Infectious Disease) clinics for example, or GU clinics which have had their HIV clinic records integrated in some way with the trust-wide records system.

Fifthly, secondary use of personal confidential information is carefully regulated so that identifiable information is only handled and processed in ‘accredited safe havens’ and only shared more widely in anonymised or appropriately pseudonymised form.

Sixthly, the patient has a right to refuse consent to the use of his or her personal confidential information for such secondary purposes.




Given all these considerations, and the immense value for patients of enabling high quality audit and analysis into the quality of their care, there is a strong argument for the routine use of the NHS number in all HIV clinics.

The original BHIVA proposal was that patients have the option of refusing the use of the NHS number for their clinic record. Given the options outlined above to refuse consent to sharing of their information, an additional option to refuse use of the NHS number in the HIV clinic may seem unnecessary.

One relevant scenario, however, which does cause difficulty is that of patients who attend for HIV treatment and care anonymously i.e with the use of a false name to hide their true identity. This has always been an option for those coming to GU clinics for screens and STI/HIV tests. In some instances the use of the pseudonym is 'carried over' into the clinic providing ongoing HIV treatment and care. In such cases communication between the HIV clinic and their GP becomes impossible – there are significant disadvantages for the quality of the patient's care. But we hesitate to end the possibility of the use of pseudonyms for HIV care – there are a very small number of people who will not test or access treatment unless their identity is hidden even from the HIV clinic itself. They should still be able to access HIV care. It is hard to reconcile this with 100% use of the NHS number.

Another issue is the degree to which data sharing between public bodies is or will be permissible. The Law Commission is currently reviewing the law in this area. NAT is, for example, immensely concerned at current rules which mean a migrant's NHS debt can be reported to the Home Office and if the debt remains unpaid the further residency applications will be refused. The HSCIC Guide states that the costs of someone's treatment is itself personal confidential information. There are similar concerns in terms of sharing, or proposals to share, health-related information with law enforcement or with benefits agencies.

A final concern raised at our expert roundtable was the worries HIV positive healthcare workers have about their status being known by healthcare colleagues. This is exacerbated by the amalgamation of NHS providers, previously discussed, meaning larger numbers of people can access a single records system.



Recommendation: NAT recommends that the NHS number be routinely used for patients in HIV clinics but that there be an option to opt out, so that the very few patients who continue to have very serious worries about their personal confidential information might not be deterred from HIV treatment and care.

Recommendation: Whilst, the consistent use of the NHS number will enable data linkage for research and other secondary uses, this does not mean we are as yet recommending that reporting from HIV clinics to Public Health England should use this NHS number. Such a significant step would require a further careful consideration by the HIV sector and should not happen without substantial consensus, especially amongst people living with HIV.

E To Summarise ...



Our work on HIV Patient Information and NHS Confidentiality has explored a wide range of often complex issues but some key messages emerge. Patients on the whole understand the need to share their personal confidential information to ensure they receive high quality, safe treatment and care, and there are no fundamental concerns with current data sharing and confidentiality processes. The one unresolved issue is the range of administrative staff who can access or know about sensitive information such as HIV status. The real problems, which the NHS has failed to address adequately and which must now as a matter of urgency be taken seriously, are casual breaches of confidentiality experienced by some patients living with HIV and the stigmatising responses from some healthcare staff to knowledge of the patient's HIV positive status.

Our investigation has set out the many advantages to research, surveillance and commissioning of the consistent and routine use of the NHS number for patients in the HIV clinic, and the significant range of protections and safeguards to ensure data remains confidential when processed for such secondary purposes. It is time that people with HIV access the full range of benefits from NHS care - the use of the NHS number on an opt-out basis in the HIV clinics will be an important step in this process.

F Conclusions and Recommendations

HIV Patient Information and NHS Confidentiality

Conclusions

- There is inconsistent practice across the country on the degree and nature of integration of HIV clinic records with that of the wider hospital trust. The trend seems to be towards such integration – which means most patients with HIV should expect the hospital trust within which their HIV clinic is based also to have a record of their HIV positive status, simply as a result of their receiving care at that HIV clinic.
- Whilst the theory of greater sharing of HIV status in healthcare seems to be known by most patients, the implications and extent of that sharing seem to be less widely understood.
- The consensus in discussion was that the right to refuse the sharing of information in direct care did not extend to a right to insist that a separate records system be established for an individual patients.
- Although more work is needed to reduce further the numbers of people surprised at how their information is or is not shared, the survey results suggest there is not a major issue of distress amongst people with HIV at current confidentiality rules and processes within the NHS.
- It is clear some explanation of rights to confidentiality in the NHS is happening but not enough, and the explanation that does take place is not consistently meeting the information needs of patients.
- The great majority of people with HIV do not experience breaches in confidentiality in the NHS - but a minority do and that minority is still far too large.

- Patients who want an SCR created will need to check with their GP as to whether their antiretrovirals have been included.

Recommendations

- HIV clinics should inform patients of how information on their HIV status is stored within clinic and trust records systems, providing assurance around confidentiality protocols and protections.
- NAT strongly supports an ongoing mandatory requirement for GU records to be kept separate from the rest of the NHS records system and for people to be able to access GU services anonymously if they wish to.
- The patient with HIV has the same right as any other patient for the out come of his or her sexual health screen or test, and any consultation, treatment and care received for STIs at a sexual health clinic, to be kept separate from their other NHS records. That information should be on the patient's GU record but not on the HIV clinic's record of their HIV treatment and care. The HIV clinic record should only include whether appropriate sexual health screens and tests were offered and taken up.
- It would be useful for BASHH to make clear and explicit that the GU records of patients with HIV should be kept separate from their HIV clinic record, and ensure via survey or audit that this is in fact the case consistently across the country.
- BHIVA should revise the 'Standards of Care for People Living with HIV' to include a Quality Statement which states that all HIV clinics must ensure that the patient is aware of how their information is stored, handled and shared. There should be constant attention to make sure there are 'no surprises' for the patient living with HIV as to how their personal confidential information is used, and that there is genuine consent to that use.
- Both HIV clinicians and GPs need to have explicit discussions with their patients living with HIV on when their HIV status would be shared with other healthcare professionals, the benefits of doing so, how implied consent works, and any preferences as to how to



involve the patient in that process.

- Universal precautions are expected of all NHS staff, and patients with HIV should not be pressurised inappropriately into sharing their HIV status on the basis of supposed risk of transmission to healthcare workers or inaccurate claims around legal liability.
- The HSCIC should commission more research on the current use and potential of sealed envelopes and other technologies to allow differentiated access to patient records, and provide advice on their website on relevant technologies and how to use them effectively. Further advice would be useful on practical ways to distinguish levels of access between different administrative staff so as to maintain confidentiality without compromising high quality care and appropriate sharing of information.
- NAT will publish a written resource explaining how the personal confidential information of people with HIV is handled and shared in the NHS. We would urge all HIV clinics and GP practices to provide this resource, or comparable ones, to all their patients living with HIV and accompany it with verbal explanation and the offer to answer any questions. This is essential for there to be genuine consent to the use of their information.
- The answer to stigma in the NHS must be a more robust response from all healthcare bodies to root it out, rather than designing a different set of confidentiality guidelines for people with HIV.
- All healthcare bodies need to train all their staff on how to avoid HIV-related stigma and discrimination, using the concrete and practical examples of such behavior, such as those set out in this report, which are repeatedly complained about by people living with HIV.
- Healthcare workers should be trained in the importance of universal precautions and that if they are followed there is no need for concern when providing care for those with HIV or another blood borne virus. Additional precautions or expressions of fear or disgust can be considered discriminatory in law. They should also be taught about the impact HIV treatment has on infectiousness.
- There should be robust disciplinary procedures for those found to have acted in a stigmatising or discriminatory way.
- Both HIV clinics and GPs should explain the benefits of the Summary Care Record to people on ongoing medication for long-term conditions such as HIV.

'Secondary Uses': Surveillance, Research, Audits and Commissioning

Recommendations

- We note that this right of refusal to secondary use of personal data is not always enshrined in law, for example use by the HSCIC or under section 251 powers. We believe it should be, apart from an overriding public interest test with a high threshold. We would be concerned if a future Government reversed its current agreement always to respect such refusal of consent.
- HIV clinics, GPs and other relevant NHS providers of care must ensure that people living with HIV are aware of planned secondary uses of their personal confidential information, and that they have the right to object should they wish.
- The NHS number should be routinely used for patients in HIV clinics but that there be an option to opt out, so that the very few patients who continue to have very serious worries about their personal confidential information might not be deterred from HIV treatment and care.
- Whilst, the consistent use of the NHS number will enable data linkage for research and other secondary uses, this does not mean we are as yet recommending that reporting from HIV clinics to Public Health England should use this NHS number. Such a significant step would require a further careful consideration by the HIV sector and should not happen without substantial consensus, especially amongst people living with HIV.

G Annex

BHIVA expert advisory group for NAT project ‘HIV Patient Information and NHS Confidentiality’

Professor Jane Anderson, Homerton University Hospital NHS Foundation Trust

Dr Guy Baily, Barts Health NHS Trust

Dr Funso Olarinde, Royal Hallamshire Hospital, Sheffield

Dr Mary Poulton, King’s College Hospital NHS Foundation Trust

Professor Caroline Sabin, University College London

Dr Lee Winter, GP, Palace Road Surgery

NAT/BHIVA Roundtable on HIV and Confidentiality, 31st July 2013

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Dr Yusef Azad, National AIDS Trust

Dr Guy Baily, Barts Health NHS Trust

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