Equality in name only?

A review of the experience of discrimination for people living with HIV in the UK

April 2025

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Foreword

“The remarkable progress on HIV from a medical and public health perspective is one of the most successful health stories we can tell.

To be within touching distance of ending an epidemic within 40 years - without a cure and without a vaccine - is remarkable.

However, the progress in reducing the stigma and discrimination experienced by people living with HIV has not matched the medical advancements – despite legislation being in place to protect from unfair treatment.

Discrimination against people living with HIV happens in many settings. This includes being denied routine cosmetic and beauty services such as ear-piercing or a tattoo, having medical appointments and procedures being pushed to the end of the day and people being told to wait in a separate room, facing inappropriate and intrusive questioning, and having personal information shared without consent.

This matters. It matters because every time someone is refused a service they're entitled to they are made to feel that they are ‘unsafe’ and unwelcome. The detrimental effect this has can last a lifetime. Too often, people living with HIV are denied basic rights that everyone should be able to take for granted: respect, fair and equal treatment under the law, and the peace of mind that they can live without fear of discrimination from people, organisations and institutions.

While discrimination can happen to anyone living with HIV, it often interacts with other forms of prejudice, including racism, homophobia, transphobia, xenophobia, misogyny. Black, Asian, and Latin American communities, as well as other marginalised groups, including people who identify as trans or non-binary, often experience greater levels of stigma and discrimination, particularly within the context of institutional racism and organisational bias. This means that addressing HIV discrimination must be done holistically, and when done so, it will have the wider benefit of everyone being treated more fairly, while working toward a more equal society as a whole.

The consequences of this lived experience of discrimination for people living with HIV are deep, many-sided, and damaging. Over a quarter of people living with HIV report being afraid to attend a healthcare appointment, and around 1 in 7 avoiding accessing healthcare services because of their HIV status.[1] Additionally, fear and experiences of discrimination have a profound impact on mental health and self-esteem. These factors are closely linked to high levels of anxiety and depression among people living with HIV, as well as contributing to increased rates of intimate partner violence and reluctance to access support services.

This not only has serious implications on a person's health, but the cumulative effect also undermines the efforts to ensure a good quality of life for everyone living with HIV. And while the UK has an ambitious goal of ending new HIV transmissions by 2030, it will not happen unless discrimination is ended once and for all."

Silvia Petretti,
Chief Executive, Positively UK

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[1] **Positive Voices, 2022. Available at:** https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report

Introduction

If government, public bodies, institutions and employers take the urgent action outlined in this report, we will end all unlawful discrimination.

This report focuses on unlawful discrimination experienced by people living with HIV from organisations, companies, and institutions.

It starts with an overview of the legal protections that are in place for people living with HIV, and then highlights evidence and data that we have gathered to show the extent and areas that discrimination occurs. We reflect on the impact this has on people living with HIV, and end with recommendations for actions that should be taken to end discrimination.

We see a concerning picture. Unlawful discrimination on the basis of HIV is prevalent and regular – in healthcare settings, places of employment, and the provision of services. Legal standards are not being reached and rights are not being respected.

Discriminatory acts often originate from stigmatised preconceptions and beliefs about HIV which are held across society and the general public. These, in turn, stem from a lack of awareness and knowledge about how HIV has changed – what effective treatment and prevention exists, and what it means to live with HIV today. While stigma or lack of knowledge cannot and should not be legally challenged, when it manifests in a discriminatory act – such as refusal of a service – it breaches the law and must be challenged.

The widespread lack of knowledge and awareness of HIV is reflected in outdated organisational policies and procedures which are not fit for purpose. This has a mutually reinforcing effect: a discriminatory organisational policy will entrench an individual's preconceptions. And when someone is predisposed to feeling and reacting negatively to HIV, that will influence reviewing and setting organisational policies, practices, and procedures that can be discriminatory. This can be the case even when someone is well-intentioned – for example, we have encountered the view from professionals who by no means want to be discriminatory, but through an attempt at treating everyone the same, do not recognise the rights of people living with HIV (for example, in requests for reasonable adjustments).

We need to break this cycle. And when we do, this will benefit everyone not just people living with HIV: workplace practices will improve to better recognise the rights of everyone protected under the Equality Act, respect for privacy of sensitive personal information will be raised across the board, and services will be more accessible for wider groups of people and communities.

Broadly, we think that the legal protections set out in the Equality Action are right: HIV is classified as a protected characteristic and discrimination due to HIV is unlawful. But not enough people know about the law and how it applies to HIV or how to comply with the legal requirements, and are working under outdated policies, procedures, and mindsets.

We know that when people learn more about what it means to live with HIV today, including what rights people living with HIV have, and how different behaviours can be stigmatising and discriminatory, things change for the better. A fundamental part of the solution has to be appropriate workplace training programmes and awareness-raising efforts to improve knowledge and understanding.

However, broad awareness-raising across a population is hard and takes time. So, while we hope that the goal of increased knowledge of HIV is part of the new HIV Action Plan for England, and a priority for all UK devolved governments, we also need additional specific and targeted actions in place which tackle and prevent discrimination in the key settings where it occurs.

If government, public bodies, institutions and employers take the urgent action outlined in this report, we will end all unlawful discrimination.

What are the laws that protect people living with HIV from discrimination?

The Equality Act 2010 and the Disability Discrimination Act 1995

People living with HIV are protected from discrimination by law.

In England, Wales and Scotland the Equality Act 2010 classes HIV as a disability – which is one of the protected characteristics – and provides for legal rights and protections.

The Equality Act covers both employment and the provision of services (private and public). People are protected if they are living with HIV, perceived to be living with HIV, or are associated with people living with HIV.

People living with HIV are protected under the Equality Act from:

- Direct discriminatory treatment
- Discriminatory organisational policies
- Discrimination arising from a disability
- Failures to make reasonable adjustments
- Harassment and victimisation

The Equality Act also contains a Public Sector Equality Duty, requiring public authorities in Great Britain to eliminate discrimination against people living with HIV, to advance equality of opportunity for people living with HIV, and to foster good relations between people who are living with HIV and those who are not.

In Northern Ireland, people living with HIV are protected by the less comprehensive, and older, Disability Discrimination Act 1995. A similar duty on public authorities to eliminate discrimination against groups exists in Section 75 of the Northern Ireland Act 1998. National AIDS Trust has identified inadequacies with this legislation and are campaigning to update the law to bolster protections for people living with, at risk of acquiring, or affected by HIV, in Northern Ireland.

Law in action case study
How Equality Act has been used to challenge HIV discrimination:

In Mr J Andrews v Greater Manchester Buses (South) Ltd and Mr S Roughley (2018), an employer was found to have discriminated against a person living with HIV by the Employment Tribunal. The employer was found to have failed to make reasonable adjustments and to have committed indirect discrimination on multiple counts: failure to adjust working hours so the employee could regularly take their medication, failure to accommodate rest days to deal with medication side effects, failure to adjust an absence management procedure, and making a requirement for the employee to do driving duties when dealing with side effects of HIV medication.

The employer was found to have harassed the employee based on their HIV status by saying that they should change their medication to improve their attendance and to prevent their job from being at risk. Discrimination arising from a disability was found to have occurred because the employee was given written warnings, was not provided with alternative duties at work and asked to change their HIV medication.

The Employment Tribunal ordered the employer pay a total of £40,000 in compensation to the employee, £22,000 of which was directly related to breaches of the Equality Act. This demonstrates that organisations that discriminate against people living with HIV are liable to pay substantial costs to the affected individuals.

Data Protection Act 2018 and the UK General Data Protection Regulation (UK GDPR)

Medical information, including HIV status, is considered ‘special category data’ under the UK General Data Protection Regulation. In order for organisations to process or share information about an individual’s HIV status, they must adhere to requirements set out in the UK GDPR.

As a starting principle, an individual’s HIV status should not be shared without their consent. However, there are times where it is necessary to share HIV information under another legal basis (for example, for the medical care of that person). In healthcare settings, information should generally be kept confidential unless sharing it is strictly necessary for their care or if there is a proven risk to others from not sharing it.

The sharing of an individual’s HIV information is often a precursor to them experiencing discrimination - for example where an individual’s status is unlawfully shared in a workplace with colleagues, which can lead to bullying or harassment.

HIV discrimination in the wider context and impact of U=U

The medical consensus and evidence, first noted in 2016, that people living with HIV who are on effective medication are unable to pass the virus on to others - known as “Undetectable = Untransmittable” (U=U) - should have been a game-changer for equality. It means that for cosmetic and beauty treatments, for example, as well as routine and medical procedures, nothing beyond universal precautions are needed. Yet, too often, that is not the case in reality.

Official communications, laws and organisational policies that were introduced in the 1980s were intended to ensure that the public took necessary precautions to avoid acquiring HIV, since a person living with HIV was at that time expected to develop AIDS and die. Many of the policies and ways of working put in place in the 80s and 90s remain in place today, and cause discrimination against people living with HIV as they have not kept pace with medical advancements on HIV.

Legislation and procedures do not automatically update. Changes have to be fought and campaigned for. National AIDS Trust (NAT) spent years campaigning to amend the Human Fertilisation and Embryology Act 1990 which discriminated against same sex couples where one partner was living with HIV from donating sperm or eggs. The Government finally changed the law in 2024. Whenever laws and policies are found that are causing discrimination against people living with HIV, they need to be campaigned against, amended or repealed.

For example, people living with HIV cannot get a licence to compete in boxing professionally. This is because of the perceived risk of HIV transmission to competitors, staff and spectators if a boxer living with HIV is bleeding – an assumption that is scientifically inaccurate and based on an outdated understanding of HIV medication and transmissibility.

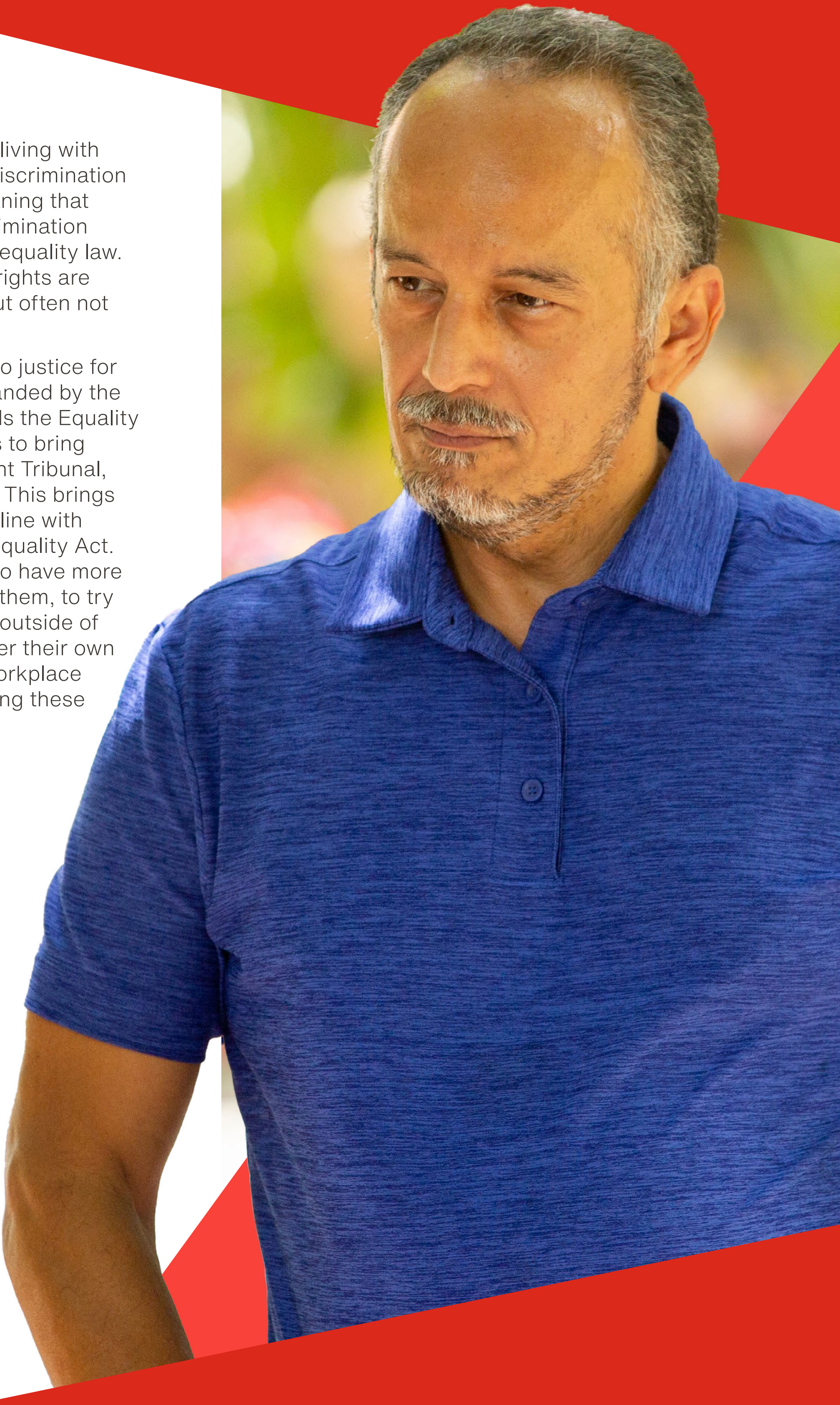
Barriers to justice and realising equality rights

People living with HIV who experience discrimination often face obstacles in realising their rights and preventing future discrimination. This can happen because:

- Many people living with HIV are not aware of their rights and protections under the law, so often do now know how to call out discrimination and how to challenge it.
- Access to a Legal Aid solicitor for people who cannot afford legal representation is severely constrained by a lack of capacity in the justice system.
- HIV discrimination often intersects with other disabilities and protected characteristics including race, gender identity and sexuality, as well as mental health conditions. This can make cases complex to pursue in courts and tribunals as it can be hard to determine whether discrimination is due to HIV status or another protected characteristic.
- Discrimination proceedings and their outcomes – such as employment tribunals - are published and publicly available. This poses a significant barrier to accessing justice for individuals who do not want their HIV status to be public. It is possible to be granted anonymisation orders, but this can be a difficult process, especially without legal support.

These barriers make it hard for people living with HIV to make formal complaints about discrimination or bring cases to court or tribunal, meaning that there are limited examples of HIV discrimination that are successfully challenged using equality law. It leaves us with a situation where HIV rights are protected in concept and legislation, but often not realised in reality.

We are, however, pleased that access to justice for employment discrimination will be expanded by the Employment Rights Bill. The Bill amends the Equality Act 2010 so that people have 6 months to bring discrimination claims to the Employment Tribunal, up from the current 3-month time limit. This brings the time limit claims for employment in line with other discrimination claims under the Equality Act. It will also allow people living with HIV to have more time to process what has happened to them, to try and resolve their discrimination issues outside of the tribunal system first and to look after their own wellbeing following an experience of workplace discrimination. We look forward to seeing these provisions becoming law.



A review of the evidence of discrimination

Data showing the extent of HIV discrimination is inconsistent. While efforts are being made to gather information about the reach and impact of stigma, there is less collection regarding discrimination. NAT has found that records are often incomplete or reporting systems are not set up to store entries of specific HIV-related discrimination. Below, we collate the available data related to HIV discrimination to highlight the extent of the issue, and where reporting systems must be improved to more accurately measure the scope of the problem.

NAT's Discrimination Service

For over two years, NAT has been running a discrimination casework service funded by the National Lottery Community Fund. The service provides free and confidential advice and support to people living with or affected by HIV who have faced discrimination. Since its inception, the service has supported 161 individuals who have sought support, including discrimination in employment, in criminal justice, in private and public services and in healthcare settings.

We have assisted individuals in all areas of the United Kingdom, demonstrating that HIV discrimination is widespread, and across a vast range of settings. Put simply, wherever people live, work, and seek services, discrimination happens. Numbers of people using our service have increased year on year, and we are now supporting more than twice the number of people that we did two years ago. While this is likely to be due to increased awareness of our service, rather than an increase in discriminatory actions, it means that the people we support are just a tip of the iceberg of the total number of people living with HIV experiencing discrimination.

Data from HIV Confident – NHS staff survey

NAT has been working in partnership with Positively UK and aidsmap to develop the HIV Confident charter mark to help organisations fulfil a commitment to welcoming and respecting people living with HIV as employees, patients, service users or customers.

The pilot phase of this programme was delivered to four NHS Trusts and three GP practices, with each organisation promoting a survey to all staff. The results show concerning evidence of discriminatory practice and an underlying lack of confidence when caring for patients who are living with HIV.

Key findings from the survey of 1454 staff in NHS showed:

- **A lack of knowledge on U=U -**
  Almost 20% of respondents either somewhat or strongly disagreed with a statement that being on treatment and having an undetectable viral load meant that a person living with HIV would not pass on HIV through sex. A further 17% responded that they did not know.
- **Misconceptions about transmission -**
  23% reported mistakenly believing that HIV could be passed on by spitting, and 5% by sharing cups and cutlery.
- **Unnecessary fears of transmission -**
  14% of respondents strongly or somewhat agreed that they would feel at risk if they were looking after someone living with HIV, with a further 18% neither agreeing nor disagreeing. When asked about specific healthcare procedures, these percentages rise, with 46% of respondents responding that they would be a little worried or worried about HIV if drawing blood from a person living with HIV and an additional 5% being very worried.
- **The routine use of discriminatory practices -**
  Fears of transmission lead to discriminatory practices as indicated by 37% of respondents who agreed that staff should take extra precautions when caring for a patient living with HIV. Over half of respondents said that they would tell others about a patient's HIV status via notes, with 59% of respondents disagreeing that people living with HIV should have the right to withhold their HIV diagnosis from medical professionals if they choose to. 7% of respondents had observed an unwillingness within their workplace to care for people living with HIV and a poorer quality of care being provided prior to completing the survey. 14% had, at some point, heard discriminatory remarks made about someone living with HIV, 3% on several occasions.
- **NHS staff don't believe that people living with HIV are generally treated fairly -**
  Only 27% of respondents somewhat or strongly agreed that people living with HIV are treated fairly in the healthcare system and 43% expressed a lack of confidence in their knowledge and awareness of HIV. In additional free text comments, a significant number of respondents identified a need for training, with many suggesting that training should be mandatory.

> This data is strikingly consistent across each of the GP practices and Trusts and across different areas of the workforce and aligns to the findings of the European Centre for Disease Prevention and Control (ECDC) survey of healthcare staff within Europe and Central Asia. The survey also validates the experiences and perceptions of stigma in healthcare reported by people living with HIV in the 2022 Positive Voices survey and suggests that the HIV Confident pilot survey results are representative of knowledge and attitudes across the NHS.

"It is a real privilege to be involved in and learn from our pilot to become HIV confident. Tackling stigma, being honest about discrimination, blame and denial is essential if we are to prevent HIV transmission and address the impact of the virus on individuals, families and communities. I am delighted to lend my support to the work we need to do as an organisation to educate our workforce, review our policies and procedures, and strengthen the voice of those living with HIV."

Annie Laverty,
Chief Experience Officer, Newcastle Hospitals Foundation Trust

Discrimination reported to public bodies – results from Freedom of Information request

In 2024, NAT attempted to determine the extent of HIV-related discrimination that was reported in 2021, 2022 and 2023 in all NHS trusts, local authorities and police forces across the UK, as well as in some selected regulatory bodies and departments. We sent requests to 673 separate institutions under the Freedom of Information Act 2000, asking questions around numbers of discrimination instances relating to disability, ethnicity, sexual orientation and HIV status, as well as whether they had any HIV-specific policies in place relating to discrimination or protection of individuals living with HIV who may work for, or come into contact with, their service.

Of the 489 institutions that responded with data for at least one question, just 28 reported instances of HIV-related discrimination, totalling 82 separate incidents across 19 NHS trusts, three local authorities, four police forces and two regulators across three years.

Given the numbers of cases that are reported to us through our discrimination service, alongside survey data from people living with HIV and within the NHS, it is our assessment that 82 incidents in total across all public bodies is very unlikely to be reflective of the real number of HIV discrimination cases that have occurred. It seems more likely that these complaints are not being recorded correctly within public authorities' complaints systems or are not being reported by the people living with HIV to which they are happening.

Public knowledge and attitudes

NAT published public opinion research on knowledge and attitudes on HIV in 2021. While the majority of respondents agreed that it should be illegal to refuse someone a service or job because they are living with HIV, one quarter of those surveyed either opposed this statement or didn't know how they felt about it. This indicates a lack of knowledge that it is illegal to discriminate against someone based on their HIV status.

A quarter of the public also stated that their employer should have to tell them if a colleague is living with HIV – which would be unlawful.

Only a third of respondents said they have sympathy for all people living with HIV, regardless of how they acquired it. This gives real cause for concern as to how people in services or employment are minded to respond to reasonable requests based on HIV, and reactions of people – for example refusing services – when someone's HIV status is disclosed to them.

Experience:

A routine appointment at a dentist

“When I arrived for my dental appointment everything was laid out ready for an extraction. The dentist reviewed my medical notes, but as soon as she reached the section where it said that I was living with HIV, she suddenly stopped, and claimed she had “run out of time” to treat me. Then she said my tooth was too fragile for the procedure, and that she thought I had an infection and so I would need antibiotics before the extraction took place.

I was confused - everything had been set up for the procedure, and now she was refusing to do it. I knew I didn’t have an infection; I had been through extractions before and recognised this pain as being the same as it had been before.

But she just handed me a prescription and ushered me out the door, leaving me in excruciating pain.

Although another dentist saw me within a few days, confirmed that there was no infection and removed the tooth quickly, I just couldn’t shake what had happened.

I filed a formal complaint with the dental company, and after weeks of waiting, they replied just before the deadline for responses - brushing it off. They claimed to have conducted an investigation and found no wrongdoing. They had attached a letter from my dentist which was full of contradictory excuses.

“For the first time, I was made to feel “diseased”. It’s taken a huge toll on my confidence, and my trust in healthcare providers.”

I took my complaint to the General Dental Council (GDC). The investigation dragged on for months, and by the time the report came back, I had missed the six-month window to file a discrimination case. But it fully sided with me, finding multiple failures of medical negligence and discrimination. My treatment had been compromised due to unjustified fears and misinformation regarding my HIV status, reinforcing the kind of harmful stigma within the healthcare system that just shouldn’t exist.

“This entire experience has left me shaken. I’ve always been upfront about my HIV status with medical professionals, and I’ve never faced discrimination like this before. But because of this incident, I will now feel paranoid about disclosing it in the future. For the first time, I was made to feel “diseased”. It’s taken a huge toll on my confidence, and my trust in healthcare providers.”

Focus on discrimination in key areas

Refusal of access to services

People living with HIV are often refused services, despite this being illegal under the Equality Act and Disability Discrimination Act. They can also experience discrimination from policies that don't take the needs of people living with HIV into account sufficiently for them to be able to access services, while others experience harassment in services because of their HIV status.

For example, we know that some people living with HIV have been refused certain financial services products (e.g. insurance) because of the incorrect assumption that they are automatically more prone to getting seriously ill or dying. We have also seen people unlawfully excluded from leisure activities, because of a perceived risk of HIV transmission to other participants.

Healthcare settings

Despite the decades of care medical professionals have provided to people living with HIV, and despite the conclusive scientific evidence that taking HIV medication means HIV cannot be passed on (“Undetectable = Untransmittable”), misinformation and stigma mean that HIV discrimination still occurs in healthcare settings. Much of this discrimination is because of inaccurate fears of HIV transmission.

Examples include people living with HIV being put to the bottom of waiting lists for operations and other procedures, or being isolated in wards with warnings to medical staff that they are an infection risk, staff wearing unnecessary personal protective equipment when working with patients living with HIV, and even patients living with HIV being denied medical treatments without a reasonable basis for doing so.

[See case study on page 15]

The cosmetic and beauty industry and tattooists

HIV discrimination often occurs in the beauty industry, including cosmetic treatments and tattooing. In George House Trust’s research into discrimination in these settings, over half of survey participants reported being refused a service after sharing their HIV status.

People living with HIV are often denied cosmetic or other beauty treatments, or refused tattoos, because of perceived risk of HIV transmission to the practitioner. Others are refused services or charged more for a procedure, with advanced cleaning and sterilisation measures given as the reason. Measures beyond standard infection control procedures are not necessary to prevent HIV transmission. All of these actions are discriminatory against people living with HIV and are unlawful.

[See case study on page 16]

Experience: **Discrimination in healthcare**

Becky Mitchell MBE

“In 2014 I had quite a serious cycling accident, which had damaged my leg, so I had to go to hospital and get some stitches in my ankle.

I let them know about my status, because HIV medications sometimes interfere with antibiotics, and I didn’t want to compromise my treatment. And I let them know about my CD4 count and viral load, in case they needed to do a skin graft or any other surgical procedure. That was all fine.

But after I was discharged from hospital I had a follow-up appointment with a young doctor. My mum was there too because she’d driven me there. The doctor looked at me and Mum, and then asked me if I was an intravenous drug user. I said no, and then he asked: well, how did you contract it? I was so taken aback that I started to explain, but then I thought: hang on a minute, this is totally irrelevant to what I’m here for. What’s that got to do with anything?

And he also told the nurse who was looking after me to make sure she took extra precautions. This nurse had worked on a ward that had looked after HIV patients, in the late 80s and early 90s, so she knew that this was not appropriate. She encouraged me to write in and complain, which I did – and got an apology from the doctor.

Another time, one nurse told another that she had to put gloves on before giving me the flu jab because “she’s HIV”; and once my dentist told his nurse that she had to wash hands after treating me, even though she had gloves on.”

Experience: Being refused an appointment for a tattoo

“After booking a tattoo, paying a deposit and approving the tattoo artwork, I was sent a disclaimer form on the evening before the tattoo day. I filled in the form fully and accurately. When asking about health, I ticked the HIV positive box and didn’t think anything of it. I had previously got a piercing that asked the same questions and nothing was commented on or raised. On the morning of the tattoo, my tattoo artist called me asking if I had ticked the HIV positive box by accident. I took this call in the middle of a busy restaurant, explaining to the artist that I was undetectable and it didn’t pose any risk to them. She still refused to take my booking, saying the risk was still too great. She offered me a refund of my deposit and just said sorry and hung up.

At first, I was a bit shocked and dazed as to what had happened. I went home, and this feeling soon changed to anger and resentment as to how someone could be so ignorant.

If anything, this instance made me feel more empowered and passionate about speaking up about HIV and educating where possible.

At first, you may feel anxious and angry about talking about your status. But don’t let any stigma you may face play negatively on your mind or devalue your self-worth. Use any opportunity you can to positively educate and inform!”

Case study:

How a local partnership is challenging discrimination in the beauty industry

Across Greater Manchester and Liverpool, George House Trust inspires people living with HIV to live healthy, confident lives by providing HIV support, advice and advocacy services.

In 2023, with funding from Manchester City Council, they were able to initiate a programme of work to understand more about where and how people living with HIV experienced discrimination when accessing cosmetic treatments or tattoos.

From a survey of over 400 respondents living with HIV, they found that:

- **79%** of respondents said that the subject of HIV had come up when accessing beauty or cosmetic treatments
- **73%** of people had seen HIV or AIDS mentioned on a consultation form
- **51%** of people who'd shared their HIV status reported being refused a treatment because of HIV status

Through focus groups with people living with HIV to discuss how discrimination and stigma could be addressed and the impact refusal of services and discriminatory practice has, people showed how it's not just about the frustration of being able to get a tattoo itself, for example, but that there are real and lasting consequences for their mental health, confidence, wellbeing and self-esteem.

With the support from a HIV ally and beauty industry professional, Sam Marshall, George House Trust initiated roundtable discussions with representatives from the cosmetic industry in Manchester to try and turn this around. Through producing awareness-raising activities and a new online training session endorsed by the Hair and Beauty Industry Authority, they are starting to turn the dial to ensure that no-one in is subject to unlawful discrimination in the cosmetic industry.

George House Trust have produced a toolkit for the beauty sector on how to ensure customers living with HIV are not discriminated against when accessing these services. **Please see here for more information.**

"Every day at George House Trust we are focused on supporting people to live healthy and confident lives with HIV. We see the impact that discrimination has on our people and communities – it's not just unlawful, it is harmful. How can people have the wellbeing and self-confidence to both be healthy, and do everything they want – and have a right - to do in their lives, when going for a beauty treatment or trying to get a tattoo runs the risk of having the door slammed in your face? At a local level here in Manchester we are seeing the impacts of how working together across sectors can really make a difference; working with politicians, local authority licensing teams, industry professionals and people living with HIV. There are many brilliant champions working in the beauty industry – it's about making those connections and having the time and capacity to support them in making changes. We can only tackle the HIV stigma that exists by working together."

- Darren Knight, George House Trust

> Places of work remain a key setting where people report instances of HIV discrimination occurring. They report experiencing discrimination in several ways.

Discrimination in the workplace

Places of work remain a key setting where people report instances of HIV discrimination occurring. They report experiencing discrimination in several ways, including breaches of confidentiality about HIV status, bullying and harassment, discriminatory health and safety or other policies, refusal of employment, failure to make reasonable adjustments to jobs or the hiring processes, being overlooked for promotion and not having insecure work contracts renewed. Harassment and victimisation can take place against people living with HIV and may take the form of bullying or prejudiced comments.

Difficulties in accessing justice via Employment Tribunals present a barrier to challenging HIV discrimination in the workplace. With only a three-month time limit from an incident of discrimination to bring a claim, many people living with HIV struggle to bring forward a claim in time. This means unscrupulous or indifferent employers never face the legal consequences for allowing this behaviour to continue.

Experience: HIV in the workplace

I was a nurse for about 13 years. I made occupational health aware from day one that I had HIV, and that my viral load was undetectable. I told them that I didn't want my manager or any colleagues to know about this, and I reiterated this each time I communicated with them.

"After I was unwell for a time, with an issue unrelated to my HIV, I asked that occupational health put procedures in place so that I didn't need to enter TB isolation rooms. I believe that at this point they disclosed my status, against my wishes, to other people working in my NHS Trust.

"When I applied for, and got, a new job as a specialist nurse, my start kept being delayed. Another person who had been appointed at the same time as me had taken up her new role, but five months later I was still waiting. My new manager was asking me intrusive questions about my health. It made me panic.

"Finally I received a phone call from the Occupational Health manager, who told me that all of my confidential medical records had been posted to the hospital dashboard. This meant all of the senior staff, management and colleagues at my level would be able to see it. It was there for a whole weekend – from Friday to Monday morning, when my then manager alerted Occupational Health and told them to remove it. She told me that only HR had seen it, but I didn't believe or trust this. I think that my record was deliberately posted, without my consent.

"Knowing that my health status had been shared without my permission sent me straight into a deep depression. I couldn't cope or comprehend what had happened to me. It was the darkest time of my life. The trauma, grief and pain of knowing what had happened – when I hadn't done anything wrong – was so great. I still experience these emotions to this day, when I talk about the situation. Since then I have not been able to work. It has drained me. The stigma has ruined me.

Sharing of HIV status without consent

The sharing of HIV status without consent is a common type of discrimination experienced by people living with HIV – across all settings.

These breaches are governed by the Data Protection Act 2018 rather than anti-discrimination legislation. However, these breaches are often discriminatory in nature, where people living with HIV have their HIV status shared in situations where other health data would not be. For example, it might be discussed in the workplace as gossip or shared with medical staff when this is not necessary for the provision of medical care. It is therefore important that tackling breaches of people's HIV status is seen an anti-discrimination activity.

How to challenge and prevent discrimination: Case studies

Whilst public bodies have specific duties under the Equality Act 2010 or Northern Ireland Act 1998 to prevent discrimination, it is important that all organisations play their part if we are to create a society where everyone is free of discrimination in every aspect of their lives.

There are best practice examples of what organisations should do when faced with a situation where someone living with HIV says that they have been discriminated against because of their HIV status:

Case study: Good practice for organisational policies:

One key way to tackle HIV discrimination in organisations is to have an HIV-specific policy which sets out the facts relating to HIV and its transmission, as well some of the key equalities provisions that organisations must comply with in order to prevent discrimination against people living with HIV (in either the Equality Act 2010 or Disability Discrimination Act 1995).

An example of good practice that we identified of this through our Freedom of Information requests is the Mid Cheshire Hospitals NHS Foundation Trust. They have a dedicated HIV Clinical Employment Policy, which covers both the Trust and staff's responsibilities under the Equality Act 2010. This includes preventing harassment against people living with HIV, not denying treatment to patients and detailed occupational requirements for different job roles for people living with HIV. The policy is also regularly reviewed and renewed every three years, to ensure accuracy and legal compliance. This is an example of best practice that other organisations, particularly public bodies, should emulate.

Case study: How to respond to HIV discrimination effectively:

An individual living with HIV told us that they experienced HIV discrimination at a pharmacy where they tried to get a COVID vaccine booster. When they mentioned that they were on HIV medication, they were told that the vaccinator would need to wear PPE when administering the vaccine and record the person's HIV status on a registration slip, contrary to data protection law. Whilst PPE was eventually not worn when the vaccination happened, this made the individual feel very uncomfortable whilst accessing a vital healthcare service, and likely constituted both direct discrimination and harassment under the Equality Act.

With the affected individual's input and support, we wrote to the pharmacy, asking them to apologise for the discriminatory treatment. Following our intervention, they reviewed their organisational policy on how they treat people living with HIV and educated their staff to ensure they manage HIV status data appropriately and effectively. These changes of processes and action are significant steps that will benefit a whole range of people using that pharmacy, ensuring equal treatment in the future for people living with HIV.

By apologising for the discriminatory treatment, and by reviewing their policies and educating staff on what they should do instead, this pharmacy demonstrated their commitment to tackling discrimination. They were also willing to take steps to prevent discrimination in the future, by reducing staff ignorance and complying with the law. This is how organisations should react when a complaint of HIV discrimination is received.

Recommendations to end HIV discrimination:

01.

Despite the existence of legislation to give legal rights and protections to people living with HIV, discrimination is taking place across the UK, in all kinds of settings and types of organisations. Greater understanding of HIV and how discrimination occurs is needed across all employers and service providers, so that appropriate procedures are in place to better prevent discrimination, and to respond swiftly to any issues.

To achieve this:

- All employers should have Equality, Diversity and Inclusion policies that specifically reference HIV and have appropriate procedures to respond to and prevent all forms of HIV discrimination, including requests for reasonable adjustments, differential treatment, and respecting privacy of personal data.
- Organisations should take seriously any complaints of HIV discrimination they receive – whether from employees, service users, and/or customers. Often, the process and experience of making a complaint for an individual living with HIV can be traumatising and difficult in itself. Complaints should be responded to sensitively and privacy should be respected throughout, and that appropriate action is taken promptly.
- All types of organisations and employers should consider signing up to HIV Confident, a charter mark programme to accredit organisations that take action against HIV discrimination.
- To address the gap between policies on HIV and implementation in practice which prevents discrimination, HIV should be included as part of regular workplace training, and in particular in institutions where occurrences of discrimination are more prevalent and harmful, such as in healthcare settings and the police force.

02.

HIV discrimination will never be challenged comprehensively unless we have a better and more complete picture of where and how it occurs. Progress must be able to be tracked and trends analysed regularly. Equality legislation that protects people from discrimination needs to be backed up with requirements on public authorities to better collect and publish data on all the levels and types of discrimination that occur in the UK today.

To achieve this:

- The UK, Scottish and Welsh Governments should, via secondary legislation using powers under Section 153 of the Equality Act 2010, mandate data collection by public bodies on all discrimination complaints that are reported to them as part of their Public Sector Equality Duty. We would encourage the publication of guidance to support public bodies to record and collect this data in a consistent manner.
- As part of their Public Sector Equality Duty (or Section 75 duty in Northern Ireland), public authorities should be required to assess discrimination complaints data - perhaps on an annual basis – to identify trends and emerging issues, or areas of particular poor practice. The analysis of this data should be made publicly available and will lead to targeted interventions to make improvements.
- Every regulatory body should take steps to understand the extent of discrimination complaints that are made to the public bodies they regulate. This should be made publicly available.
- As the responsible bodies for promoting good practice in equality, the Equality and Human Rights Commission (EHRC) and Equality Commission for Northern Ireland (ECNI) should collect and publish data on the nature and extent of discrimination complaints that they are aware of.
- To support the better collection, storing, and availability of data relating to discrimination, the Information Commissioner's Office (ICO) should produce additional guidance for public authorities on how to effectively record discrimination complaints data on their systems. This should include specific categories for discrimination complaints - for example, disability, race or ethnicity and sexual orientation discrimination, and, ideally, new sub-categories such as HIV discrimination. Many organisations said they did not have the capability to search for keywords such as "HIV", which makes tracking incidents and progress challenging and causes inconsistency.
- The lack of consistency and compliance in responses to our Freedom of Information requests made to around 600 public authorities gives cause for concern. ICO enforcement and guidance should be stronger to ensure that organisations' compliance is improved across the board. The fact that 128 organisations had not provided any response nearly two months after the legal time limit had passed is evidence that compliance with the Freedom of Information Act is low and must be addressed.

03.

Legal rights must be able to be realised, and everyone should have the same level of protection under the law. Too often, timelines have prevented people from bringing cases, and access to justice and swift resolution of discrimination complaints is not possible.

To achieve this:

The Northern Ireland Executive and Assembly should legislate to ensure that disability discrimination law in Northern Ireland is at least as robust as in the rest of the United Kingdom, in line with recommendations made by the ECNI and National AIDS Trust.

EHRC should work with the ICO to produce additional guidance for employers and service providers about how to handle and respond to discrimination complaints in a sensitive way, with particular regard to appropriate handling of personal data in a way that does not cause further harm. Too often, people living with HIV are re-traumatised by the way that a complaint is handled or have their HIV status shared unlawfully with colleagues during a complaint process.

04.

Unlawful discrimination should be seen in the wider context of the experiences of people living with HIV, the everyday stigma that they experience, and the impact it has on their lives.

To achieve this:

- To increase knowledge and understanding about nature and extent of discrimination experienced by people living with HIV, the UK Health Security Agency should collect data specifically about HIV discrimination in future “Positive Voices” surveys of people living with HIV. This should include data on the types of discrimination experienced, and the settings where this discrimination occurs, to best inform further actions and interventions.

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.

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