

Data protection & HIV status



Briefing paper
National AIDS Trust
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1. Context

An issue commonly reported to National AIDS Trust's [Discrimination Advice & Support Service](#) is the sharing of peoples' HIV status without their consent. This happens in many settings, including in the workplace, by the police, in healthcare settings, and in individual's personal lives.

A person's HIV status should be treated like any other piece of personal data and should not be shared without their explicit and informed consent. In addition to this, an individual's HIV status is classified under the law to be [special category data](#), meaning that it can only be processed for certain specified reasons, in line with data protection law. For example, it would be lawful under the [Data Protection Act 2018](#) to share a person's HIV status if explicitly required for an employer to meet their obligations under employment law, if strictly necessary to provide a person with the correct healthcare, or for other statutory purposes.

A key factor contributing to the unlawful sharing of HIV status is stigma. Stigma still commonly persists in relation to HIV, which means that people still view it negatively and have misconceptions about the realities of living with HIV today. This stigma leads to peoples' HIV status being shared without their consent – often for either malicious reasons or under misguided attempts to safeguard others.

The results of such sharing of HIV status can be damaging to the wellbeing of the individuals involved and contribute to the perpetuating of HIV stigma. There are common misconceptions about HIV and its

transmission that sharing of HIV status without consent can help perpetuate. For example, HIV cannot be passed on by the [97% of individuals living with HIV today](#) who are virally suppressed, and for the remainder of people living with HIV, transmission can only occur via specific routes involving exchange of bodily fluids (blood, semen, vaginal fluid etc.)

It is also important to note that an individual's personal circumstances, including their economic security and migration status, can impact on the levels of damage a sharing of HIV status without consent can have, and can increase their risk of harassment.

People living with HIV should have the right to determine when, or even if, they share their status – in any environment. It is therefore vital that the ICO, the Government, employers, public authorities, clinicians, and others take action to stop this sharing without consent from happening.

We therefore recommend that the ICO do the following to prevent people living with HIV from having their status shared without their consent:

- **Simplify the ICO website to make the process of reporting breaches of special category data easier.**
- **Overhaul complaints mechanisms to expedite investigation outcomes & examine sectoral patterns of data protection breaches.**
- **Create additional guidance related to data protection, health data & HIV status.**

(See [Page 3](#) for more details).

2. Case studies of discrimination reported to National AIDS Trust by people living with HIV

A) Sharing of HIV status in the workplace due to employee ill health

An individual who had recently been diagnosed with HIV found that sharing of their HIV status in the workplace had a negative impact on their physical & mental health, as well as their economic circumstances.

The individual worked in the crew of an entertainment venue and was required to take sick leave due to opportunistic infections because of advanced HIV. They were under a temporary work contract, which is common practice within their industry. Once they returned from sick leave, they shared their HIV status to a company manager, who then shared this personal information to their Head of Department and producer. This was followed by a barrage of inappropriate questions, including about the treatment for their HIV and the infections they had been dealing with. Their HIV status had also been shared by the doctor the individual's organisation encouraged them to meet with to discuss their health – a breach of data protection law if this information was not confined to what was strictly necessary.

Over time, the questioning got worse, and the stigma the individual was met with intensified - believing that they were treated differently by colleagues directly because they were aware of their HIV status. The individual's work contract was eventually terminated because of the continuing dispute over sick leave, and there were continuing disputes over the pay that they were entitled to, including sick pay. They also were denied the opportunity of a promotion, had deductions to their holiday pay and were the subject of negative public discussions in the workplace.

These disputes were intensified and made more toxic because of the sharing of the individual's HIV status. The individual contacted National AIDS Trust for assistance, and we connected them to legal advice from an employment solicitor, who determined they had been discriminated against under the Equality Act. This included incidents of 'direct discrimination' ([Section 13](#)), 'discrimination arising from a disability' ([Section 15](#)), 'indirect discrimination' ([Section 19](#)),

failure to make 'reasonable adjustments' ([Sections 20](#) and [21](#)), 'harassment' ([Section 26](#)) and 'victimisation' ([Section 27](#)).

This individual has brought a discrimination case to the Employment Tribunal, that has been accepted. We are awaiting the outcome of the Tribunal. What is however clear is that this individual would likely not have been discriminated against to the same degree if their HIV status was not shared without their consent to those who did not need to know the information.

B) Sharing of HIV status by the police after criminal charges

We have received reports of individuals living with HIV who have experienced discrimination when their HIV status has been shared without their consent by the police. This sharing without consent has been both between police officers, and from police officers into the wider communities that they serve.

For example, National AIDS Trust were made aware of an individual living with HIV who was charged with and eventually convicted of, several sexual offences. Whilst being questioned in connection with these offences by the police, the police were made aware of the suspect's HIV status and undetectable viral load by the suspect themselves.

After this information was shared with them, the police officers asked the suspect personal questions about their HIV status and alleged that they had attempted to transmit HIV to the victims of these offences. Contemporaneous medical evidence demonstrated that the offender had an undetectable viral load and was therefore unable to transmit HIV sexually.

Despite this, the individual alleges that police officers who were privy to information on their HIV status shared this more widely, to their friends, neighbours, and employees within the wider community. Regardless of the nature of the prosecution against an individual, police officers sharing their HIV status in this way was completely unacceptable and a possible breach of the Data Protection Act 2018.

If a person's HIV status is shared without their consent in this way, there would likely also be breaches of the Equality Act 2010 on the grounds of disability discrimination. This could include 'direct discrimination' ([Section 13](#)), 'discrimination arising from a disability',

([Section 15](#)), 'indirect discrimination' ([Section 19](#)), 'harassment' ([Section 26](#)) and failure to adhere to Public Sector Equality Duty ([Section 149](#)), as the police force are a public body.

Whilst this specific complaint does not appear to have been upheld by the ICO, it demonstrates that poor police behaviour relating to data protection of suspect health data could breach both data protection and equalities legislation. Police officers must therefore handle individuals' private data such as about their HIV status, with the highest levels of protection – regardless of the nature of offence the individual may be accused or even convicted of. These regulations must be applied consistently, to prevent furthering of both institutional and wider societal prejudice against people living with HIV.

C) Sharing of HIV status within healthcare

Healthcare remains a common setting where people's HIV status is shared without their consent. National AIDS Trust have been made aware of cases of both clinical and non-clinical staff having shared patients' status without their consent in multiple healthcare settings. Examples include in GP surgeries, in dental practices and within hospital settings.

For example, an individual living with HIV approached us about how their HIV status was recorded on their GP records. They work in an offshore setting in various countries, including some where employer knowledge of their HIV status would put them at physical risk due to criminalisation of HIV. Therefore, for many years they opted to access their HIV treatment through sexual health services, in order that their HIV status would not appear on their GP records shared with employers in these countries.

However, a few years ago, the sexual health service began data sharing with their GP, which meant that this data was now added to their GP records, meaning that it was visible to their employers. Given their personal circumstances, this individual understandably did not want this information on their health records. Since then, this individual has had considerable difficulty in having their HIV status removed from their medical records, even though leaving the status on there might subject them to material risk of physical harm.

Despite this clear lack of consent from the patient, and a strong reason for not sharing this data, the GP surgery refused to remove or redact this data from these records when sharing. Given that this situation would possibly place the patient in danger when working abroad, it is possible to argue that this situation breached his rights under the [Human Rights Act 1998](#) in relation to prohibition of torture.

In situations where a person's HIV status is shared without their consent, the Equality Act provides protections against such situations happening. This could include 'direct discrimination' ([Section 13](#)), 'discrimination arising from a disability' ([Section 15](#)), 'indirect discrimination' ([Section 19](#)), 'harassment' ([Section 26](#)) and failure to adhere to Public Sector Equality Duty ([Section 149](#)) by the NHS bodies responsible.

3. National AIDS Trust policy recommendations to the ICO

From our experiences of assisting individuals whose HIV status has been shared without their consent, it has become clear that individuals value the independent regulatory function that the ICO has, to protect their personal data when data protection breaches occur.

However, it has also become clear that the systems within the ICO can be difficult to navigate for both individuals living with HIV trying to protect their special category data, and for those who are supporting them to do so.

Clear guidance is needed to ensure that people living with HIV can feel comfortable reporting any data breaches about their HIV status.

To make the process of reporting a breach of GDPR regulations in relation to HIV status easier, and so that the ICO can fulfil their Public Sector Equality Duty to eliminate discrimination against people living with HIV, we make the following recommendations to the Information Commissioner's Office:

A) Simplify the ICO website to make the process of reporting breaches of special category data easier:

1. *Streamline ICO services to make them more user friendly to members of the public:*

People living with HIV whose HIV status has been shared without their consent often report to us that they find the ICO website complex to navigate and find it hard to understand what steps they can take. In order that members of the public who are not subject matter experts on data protection are able to report breaches of data protection law to the ICO, it is vital that the ICO's reporting mechanisms are as accessible as possible.

We recommend that the ICO creates clear user guides for their website, in lay language, so that members of the public understand exactly what the ICO's processes are for assessing breaches of data protection law, and exactly what they can expect when they make a data protection complaint. This could prevent confusion about the ICO's remit and may reduce the need for cases to be reviewed.

2. *Publish defined thresholds for reaching regulatory action in a case involving an individual's special category data:*

For individuals who have had their HIV status shared without their consent, it can be difficult to understand what the thresholds for the ICO to take regulatory action are.

We therefore recommend that the ICO publish clearly defined thresholds for when they will take regulatory action such as fines for noncompliance with ICO powers including information notices, enforcement notices, penalty notices and inspection powers. This would create better public understanding of the likely outcome of a complaint for individuals whose personal data has been breached.

B) Overhaul complaints mechanisms to expedite investigation outcomes & examine sectoral patterns of data protection breaches:

3. *Where possible, shorten investigation length to ensure individual data protection complaints related to special category data are dealt with in good time:*

It can take a long time for the ICO to investigate individual complaints – and this often means that the individuals whose data has been breached find it difficult to get recourse in an appropriate amount of time. This could affect individuals' ability to bring a case to court or Employment Tribunal due to statutory time limitations when a data protection breach is an aggravating factor.

As ICO capacity is stretched, some cases are not actioned for months, but the data protection breaches continue to be harmful. If an individual had applied to the ICO for clarification about a potential breach of their special category data, by the time the ICO have been able to act, the time limit to bring a discrimination case could have passed. This is a particular issue when data protection breaches occur in employment settings, when an individual has limited time from an incident of discrimination to bring a case.

4. *Examine patterns of data protection breaches at a wider level than organisational level and make regulatory or legislative recommendations from these:*

In relation to breaches of data protection law about individuals' HIV status, we see patterns within specific settings. This includes within healthcare, by police forces and by employers.

To enact meaningful compliance with the GDPR related to special category data, we recommend that the ICO examine patterns of data protection breaches across sectors, and beyond organisational level. If there are found to be recurring clear breaches of the GDPR in particular sectors or types of public body (such as police forces), we believe that the ICO should be making sector-wide recommendations to encourage compliance with the UK GDPR. Tackling these issues at a systemic level may enact more meaningful compliance with the GDPR than making

regulatory sanctions at the level of the individual organisation.

C) Create additional guidance related to data protection, health data & HIV status.

5. *Commit to producing further guidance on how information on individuals' health status is protected, and publish existing draft guidance as official guidance as soon as possible:*

The ICO have already produced excellent [draft guidance](#) on 'Employment practices and data protection: information about workers' health'. This guidance looks practical and ultimately likely to be very useful to employers who may breach GDPR regulations when sharing personal health information about workers without their consent.

We recommend that the ICO officially publishes this draft guidance as soon as possible, to provide clarity to organisations about what actions are and are not in contravention of the GDPR.

We also recommend that the ICO produce similar draft guidance on this issue in other settings, including in healthcare settings and for the police, to bring similar clarity.

The ICO should also consider producing similar guidance for the general public, written in layman's language, to improve public awareness of when they should make a complaint to the ICO about breaches of their personal data. This should be made available on [this page](#) for the public.

6. *Create clear guidance on the extent of the ICO's powers for individuals who have experienced a personal data breach, and how they might get recourse if protection of their special category data is breached:*

The ICO often do not provide remedy for individuals to get recourse when their personal data is breached. People living with HIV who have raised concerns about how organisations have handled their personal data often find that the ICO are more likely to sanction based on overall organisational behaviour, as opposed to forcing compliance in relation to a particular case.

This acts as a barrier to individuals reporting to the ICO. This is because there often is not a route to take action via the ICO in individual cases. For example, when an individual is seeking compensation for a data protection breach, or for an organisation to comply with GDPR.

We therefore recommend that the ICO produce clear guidance for individuals about how they might get specific recourse (such as compensation through the court system) when their special category health data has been shared without their consent in any setting.

We also recommend that the ICO should consistently provide clear and detailed reasons for their judgements, so that if a specific sanction is not applied to an organisation, the affected individual understands why, and how their report is used by the ICO.

7. *Produce guidance related to individuals breaching regulations on protection of special category data:*

One of the most common breaches of data protection in relation to an individual's HIV status is when someone they personally know, such as a family member, friend or acquaintance, shares their status without their consent. Whilst the Equality Act 2010 does provide for individuals to get recourse to justice if they are harassed because of their HIV status (see below), current ICO guidance does not currently provide clear enough information on when data protection law has been breached.

We therefore recommend that the ICO produces specific guidance for individuals whose special category data (such as health data) is shared without their consent by individuals, as opposed to organisations. These individuals need clarity on what the legal and regulatory framework is for challenging these incidents under data protection law, not just equality or human rights law.

4. The Data Protection and Digital Information (No.2) Bill

The Government's [Data Protection and Digital Information \(No.2\) Bill](#), currently passing through Parliament, intends to strengthen the UK's data protection regime and legislation and differ from the EU GDPR in several ways.

Whilst National AIDS Trust are supportive of the Bill as a whole, we have some concerns that the Bill as currently drafted does not go far enough to prevent individuals' HIV status being shared without their consent in a variety of settings. We believe that the Bill must:

- Clarify what an 'administrative purpose' is for organisations processing employees' personal data.
- Retain the duty on police forces to justify why they have accessed an individual's personal data.
- Mandate that a third country's 'data protection test' is reviewed annually to ensure ongoing suitability of international data transfer.
- Remove the proposed powers of the Secretary of State to assess other countries' suitability for international transfers of data and place these on the new Information Commission instead.

We detailed suggestions for amendments to the draft Bill, and our rationale for these, in [our evidence submission](#) to the Public Bill Committee. We are conducting a programme of Parliamentary engagement to attempt to have the Bill amended before it becomes law, in order to prevent people's HIV status being shared without their consent wherever possible.

Appendix 1. HIV & data protection within the Equality Act 2010: some worked examples

To feel comfortable sharing their status with others, people living with HIV need to be treated with equality, dignity, and respect. A person living with HIV is classified under the protected characteristic of 'disability' within [Schedule 1](#) of the Equality Act 2010, they must not be discriminated against purely because they are living with HIV.

This includes both ensuring that they are free from discrimination because they are living with HIV, and that they are free from harassment and victimisation. Relevant sections within the Equality Act 2010 that are relevant to this issue include:

Direct discrimination ([Section 13](#)): A person must not be treated unfavourably because of any protected characteristic. This discrimination must be a conscious decision by an individual or organisation and will often

require a comparator to prove discriminatory treatment.

For example, a doctor would commit direct discrimination if they discovered that a patient was living with HIV and then gave them a poorer standard of care than a patient not living with HIV.

Discrimination arising from a disability ([Section 15](#)): Discrimination arising from a disability occurs when a person is treated unfavourably because of something connected to their disability, rather than the disability itself, and it cannot be justified. The person discriminating needs to know, or be reasonably expected to know, that the individual has a disability. Unlike direct discrimination, there is no need for a comparator and justification can be made. Discrimination arising from a disability occurs with regards to a person living with HIV if discrimination occurs that is connected to their HIV status, rather than discrimination against the person themselves.

For example, if an employer learnt of their employee's HIV status and then required the employee to share their HIV status with other organisations they worked with, this would be considered 'discrimination arising from a disability'.

Indirect discrimination ([Section 19](#)): Indirect discrimination is where a provision, criterion or practice is applied to everyone however it puts a person/people at a disadvantage when compared to others who do not share that particular protected characteristic. This can only be justified if it can be claimed to be a 'proportionate means of achieving a legitimate aim'.

For example, if an individual in police custody shared their HIV status with the officers on duty in that police station, who then subsequently followed a station policy to record all health data on a file visible to officers who did not need to view this information, this could be considered 'indirect discrimination' on the grounds of HIV status.

Failure to make reasonable adjustments ([Sections 20 and 21](#)): Organisations must take positive steps to actively remove disadvantages that people with a disability face in the context of their employment. This should be done by accommodating requests for flexibility within the workplace. What is considered a 'reasonable adjustment' will depend on the nature of the request (including cost, practicality, and

implications) and the size of the organisation(s) involved.

For example, if an employee living with HIV required time off during their working hours to attend medical appointments and this was refused after they shared their HIV status to their line manager, this would be considered a failure to make reasonable adjustments.

Harassment (Section 26): An individual or organisation must not subject a person living with a disability to behaviour that has the purpose or effect of violating a person's dignity, or creating an intimidating, hostile, degrading, humiliating or offensive environment for them.

For example, an individual living with HIV shares their HIV status with their new partner. They are subsequently called unpleasant names by them and are threatened with having their HIV status shared on social media. This would be classified as 'harassment' under the Equality Act.

Victimisation (Section 27): An individual or organisation must not treat a person with a protected characteristic less favourably because they have (or are thought to have) done a protected, such as made or supported a claim about discrimination.

For example, a person living with HIV launches a claim against their healthcare provider on the grounds of direct discrimination for sharing their HIV status without their consent. The healthcare provider finds out and subsequently gives them a poorer standard of care or refuses them care. This would be classified as 'victimisation' under the Equality Act.

Public sector equality duty (Section 149): The Equality Act contains a duty for public authorities to combat institutional discrimination, against all protected characteristics.

This includes a duty to have due regard to eliminate discrimination, foster good relations and advance equality. This includes removing disadvantages, encouraging participation, taking account of disabilities, tackling prejudice and promoting understanding.

For example, if a public body such as a police force or an NHS trust do not actively attempt to prevent discrimination resulting from the sharing of a person's HIV status, they would be in breach of their Public

Sector Equality Duty. Regulators such as the ICO must also adhere to this Duty.

Appendix 2. Data protection legislation (GDPR) and how it applies to HIV status data

The [Data Protection Act 2018](#) (GDPR) provides the legal framework within the UK regarding data protection, including the protection of personal data. An individual's HIV status is regarded as special category data within the UK GDPR and is afforded specific protections by law.

The GDPR sets out specific [rights for individuals](#) in relation to their personal data such as their HIV status. These include the following rights which can be complied with in relation to HIV status in the following ways:

1. [The right to be informed](#) – To comply with this right, people living with HIV should be informed before information about their HIV status is recorded by an organisation.
2. [The right of access](#) – To comply with this right, organisations should comply with Subject Access Requests from individuals related to their special category data such as their HIV status.
3. [The right to rectification](#) – To comply with this right, organisations should rectify inaccurate data about an individual's HIV status, if requested.
4. [The right to erasure](#) – To comply with this right, organisations should erase data related to HIV status where it is no longer relevant for them to continue to store this data. This includes when the data is held by public authorities such as the police, after it is no longer necessary for them to hold such information.
5. [The right to restrict processing](#) – To comply with this right, organisations should not use data related to an individual's HIV status for any purpose if a request to restrict processing is submitted to them. This would include using it as part of internal monitoring of data on employee disabilities, for example.

6. [The right to data portability](#) – This right is less likely to be relevant in the context of sharing of HIV status but should still be complied with if required.
7. [The right to object](#) – To comply with this right, an organisation should ensure that if an individual objects to data related to their HIV status being processed, they should comply with this within the timeframe required by the law. It is important to note that there are certain situations where this may not be possible, such as in part of legal proceedings.
8. [Rights in relation to automated decision making and profiling](#) – To comply with this right, an organisation should not employ automated decision making in relation to an individual's health data, including their HIV status.

Contact us

To discuss the contents of this briefing in more detail, please contact:

Adam Freedman
Senior Policy & Campaigns Officer
National AIDS Trust

Adam.freedman@nat.org.uk