

Protected on Paper

Exploring HIV, legal rights and the gap
between law and lived experience - findings
from a survey of people living with HIV



Executive summary

People living with HIV have clear legal protections from unlawful discrimination under the Equality Act 2010 and confidentiality under Data Protection legislation.

HIV is legally recognised as a disability from the point of diagnosis, meaning people living with HIV are protected from discrimination, harassment and victimisation in areas including work, education, housing and access to services.

Yet the results of this survey show that legal protection does not always translate into practical protection. Too many people living with HIV have experienced unlawful discrimination, are worried about it happening in the future, are put off challenging unlawful action, and do not have clear, timely and accessible information about their rights.

This has a direct impact on wellbeing and mental health, quality of life, confidence, and feelings of safety and security. It is no wonder that in this context, UKHSA's Positive Voices research found that "Stigma, anxiety and depression and the stark inequalities experienced in health and other settings not only affect health and welfare of people with HIV, but also their ability to seek healthcare, engage in treatment and retention in care."¹

“

I don't remember ever having been told about my rights. I've been HIV+ since 1994.”

Survey participant

At a time when Governments across the UK have committed to ending new HIV transmissions by 2030, continuing stigma and discrimination are not only harmful to the individuals who directly experience them, but must be addressed in order to achieve the aims of national HIV action plans.

More work is needed to ensure that people living with HIV are treated fairly and without prejudice, and that there are clear and safe pathways for people to challenge unlawful discrimination, so that people living with HIV have the knowledge and confidence to realise their lawful rights.

1. <https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report#conclusion>

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Key findings

- **Discrimination remains a reality for many people living with HIV**

Healthcare was the most commonly reported setting, with 92% of respondents saying they had experienced discrimination in a healthcare setting (51%) or were worried about it happening (41%). Respondents also reported discrimination in employment, access to other services, and unauthorised sharing of HIV status by organisations.

- **The reality and fear of someone's HIV status being shared without their consent is widespread**

Three quarters of respondents said they either had experienced their status being shared without their consent (32%) or worried about it happening (43%). In our focus group, people told us that this had a real impact on their daily lives – affecting the choices and decisions they make about work and socialising that others wouldn't think twice about.

- **There is a substantial gap between when people think they should be provided with information on their rights and when they actually receive it.**

60.5% of respondents said rights information should be given at the point of diagnosis, but only 18.2% reported receiving it then. Some respondents described not learning about their rights for many years, while others only became aware of them after experiencing discrimination.

- **Knowledge was uneven across different areas of rights.**

Respondents were most likely to feel they understood the concept of protection from discrimination because of HIV status, while confidence was lower in relation to reasonable adjustments at work and privacy and data protection. Just 45.4% rated their knowledge of reasonable adjustments at work as good or very good.

- **Concerns on the impact of mental health was a significant reported barrier to people making complaints about breaches of their rights**

Over half of respondents (54%) said this was a factor for them – closely aligning with 51% of people that reported the worry of their status being shared as a consequence of making a complaint as a barrier to them making a complaint.

Key messages

- **Discrimination**, and fear of discrimination, remains a daily reality for many people living with HIV
- **Rights must be explained earlier:** information should be not just accessible, but proactively provided from the point of diagnosis wherever appropriate and reinforced over time
- **Knowledge is not enough:** people also need confidence, support, and reassurance to challenge discrimination and have safe routes to do this without concerns about repercussions
- **Voluntary sector organisations** have a key role to play in supporting people when they experience breaches of their rights, and healthcare professionals – particularly HIV clinicians – have a key role in providing information to people about their rights
- **Complaints processes** must be safe, accessible, and clearer and easier to use
- **Systems must take responsibility** so people living with HIV are not left to educate professionals or fight alone



Regardless of the knowledge I have about my rights, when I've been vulnerable or insecure it's easier to put up with the discrimination rather than to challenge it."

Survey participant

1. Introduction: why rights matter

Under the Equality Act 2010, HIV is legally recognised as a disability from the point of diagnosis. This means that people living with HIV are protected from discrimination, harassment and victimisation in areas including work, education, housing and access to services. People living with HIV also have rights of privacy and confidentiality, with unlawful sharing of their HIV status without their consent being prohibited under data protection legislation.

But rights only make a difference when people know about them, understand what they mean and feel able to use them. This survey shows that, for too many people living with HIV, there remains a gap between legal protection and lived experience. Some people are not told about their rights at diagnosis. Others only learn about their rights after they have already experienced discrimination. Many people worry that challenging discrimination could lead to further disclosure, worse treatment, stress or no meaningful change.

This matters because HIV-related discrimination continues to affect people's health, wellbeing, privacy, employment and access to services. The British HIV Association (BHIVA) – the leading UK association representing professionals in HIV care – highlight the impact and importance of stigma to health in their recognised standards of care *“Fear of stigma and discrimination is a leading contributor to poor health outcomes for people living with or affected by HIV.”*²

This report sets out what people living with HIV reported about their knowledge of rights, their experiences of discrimination, and the barriers they face when trying to challenge unfair treatment. These experiences are not only individual injustices. They also point to wider failures in how laws, services and complaints processes work for people living with HIV.

Our overall finding is that there are too many expectations and a heavy burden on individuals to self-educate and self-advocate, and that systems and organisations must do more to proactively inform and support the full realisation of rights for people living with HIV.

Q2.

How confident do you feel that you understand your rights as a person living with HIV?

Answer Choices	Response Percent	Responses
Very confident	22.7%	42
Quite confident	38.92%	72
Neither confident nor unconfident	18.38%	34
Not very confident	14.59%	27
Not at all confident	3.78%	7
Don't know	1.62%	3
	Answered	185
	Skipped	3

2. <https://bhiva.org/standards-of-care-2018/>

2. Methodology and who responded

National AIDS Trust ran an online survey of people living with HIV across the UK. The survey received 185 responses, with the number of responses per question varying between 146 and 185. It combined structured multiple-choice questions with optional open-text responses.

The aim of the survey was to gather evidence about knowledge of rights, experiences of discrimination and barriers to making complaints among people living with HIV. This included a mix of set questions with rating scales and agreement, as well as free text boxes for people to explain their answers or to share experiences in their own words.

All participants were aged 18 or over. Among respondents who chose to answer demographic questions, the largest age group was 55 to 64 (27.6%). Respondents' length of time living with HIV varied widely, 29.8% of respondents had HIV for more than 20 years and 35.1% of people for 10 to 20 years. Respondents were drawn from across UK nations and regions, with 84% being based in England and the largest proportion based in London. 63.1% identified as a man (including trans man), and 28.9% identified as a woman (including trans woman). 80% of respondents told us they were

White and 11.7% told us they belonged to a Black background.

The findings presented here should be read in light of the survey sample. The results may reflect the experiences of older and long-term diagnosed respondents more strongly than those of younger or more recently diagnosed people. They may also be less reflective of women, heterosexual respondents and people from minoritised ethnic communities. The small sample size from some groups means that meaningful analysis of differences between experiences of groups is not possible across all questions. Where demographic differences are discussed, they should be interpreted cautiously.

Similar themes covered in the survey were explored in a discussion group of 8 people living with HIV where conversations took place on experiences and impact of stigma and discrimination, knowledge of rights, and thoughts on how to support people living with HIV.

The survey questions, responses, and participant information is available in the appendix at the end of this report.

“

I was diagnosed in 1989. It was a very different world back then. I am still haunted by the attitude of people back then which makes it hard for me to disclose my HIV status. I would hope people being diagnosed today are given the appropriate information about their rights.”

Survey participant

“

I think that every healthcare employee should have to undertake training through the HIV Confident charter, and that it should be made mandatory through employment law in health settings.”

Survey participant

3. Rights are not being explained early or consistently

Respondents were clear that people living with HIV should receive information about their rights as early as possible. 60.5% said information about rights should be provided at the point of diagnosis, and 53.7% said it should be provided within the first six months after diagnosis.

This contrasts with the lived experience of people in the survey, with only 18.2% of respondents reporting that they received rights information at diagnosis, while 28.3% received it shortly after diagnosis. The majority waited up to two years, more than two years, or never received clear information. This is a significant gap between what people living with HIV say they need and what they are being given.

Open-text responses underline the impact of this gap. Some respondents described waiting years or even decades before learning about their rights. One respondent said they still did not know their rights ten years after diagnosis. Another said that “no one ever mentioned my rights”. One respondent said they first became aware of their rights through this survey. Most concerning, some people only learned about their rights after experiencing discrimination. That means rights information is too often reaching people after harm has already occurred, rather than helping to prevent discrimination or giving people the confidence to respond early.

“

I still don't have a clear idea what my rights are 15 years since the diagnosis.”

Survey participant

Knowledge of rights is uneven

Overall confidence around knowledge of rights appeared relatively positive: 61.6% of respondents described themselves as either very confident or quite confident that they understood their rights as a person living with HIV. However, this broad confidence was not evenly reflected across specific areas of rights.

Understanding that individuals are protected from discrimination because of HIV status was rated good or very good by 68.65% of respondents. Understanding of privacy and data protection was

rated good or very good by 62.64%. Knowledge of how to request reasonable adjustments at work was lower, with only 45.36% rating their knowledge as good or very good.

This is a critical gap. Reasonable adjustments are not discretionary acts of goodwill. They are a legal right under the Equality Act, designed to prevent disabled people, including people living with HIV, from being placed at a disadvantage at work. If people do not understand this right, they are less able to ask for adjustments or challenge poor practice when support is refused.

“

The problem here is that I am not sure what reasonable adjustments I can request.”

Survey respondent

3. Rights are not being explained early or consistently

Implications for policy and practice

- Information should explain what the law means in everyday language, not simply state that protections exist, and must be proactively provided
- Employers, trade unions, HIV clinics and voluntary organisations all have a role in helping people understand reasonable adjustments and HIV stigma, for example Unison have a model policy for supporting workers living with HIV ³

3. Unionising against HIV stigma: Leaving no one behind on our way to 2030 | UNISON - the public service union

Q13.

Which of the following might you be worried about when thinking about challenging any breach of your rights in the future? (choose as many as apply)

Answer Choices

The impact on my mental health and wellbeing	64.15%
A negative experience of making a complaint in the past	29.56%
My HIV status being shared as a result of making a complaint	61.01%
Problems accessing that service or setting in the future	50.94%
Receiving worse/discriminatory treatment in the future	52.83%
A belief that nothing will change	37.11%
My immigration status	7.55%
Complexity of a complaints process	38.99%
Lack of support or help to put forward a complaint	30.19%
Access to my benefits	7.55%
Other (please specify)	5.03%

4. Trusted rights information comes from specialist and community sources

HIV clinics and HIV voluntary and community organisations, including peer support workers, were the main places where respondents said they gained information about their rights. They were also among the sources most often identified as trustworthy and helpful.

This shows the value of specialist knowledge and community trust. HIV clinics, voluntary organisations and peer support are already playing a critical role in helping people living with HIV understand their rights. These trusted routes should be strengthened and resourced, not treated as optional extras.

Online spaces also matter. Respondents used social media and online forums, but trust differed sharply between sources. Online forums were considered more trustworthy than social media. This points to an opportunity to make reliable rights information available in the digital spaces that people already use, while recognising the need to combat misinformation and ensure information is accurate, accessible and up to date.

In addition, employers can do more to ensure that their staff, including people living with HIV, are aware of their organisational responsibilities to ensure people with protected characteristics such as HIV are treated fairly in the workplace, and should be proactive in communicating accessible policies that support people living with HIV – such as how to make a request for reasonable adjustments.

Q18.

Did any specific event trigger you finding out about your rights as someone living with HIV?

Answer Choices	Response Percent	Responses
After experiencing discrimination myself	29.19%	47
When someone else told me about discrimination they'd experienced	24.22%	39
When someone else told me about experiencing another form of discrimination	11.8%	19
As part of my job, or starting a new job	19.88%	32
As part of volunteering or providing peer support	22.36%	36
When joining community activities or events (including joining an online forum)	16.15%	26
Never	19.88%	32
Other (please specify)	6.83%	11
	Answered	161
	Skipped	27

5. Discrimination remains common, especially in healthcare

Healthcare settings

Healthcare was the domain in which discrimination was most commonly reported. 60.1% of respondents said they had experienced discrimination in a healthcare setting in the past, 48.7% of respondents worry about this happening, and 25.5% knew another person living with HIV who had experienced it.

The contrast between specialist and non-specialist settings was striking, if not surprising. Positive accounts of healthcare often related to HIV clinics and specialist staff. Negative accounts more often related to non-specialist settings such as dentists, GPs, general hospital wards, mental health institutions and opticians.

Respondents described practices including repeated cancellation and rebooking of appointments, being scheduled at the end of the day, being moved down waiting lists, refusal of services, visible marking of HIV status, double-gloving and inappropriate use of PPE. These practices are not justified by modern understanding of HIV and can amount to discriminatory treatment.

Undetectable equals Untransmittable (U=U) has transformed what it means to live with HIV. People living with HIV on effective treatment cannot pass HIV on sexually and can live long and healthy lives. Yet public attitudes and some institutional practices have not kept pace with medical progress.

“

When first diagnosed nursing staff would not enter the room I was in, at the time the pads at the end of the bed were in use someone had put HIV in huge letters that everyone could see if they walked past.”

Survey participant

“

Surprising to me, the most problems I have experienced have been in medical settings, where you would expect them to know better.”

Survey participant

Access to other services

For non-healthcare services (including tattooing or cosmetic and beauty treatment for example) the level of worry about discrimination was higher than direct reported experience. Over half of the respondents (51%) said they worried about discrimination in other services, while a quarter (23.2%) had experienced it first-hand and over knew someone else who had experienced it.

Respondents described concerns or experiences relating to services such as tattooing, massage, laser treatment and financial services. Some people reported feeling they had to withhold their HIV status on forms because they feared rejection or discriminatory treatment.

These examples show how outdated assumptions about HIV can restrict ordinary life. People living with HIV should not have to rely on their own ability to educate service providers in order to access services fairly.

5. Discrimination remains common, especially in healthcare

Employment and reasonable adjustments

Workplace discrimination was also reported. 25.8% of respondents said they had experienced discrimination at work, and 32.8% knew other people living with HIV who had experienced it. 41.4% worried about this happening. Respondents described the difficulty of proving discrimination where HIV status was suspected to be an unstated factor in redundancy, dismissal or poor treatment.

Reasonable adjustments were another area of concern. 44.9% of respondents had previously requested a reasonable adjustment at work. However, 25.3% did not know they had the right to do so, 13.2% were worried about making the request and 6.3% did not know how. This means some people were unable to access a legal right because they did not know about it, did not know how to use it or did not feel safe doing so.

“

I worry about my colleagues finding out about my status as I have seen how they have reacted when other patients have been seen with a HIV diagnosis.”

Survey participant

Confidentiality and sharing of HIV status without consent

Privacy and unauthorised sharing of an individual's HIV status also emerged as a significant issue. A third of respondents (32.1%) said that HIV status had been shared without their consent, and 42.4% worried about this happening. Instances of data sharing without an individual's consent were reported across employers, healthcare settings, and service providers, but the data gathered in the survey does not give us proportions of numbers of breaches in different situations.

Confidentiality is fundamental to trust, dignity and safety as well as confidence in healthcare systems and services. However, this is also an area of increasing complexity and nuance – particularly within healthcare systems, where the direction of travel in health policy is towards greater access to and sharing of data to deliver better joined up care and reduce risks associated with aspects of an

individual's health record being kept separate. The question of when data can be shared lawfully in healthcare is one that generated mixed responses and views in our discussion group, indicating that there is not a common understanding of what is lawful data sharing and what is not.

An important point coming from this is that people clearly feel uninformed about how and where their data will be accessed and by whom, that they often do not feel in control and have full choice about their HIV status being shared, and that they often feel that it has been shared without their consent.

The fear of an individual's status being shared was also identified as a significant barrier for people making a complaint about experienced discrimination, with over half of the respondents (61.1%) saying that it would stop them from making a complaint.

6. Complaints processes are too difficult, risky or unsupported

Many respondents said they would complain if they experienced discrimination. Willingness was highest in relation to privacy breaches, followed by workplace discrimination, healthcare discrimination and discrimination in other services. On paper, willingness to act was high and outright refusal to complain was relatively rare.

However, this willingness sat alongside substantial fears. 64.1% of respondents feared the impact of challenging discrimination on their mental health and wellbeing. 61.1% feared their HIV status would be revealed. Many people reported fearing repercussions in the future (which would likely to be classed as victimisation or harassment under the Equality Act) with 52.8% fearing receiving worse treatment in the future, and 50.9% fearing that they would experience problems accessing a service in the future, such as being refused a further appointment.

This helps explain why 58.17% of respondents had never made a complaint. For some people, silence may feel safer than entering a complaints process that could be stressful, ineffective or expose them to further harm. But a significant proportion of people also believed that there was no point in making a complaint, with almost a third (37.1%) saying that they wouldn't do so because they believed that nothing would change.

Among those who had complained, the process was not always positive. 29.4% of respondents reported experiencing negative issues as a result of making a

complaint about discrimination, compared with 12.4% who complained without experiencing a negative impact. Open-text responses described complaints as stressful and leaving people feeling more vulnerable.



I found the process of having to complain very stressful. I felt even more vulnerable after and at times I wished I hadn't challenged them. It did, however, improve the situation some what but I was left feeling less confident in the service I was accessing afterwards."

Survey participant

A number of people also told us that a barrier for them was that complaint processes were too complex or would take too long (33%) and a quarter (25%) said that, for them, a lack of support in putting forward a complaint was a barrier. This shows us that it is not just a fear of consequences which stops people from challenging discrimination, but that processes are not straightforward and need to be more accessible.

What respondents told us were barriers

- Fear of harm to mental health and wellbeing.
- Fear that HIV status would be disclosed further.
- Fear of worse future treatment or losing access to services.
- Belief that nothing would change.
- Lack of knowledge about how to complain or who to complain to.
- Lack of support, advocacy or legal advice.
- Cost, complexity and practical burden.
- Concerns linked to benefits, employment or immigration status.

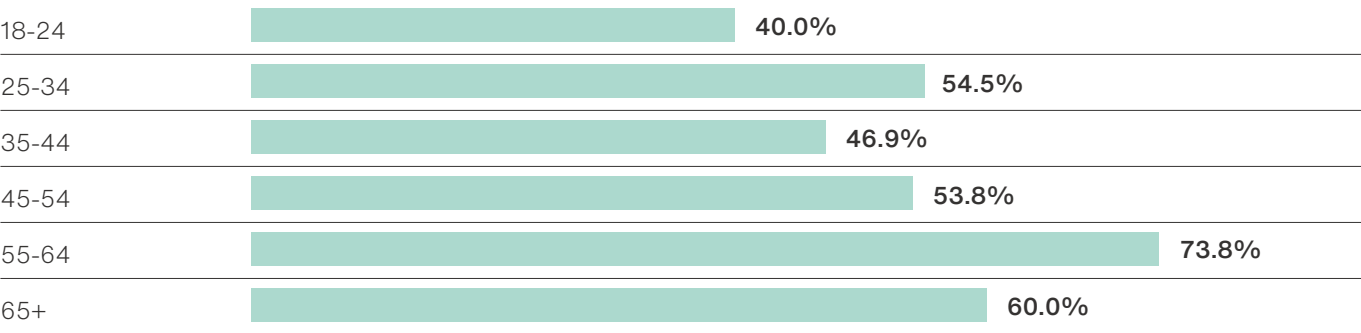
7. Differences across respondent groups

The survey suggests that experiences of discrimination, confidence and routes to support may vary across respondent groups. These findings should be interpreted cautiously because subgroup response numbers vary and are small in some cases, so meaningful analysis across all questions asked is not possible.

However, some areas do provide indications that there are likely to be important differences of experience that should be borne in mind, explored further, and responded to. The most significant and consistent variation in responses was in age groups.

Age

Reported experience of discrimination in healthcare rose with age, but older groups said that they would be less likely to complain about it.



Likelihood to complain was highest among respondents aged 25 to 44



7. Differences across respondent groups

Younger respondents' fears sometimes ran ahead of their direct experiences, with some worrying about discrimination while their level of direct experience of discrimination was lower than older people.

Respondents who had lived with HIV for more than 20 years reported higher levels of experienced discrimination and were more likely to identify “the belief that nothing will change” as a barrier to challenging discrimination. This may reflect cumulative experience and fatigue from repeated exposure to stigma or poor treatment over time.

The differences in experience and perspectives from people across different age groups suggests a need for future work and action to be tailored for better accessibility and effectiveness. When considering what steps to be taken to ensure that people living with HIV are provided with information, a one-size

fits all approach is unlikely to be most accessible or meaningful for everyone.

Specific resources, advice, or support is likely to be needed to speak to older people who are more likely to have experienced discrimination in the past. For younger people, advice and guidance should recognise that they may be more likely to be worried about instances of discrimination rather than have already experienced it, and perhaps more action-oriented given that they report being more likely to challenge discrimination should it occur. In all cases, resources must be inclusive, culturally competent and designed to reach people who may be less connected to existing services, peer networks or formal advice channels.

Groups for whom targeted action may be needed

- Older and long-term diagnosed people who may not have received rights information at diagnosis.
- Younger and newer-diagnosed people who may not yet have used HIV community organisations and so do not have the same level of trust in services available.
- Women
- People with immigration-related concerns.
- People from minoritised ethnic communities.
- People outside London who may have poorer access to legal advice or specialist support.
- Heterosexual people living with HIV who may be less connected to existing HIV community spaces.



Shortly after diagnosis, people living with HIV need more information on their rights and legal issues. They need to be signposted to the right places where there's information, and more webinars to teach and advise.”

Survey participant

8. Conclusion: from individual burden to system responsibility

The evidence from the survey tells a clear story. People living with HIV have rights in law but these are not respected in practice. Too many people are not told about their rights early enough, do not know how to use them, or do not feel safe challenging discrimination when it happens.

The research also shows that discrimination continues to occur in places where people should be able to expect safety, respect and professionalism, including healthcare and employment. It shows that complaints processes can feel difficult, risky and unsupported, and that people living with HIV may be left weighing the cost of speaking up against the harm of staying silent.

There is trust and confidence in HIV clinics, specialist staff, voluntary sector organisations and peer support as routes and settings that people can turn to for help in understanding HIV and the lawful rights and protections that come from it. But more support is needed, tailored resources are required, and a more proactive and joined-up approach is needed. In addition, across other settings (such as non-specialist healthcare, employment, public services

and service providers) the policies and practices, as well as outdated behaviours and attitudes need to be addressed to prevent discrimination from happening, as well as to provide reassurance and confidence to people that they won't experience repercussions of making complaints and that the process won't be unduly burdensome.

The HIV voluntary sector can also do more, and work more effectively. While the UK, and particularly England, has a wide variety of voluntary sector organisations, people living with HIV reported that they didn't know where to go to find clear information. As a sector we must do better to ensure information is shared and available and that referrals and signposting between organisation are easy and efficient.

People living with HIV should not have to become experts in equality law, privacy rules and complaints processes simply to receive lawful and respectful treatment. They should not have to educate professionals about HIV in order to access care or services fairly. Responsibility must shift from individuals to the systems, services and institutions that are meant to inform, support and protect them.

“

Provide staff with the appropriate information, resources & knowledge around things that affect people living with HIV at various stages of our HIV journey. Keep funding third sector organisations, peer support groups & workshop delivery educating us on these issues, changes & how we can challenge things.”

Survey participant

9. Recommendations

1. Make rights information routine and accessible from diagnosis onwards

- BHIVA is planning to review its Standards of Care and during this process should specifically consider how to ensure that rights information is provided at diagnosis wherever appropriate, and throughout ongoing care
- National Health Services across the UK should include the provision of rights information as part of the national service specifications for HIV
- Voluntary sector organisations should coordinate the provision of clear and tailored information more effectively
- Create a “catch-up” route and check-in process as part of routine HIV specialist appointments and at clinics for people who have been diagnosed with HIV for some time to provide reminders about their rights or for those who were not given rights information earlier or were less able to take the information in at the time.
- In every setting that information is provided – whether in healthcare settings or voluntary sector organisations – effort should be made to produce information in accessible formats, a range of languages, including easy-read resources, translated materials, short printed guides and digital resources

2. Improve HIV training across healthcare and other services

- Within healthcare settings, training for healthcare professionals on HIV today, U=U, confidentiality and equality law should be provided, and made mandatory wherever possible
- For other services and employers, embed HIV knowledge and awareness learning modules, including Equality Act and data protection responsibilities into staff training, organisational policies, and professional development

9. Recommendations

3. All organisations should ensure complaints policies and processes are safe, clear and accessible

- All organisations should review, and wherever needed, improve signposting so people know where and how to complain and what support is available.
- Complaints policies must be easy to use, clear, and accessible. They must also be transparent about how complaints will be handled, for example who will see it and how decisions are made.
- Organisations and employers should provide reassurance about how people can raise concerns and how they will be responded to without fear of repercussions of harassment and victimisation that are protected under the Equality Act.
- Explore anonymous or protected reporting routes where appropriate, particularly in healthcare and public services.
- Public bodies should record, and make available, information about the numbers of complaints that they receive on HIV-related discrimination.

4. Invest in peer, community and legal support

- Local commissioners and other funders should consider funding HIV voluntary and community organisations to provide rights education, peer support and advocacy.
- Healthcare systems should integrate opt-out peer support into clinical pathways so people are routinely connected to support after diagnosis.
- Voluntary sector organisations should work together to best coordinate, signpost, and refer individuals for support, and create safe spaces where people can share experiences, understand their options and rebuild confidence after discrimination.

Appendix

Survey questions and responses

Q2.

How confident do you feel that you understand your rights as a person living with HIV?

Answer Choices	Response Percent	Responses
Very confident	22.7%	42
Quite confident	38.92%	72
Neither confident nor unconfident	18.38%	34
Not very confident	14.59%	27
Not at all confident	3.78%	7
Don't know	1.62%	3
	Answered	185
	Skipped	3

Q3.

How would you rate your level of knowledge of your rights in the following areas:

Answer Choices	Very good	Good	Neither good nor bad	Not very good	Not good at all	Don't know	Total
Protection from discrimination because of your HIV status	50	77	24	23	9	2	185
Making a request for reasonable adjustments at work because of my HIV	46	37	29	36	23	12	183
Privacy and data protection	52	62	20	25	16	7	182
				Answered			185
				Skipped			3

Q4.

Please select any of the following statements that apply to you: (you can pick more than one)

Answer Choices	Response Percent	Responses
I have experienced discrimination in healthcare settings in the past	60.13%	95
I worry about this happening	48.73%	77
I know others who are living with HIV who have experienced this	37.34%	59
	Answered	158
	Skipped	30

Q5.

If you experienced discrimination in healthcare in the future, do you think you would be likely to make a complaint?

Answer Choices	Response Percent	Responses
Yes	63.86%	106
No	7.23%	12
Don't know / it depends	28.92%	48
If you would like to tell us anything else about your experience or thoughts on discrimination in healthcare, please do so here		57
	Answered	166
	Skipped	22

Q6.

Please select any of the following statements that apply to you: (you can pick more than one)

Answer Choices	Response Percent	Responses
I have experienced discrimination in accessing other services	29.61%	45
I worry about this happening	65.13%	99
I know others who are living with HIV who have experienced this	32.89%	50
	Answered	152
	Skipped	36

Q7.

If you experienced discrimination in accessing other services, do you think you would be likely to make a complaint?

Answer Choices	Response Percent	Responses
Yes	59.88%	97
No	12.35%	20
Don't know / it depends	27.78%	45
If you would like to tell us anything else about your experience or thoughts on discrimination in accessing other services, please do so here		29
	Answered	162
	Skipped	26

Q8.

Please select any of the following statements that apply to you: (you can pick more than one)

Answer Choices	Response Percent	Responses
I have experienced discrimination at work in the past	31.37%	48
I worry about this happening	50.33%	77
I know other people living with HIV that this has happened to	39.87%	61
	Answered	153
	Skipped	35

Q9.

If you experienced discrimination at work, do you think you would be likely to make a complaint?

Answer Choices	Response Percent	Responses
Yes	68.13%	109
No	11.88%	19
Don't know / it depends	20.0%	32
Other (please specify)		20
	Answered	160
	Skipped	28

Q10.

Have you ever made a request for a reasonable adjustment at work?

Answer Choices	Response Percent	Responses
Yes	44.94%	71
No – I didn't know I had the right to	25.32%	40
No – I was worried about making the request	13.29%	21
No – because I didn't know how to	6.33%	10
No – because I'm not, or haven't been, in paid employment	10.13%	16
If you would like to tell us anything else about your experience of making a request for reasonable adjustments at work, please do so here		41
	Answered	158
	Skipped	30

Q11.

Please select any of the following statements that apply to you: (you can pick more than one)

Answer Choices	Response Percent	Responses
My HIV status has been shared without my consent by an organisation in the past (an employer, healthcare setting, or service provider)	41.06%	62
I worry about this happening	54.3%	82
I know other people living with HIV that this has happened to	32.45%	49
	Answered	151
	Skipped	37

Q12.

If your HIV status was shared by an organisation without your consent in the future, do you think you would be likely to make a complaint?

Answer Choices	Response Percent	Responses
Yes	75.93%	123
No	5.56%	9
Don't know / it depends	18.52%	30
If you would like to tell us anything else about your experience or thoughts on privacy and data protection, please do so here		32
	Answered	162
	Skipped	26

Q13.

Which of the following might you be worried about when thinking about challenging any breach of your rights in the future? (choose as many as apply)

Answer Choices	Response Percent	Responses
The impact on my mental health and wellbeing	64.15%	102
A negative experience of making a complaint in the past	29.56%	47
My HIV status being shared as a result of making a complaint	61.01%	97
Problems accessing that service or setting in the future (e.g, being refused future appointments)	50.94%	81
Receiving worse/discriminatory treatment in the future	52.83%	84
A belief that nothing will change	37.11%	59
My immigration status	7.55%	12
Complexity of a complaints process, or how long it might take to be resolved	38.99%	62
Lack of support or help to put forward a complaint	30.19%	48
Access to my benefits	7.55%	12
Other (please specify)	5.03%	8
	Answered	159

Q14.

And have you experienced any of these issues in the past when making a complaint?

Answer Choices	Response Percent	Responses
Yes	29.41%	45
No - I have never made a complaint relating to discrimination or a breach of my rights relating to HIV	58.17%	89
No - I made a complaint, but didn't experience any negative impacts	12.42%	19
If you would like to tell us any more about any experience of making a complaint in the past, please do so here		16
	Answered	153
	Skipped	35

Q15.

Where do you think you have gained information about your rights as a person living with HIV from? (select all that apply)

Answer Choices	Response Percent	Responses
At an HIV clinic	45.68%	74
General healthcare settings	10.49%	17
HIV voluntary and community organisations (including peer support workers)	61.11%	99
Other people living with HIV and communities	41.36%	67
Friends or family	6.79%	11
Social media	21.6%	35
Online forums (such as UK-CAB or THT's My Community)	30.25%	49
Faith groups	4.32%	7
Trade unions	10.49%	17
Legal advice services (for example, Citizens Advice)	10.49%	17
I have never gained information about my rights as someone living with HIV	12.35%	20
Other (please specify)	11.11%	18
	Answered	162
	Skipped	26

Q16.

And which sources do you think are most trustworthy and helpful to help people living with HIV know about their rights? (select all that apply)

Answer Choices	Response Percent	Responses
At an HIV clinic	64.81%	105
General healthcare settings	13.58%	22
HIV voluntary and community organisations (including peer support workers)	73.46%	119
Other people living with HIV and communities	34.57%	56
Friends or family	6.79%	11
Social media	6.17%	10
Online forums (such as UK-CAB or THT's My Community)	33.33%	54
Faith groups	4.94%	8
Trade unions	11.73%	19
Legal advice services (for example, Citizens Advice)	17.28%	28
Other (please specify)	4.94%	8
	Answered	162
	Skipped	26

Q17.**When did you first gain knowledge about your rights as a person living with HIV?**

Answer Choices	Response Percent	Responses
When first diagnosed	18.24%	29
Shortly after diagnosis (e.g, up to 6 months after diagnosis)	28.3%	45
Up to 2 years years after being diagnosed	9.43%	15
More than 2 years after being diagnosed	30.19%	48
Other (please specify)	13.84%	22
	Answered	159
	Skipped	29

Q18.**Did any specific event trigger you finding out about your rights as someone living with HIV?**

Answer Choices	Response Percent	Responses
After experiencing discrimination myself	29.19%	47
When someone else told me about discrimination they'd experienced	24.22%	39
When someone else told me about experiencing another form of discrimination	11.8%	19
As part of my job, or starting a new job	19.88%	32
As part of volunteering or providing peer support	22.36%	36
When joining community activities or events (including joining an online forum)	16.15%	26
Never	19.88%	32
Other (please specify)	6.83%	11
	Answered	161
	Skipped	27

Q19.**When do you think generally is the most appropriate time for someone who is newly diagnosed with HIV to be proactively provided with information about their rights?**

Answer Choices	Response Percent	Responses
When first diagnosed	60.49%	98
Shortly after diagnosis (e.g. up to 6 months after diagnosis)	53.7%	87
After having been diagnosed for at least 6 months	9.26%	15
Other (please specify)	5.56%	9
	Answered	162
	Skipped	26

Q23.

How long have you been living with HIV?

Answer Choices	Response Percent	Responses
Less than a year	1.99%	3
1-5 years	15.89%	24
5-10 years	17.22%	26
10-20 years	35.1%	53
Over 20 years	29.8%	45
	Answered	151
	Skipped	37

Q24.

What is your age?

Answer Choices	Response Percent	Responses
Under 18	0.0%	0
18-24	3.29%	5
25-34	14.47%	22
35-44	21.05%	32
45-54	17.11%	26
55-64	27.63%	42
65+	16.45%	25
	Answered	152
	Skipped	36

Q25.

How do you identify your gender?

Answer Choices	Response Percent	Responses
Woman (including trans woman)	28.95%	44
Man (including trans man)	63.16%	96
Non-binary	3.29%	5
Prefer not to say	1.97%	3
In another way	2.63%	4
	Answered	152
	Skipped	36

Q26.

What is your sexuality?

Answer Choices	Response Percent	Responses
Gay or lesbian	60.26%	91
Bisexual	10.6%	16
Heterosexual	25.17%	38
Other (please specify)	3.97%	6
	Answered	151
	Skipped	37

Q27.

To which of these groups do you consider you belong?

Answer Choices	Response Percent	Responses
White English, Welsh, Scottish, Northern Irish or British	68.42%	104
White Irish	3.29%	5
White Gypsy or Irish Traveller	0.66%	1
White Roma	1.97%	3
Any other white background	5.92%	9
Black British	1.97%	3
Black Caribbean	0.0%	0
Black African	9.87%	15
Any other black background	0.0%	0
Mixed white and black Caribbean	0.0%	0
Mixed white and black African	0.66%	1
Mixed white and Asian	0.0%	0
Any other mixed background	0.66%	1
Asian British	0.0%	0
Asian Indian	0.0%	0
Asian Pakistani	0.66%	1
Asian Bangladeshi	0.0%	0
Asian Chinese	0.0%	0
Any other Asian background	0.66%	1
Arab	0.0%	0
Hispanic American/Latinx	1.32%	2
Prefer not to say	1.97%	3
Other (please specify)	1.97%	3
	Answered	152
	Skipped	36

Q28.

Is your ability to carry out day-to-day activities affected by any physical and mental health conditions or illnesses, lasting or expected to last 12 months or more?

Answer Choices	Response Percent	Responses
Yes, a little	39.74%	60
Yes, a lot	22.52%	34
No	37.75%	57
	Answered	151
	Skipped	37

Q29.

Where in the UK do you live?

Answer Choices	Response Percent	Responses
East of England	4.11%	6
London	25.34%	37
South East	13.7%	20
South West	8.22%	12
East Midlands	4.79%	7
West Midlands	4.79%	7
Yorkshire and the Humber	5.48%	8
North East	10.27%	15
North West	6.85%	10
Scotland	8.22%	12
Wales	4.11%	6
Northern Ireland	4.11%	6
	Answered	146
	Skipped	42

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