



**NATIONAL
AIDS
TRUST**

Securing rights
Stopping HIV

HIV & Data Protection

Managing difficult conversations



We're the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions.

We run a Discrimination Advice service for people living with HIV who have experienced discrimination because of their HIV status.



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What will we cover today?



Give context to data breaches



Having sensitive conversations



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**Why is this important for
the ICO?**



The [Public sector equality duty](#) came in to force in April 2011 (s.149 of the Equality Act 2010) and public authorities like the Ministry of Justice are now required, in carrying out their functions, to have due regard to the need to achieve the objectives set out under s149 of the Equality Act 2010 to:

- (a) eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Equality Act 2010;
- (b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
- (c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.



How does HIV relate to data protection?

“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**”**

Adam Freedman
Policy Research and
Influencing Manager



HIV and AIDS are not the same thing

HIV can affect anyone – no matter your gender, age, sexuality or ethnicity

Most people with HIV (95%) know their status because they have been diagnosed

Around 98% of people who are receiving treatment have an undetectable viral load. People with an undetectable viral load cannot pass on HIV.

Undetectable = Untransmissable (U=U)

There's a pill you can take to protect against HIV

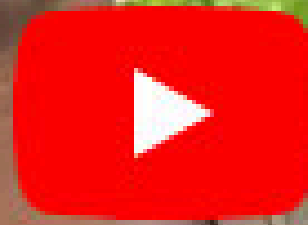




Tresca talks about the impact that HIV stigma has had on her life



Share



Watch on  YouTube

There are 16 million disabled people in the UK

3 out of 4 disabled people (72%) have experienced negative attitudes or behaviour in the last 5 years

9 out of 10 disabled people (87%) who had experienced negative attitudes or behaviour said it had a negative effect on their daily lives

It is estimated that 70-80% of disabilities are invisible

Disability

Race

Nationality

Ethnic or national origin

Religion or belief

Sex

Age Gender Reassignment

Marriage and Civil Partnership

Sexual Orientation

CASE STUDIES

Scary Upset Scary Alone
Some days its too much
Ability to trust Alone
fears too much
Angry trust
Daily distrust Unfair
worry
Not ready
Betrayal No control Shame
Upset Burden Scary Nightmare
Feelings of isolation Not ready Burden Scary Nightmare
Judgement distrust Upset
Disowning me No control Shame
Weight to bear Alone Ability to trust Alone
Angry No control Shame
Weight to bear Alone Ability to trust Alone
Reignited fears
Angry Alone Not ready Disowning me
Illness Shame Punishment
Punishment Alone Disowning me Cruelty
Unfair Reignited fears
Angry Ability to trust Cruelty
Illness Betrayal Punishment
Daily distrust Unfair Upset
worry Ability to trust
Unfair Betrayal Upset
Nightmare Not ready scary Disjointed relationships Daily worry
Punishment Shame Burden
Some days its too much Reignited fears

Gemma was diagnosed with HIV last year. She is on effective treatment and is undetectable

She is still coming to terms with her diagnosis and hasn't shared her HIV status with anyone yet

Gemma starts work in an office. She needs some time off for medical appointments, and requires some flexibility with hours as her medication can make her tired

She decides to share her HIV status with her line manager to make these requests, and asks that it be kept confidential

Her manager is shocked, asking intrusive questions about how she acquired HIV and showing concern that Gemma may pose a risk to other members of staff



Her manager schedules a meeting for a week's time, putting it in her calendar as 'Discussion with Gemma about managing her HIV'

One of Gemma's colleague, Luke, sees the meeting. It can be accessed by anyone

Luke tells a colleague, and soon word spreads that Gemma is living with HIV

Gemma starts getting harassed at work, she is told that she is dirty and that 'women don't get HIV'.

Management are aware of this harassment but don't do anything about it.

Gemma's line manager also starts treating her differently, avoiding talking to her, not giving her work, not putting her forward for promotion



The situation becomes unbearable and Gemma is forced to leave the job as she receives no support

She wants to do something about it but doesn't know what. It is hard for her to talk about, and she can't reach out to friends or family as they don't know about her HIV status and she is afraid they would be judgmental

She contacts the Discrimination Service 4 months after leaving the job

She is advised that she has discrimination claims with merit, but she is unfortunately out of time to bring a legal claim (3 months time limit)

She is advised that she could report the situation to the ICO, who can identify whether her manager putting her HIV status on the public calendar would constitute a data breach

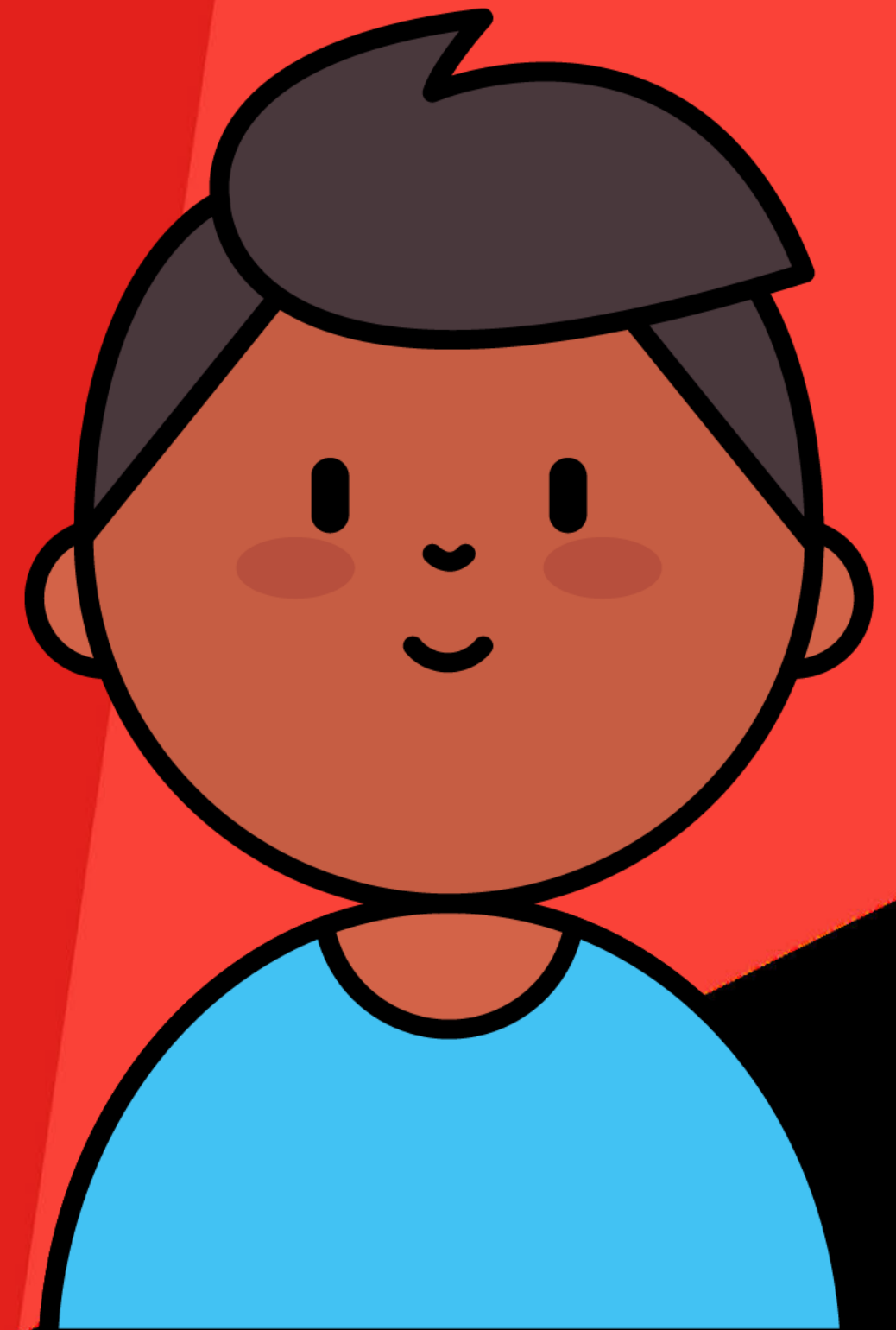


Jordan Isaacs is living with HIV and diabetes.

They had to go to A&E for an unrelated medical issue

When they arrived, they shared their medical conditions. They were immediately separated into an isolated room

Noone came to see them for 12 hours. They were in excruciating pain, had no food or water, nearly went into hypoglycaemic shock and had to remove their own canula



Jordan asked why noone had come in, and was told there was a sign on the door saying

JORDAN ISAACS - HIV POSITIVE - RISK OF INFECTION UPON ENTRY

Jordan was upset, embarrassed, angry, exhausted

They contacted the discrimination service. They were advised to bring a legal claim and report the situation to the Care Quality Commission

Jordan is most upset that anyone in the hospital could see their name and HIV status. They have since disengaged from care, cancelling important appointments and missing check ups due to the trauma



Carl is living with HIV. He is in prison for a minor offence.

A prison officer sees him taking medication and asks what it is for

He doesn't want to answer as he can be heard by other people in the prison

He shares his HIV status and the prison officer calls him an 'old infected f*g'

The officer tells other people on the wing, and Carl becomes a target in the prison. He is subjected to harassment, abuse and violence

Eventually he is transferred to another prison due to concerns for his safety



Zeinab is living with HIV and lives in a small town

She was the victim of domestic abuse from an ex-partner

Her ex-partner is threatening to share her HIV status with the local community, harassing her by texts and and leaving notes on her door

Zeinab is terrified because she doesn't know anyone else living with HIV and is afraid of how people will react

Zeinab makes the decision to move to another town for her own safety



SENSITIVE CONVERSATIONS

People First Charter



Person-first language simply puts **people before their condition**, recognising that people are people, and not defined by their condition. In HIV care we should avoid terms like **'HIV-infected people'** and use **'people living with HIV'**



AIDS

HIV patient/ HIV infected
Spread HIV/ Catch HIV
Disclose HIV status

HIV

Person living with HIV
Transmit HIV/ Acquire HIV
Share HIV status

There are **no fixed rules** and what is considered 'correct' will vary by condition, over time, and between individuals.

What is **critical** is to ask the communities with a given condition or characteristic **how they prefer to be described** and to revisit this regularly.

We will never get it right all of the time but **open discussion** about preferred terminology will **drive understanding and change**.

Things to keep in mind

Disabled people are likely to have experienced stigma or discrimination. Bear this in mind when speaking about disability-related data breaches

For some individuals, the ICO is the only mechanism to hold organisations accountable

Data breaches are one part of a much larger story

Everyone has their own preferences with how they want to be addressed: if you are unsure, ask or mirror their language



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Questions?

