

Experiences of HIV stigma:

A service evaluation among
Blue Sky Trust members

2022



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02 Background

This report relates to a service evaluation project that was carried out by Blue Sky Trust and the HIV psychology team at Newcastle upon Tyne Hospitals (NuTH) NHS Foundation Trust.

Blue Sky Trust (BST) is a registered charity that supports and connects people living with HIV in the North East of England and Cumbria. BST has been established for 30 years. They currently support over 200 adults and children through one-to-one support, peer mentoring, support groups and webinars. Training and education sessions are delivered by BST to workplaces and schools to raise awareness of HIV and reduce HIV-related stigma.

The HIV psychology team, based at the Royal Victoria Infirmary (RVI), looks after the majority of people living with HIV in the North East of England. They provide support to people living with HIV, their partners, family members and carers to encourage psychosocial change. The team conduct research and service evaluation projects, aiming to reduce stigma and improve quality of life for people living with HIV.



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Local HIV Statistics

In 2018, there were approximately **1,920** people living with HIV in the North East of England. There were 105 new diagnoses in the region, a fall of 9% from the year before (Public Health England, 2021).

Treatment for HIV works by reducing the amount of HIV in the body. This allows the immune system to work normally, meaning that someone with HIV can expect to live a **long and healthy life**.

Taking regular antiretroviral medication also suppresses the virus, preventing it from being transmitted to other people.



Of all people living with HIV in the UK, approximately **89% were virally suppressed** in 2019 (NAT, 2022). There have also been improvements in prevention, with prophylaxis treatments (PrEP and PEP) becoming more readily available, reducing new HIV diagnoses (CDC, 2022).

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HIV Stigma

Despite advances in prevention and treatment, mental health inequalities remain between people living with HIV and the general population (All Party Policy Group on HIV & Aids, 2020).

HIV stigma, defined as negative attitudes and beliefs held about people with HIV, perpetuates this inequality (CDC, 2022).

Stigma is associated with higher rates of **depression**, less social support, **lower adherence** to antiretroviral medication and **poorer physical health** (Rueda et al., 2016). It is also a barrier to HIV prevention, affecting testing, help-seeking and starting treatment (NAT, 2015).

HIV stigma represents one of the biggest current challenges in the response to HIV. It can occur at multiple levels including within relationships and communities, organisations, and at a societal level. Individuals with HIV may also experience self-stigma. (Chambers et al., 2015).



05 Project Aims

Recognising the importance of tackling HIV stigma in our local area, we carried out a service evaluation project to meet the following aims:

- To gather examples of HIV stigma from BST members.
- To identify the types of setting where stigma occurs to inform BST strategies to reduce stigma in these settings.
- To find out what members think BST could do to support them with experiences of stigma, and to tackle stigma.



06 Methods

Approval for this project was given by the Blue Sky Trust advisory board. The project was also registered as a service evaluation with NuTH.

BST members received an email inviting them to take part in the project. Participation was voluntary, and those who took part provided written informed consent.

Participants firstly completed a survey. This could be done in paper format at BST or online. Participants reported their age, gender, ethnicity, length of time since diagnosis, and sexuality. They were asked about experiences of HIV stigma, including where these experiences took place, who was involved, and the personal impact. Participants were asked about how they would like services like Blue Sky Trust to respond to stigma.

There also was an option to take part in an interview for anyone who wanted to share their experiences in more depth. Interviews were carried out by the project team. We had created a list of questions in advance, but we used the topic guide flexibly so interviews felt conversational. Interviews were audio recorded on a BST dictaphone and typed up.

Data analysis was led by the HIV psychology team. Thematic Analysis was used, following the method outlined by Braun & Clarke (2006). The process involved becoming familiar with the data, generating initial codes, developing themes and producing the report. An inductive approach was followed, where themes were developed from the bottom-up, based on what participants said.



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Confidentiality & Data Governance

We did not collect or report any identifiable data (e.g. participant names or dates of birth). Although no directly identifiable information was included, we recognised that when different bits of information were pieced together, it was possible that a participant could be identified. For example, participants talked about countries they had lived in, or employment in particular sectors, which could be identifiable to people who know them well.

We were cautious about redacting or changing this information as participants had consented to their stories being shared. To ensure that interview participants were comfortable with the level of detail reported, and with how their quotes had been used, we showed them a draft version of the report to comment on. Amendments were made in response to their feedback.

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Demographics

A total of 20 people took part. Their demographic characteristics are shown in Table 1. The majority of participants were White (85%) and male (65%). Half of the respondents identified as heterosexual. Most participants were aged between 50-59 years (55%), and had lived with HIV for over ten years (55%).

Table 1: demographic information reported by participants

<i>Demographic</i>	<i>Number</i>	<i>%</i>
Age		
<i>18-29</i>	2	10%
<i>30-39</i>	2	10%
<i>40-49</i>	5	25%
<i>50-59</i>	11	55%
Sex		
<i>Male</i>	13	56%
<i>Female</i>	7	35%
Ethnicity		
<i>White/ White British</i>	17	85%
<i>Mixed/ Multiple ethnicities</i>	1	5%
<i>Black/ African/ Caribbean/ Black British</i>	2	10%
Sexuality		
<i>Heterosexual</i>	7	35%
<i>Gay/Lesbian</i>	10	50%
<i>Fluid</i>	1	5%
<i>Pansexual</i>	1	5%
<i>Prefer not to say</i>	1	5%
Time Since Diagnosis		
<i>Under 1 year</i>	3	15%
<i>1-5 years</i>	1	5%
<i>6-10 years</i>	5	25%
<i>Over 10 years</i>	11	55%

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Experiences of HIV Stigma

Of the twenty respondents, 85% said that they had experienced HIV stigma at some point in their lives. Table 2 outlines the sources of stigma reported by participants. Over half of those who had experienced stigma encountered it on dating apps, and just under half reported experiencing it in the workplace. Stigma in a medical setting was reported by 41% of participants. It was noted that 60% of those who experienced stigma had experienced it on more than one occasion, in more than one place.

Table 2: Reported sources of HIV stigma

<i>Source of HIV Stigma</i>	<i>Number</i>	<i>%</i>
<i>Dating Apps</i>	9	53%
<i>Workplace</i>	8	47%
<i>Dating</i>	7	41%
<i>Medical Setting</i>	7	41%
<i>Family</i>	6	35%
<i>Friends</i>	6	35%
<i>Partner</i>	5	29%
<i>Dental Practice</i>	4	24%
<i>Police</i>	2	12%
<i>Religious Setting</i>	2	12%
<i>Addiction Services</i>	1	6%
<i>Bank/Building Society</i>	1	6%
<i>Department for Work and Pensions</i>	1	6%
<i>Education Setting</i>	1	6%
<i>Financial Services</i>	1	6%
<i>Hair/Beauty</i>	1	6%
<i>In a Public Place</i>	1	6%
<i>Job Searching</i>	1	6%
<i>Social Media</i>	1	6%
<i>Social Services</i>	1	6%
<i>Tattoo/Piercing</i>	1	6%

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Impact of HIV Stigma

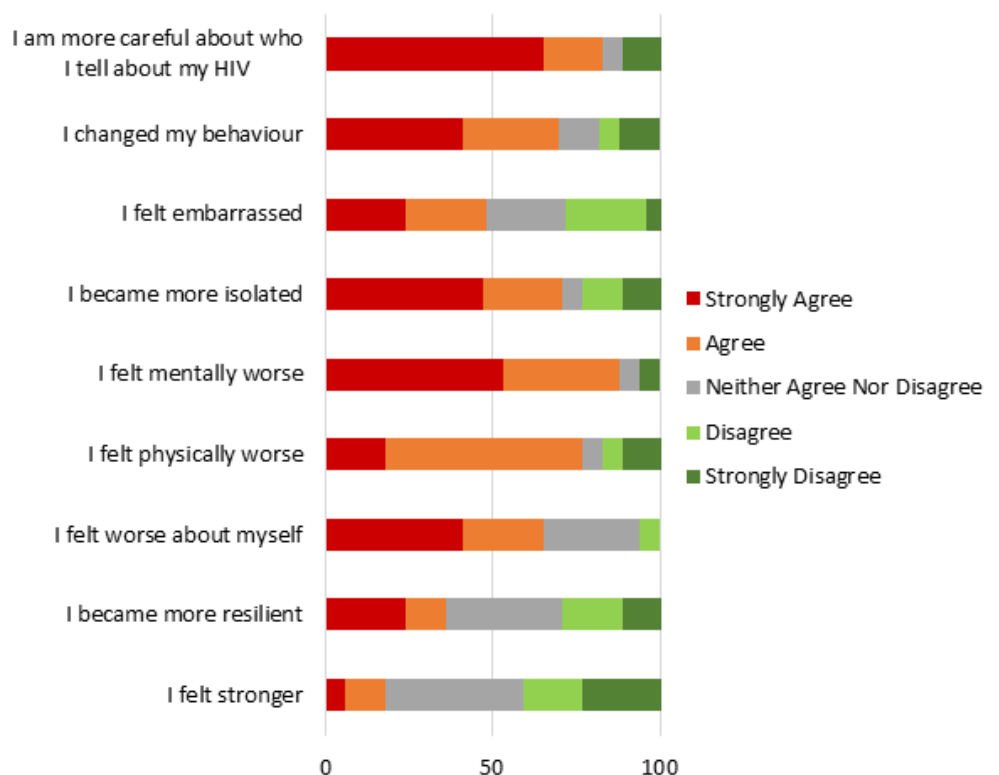
Figure 1 illustrates participants' responses to questions about the impact of HIV stigma. 65% of participants agreed or strongly agreed that the experience(s) had made them feel worse about themselves. Feeling physically worse was reported by 77% of respondents, and feeling mentally worse was reported by 88% of participants.

Isolation and embarrassment were reported by 47% and 48% of respondents, respectively. A total of 71% of participants reported that they had changed their behaviour after experiencing stigma, and 82% agreed that they were now more cautious about who they told about their HIV.

Although some people who had experienced stigma reported that it had made them feel stronger (18%), 41% reported this had not been the case, and the remaining 41% neither agreed nor disagreed.

Similarly, 35% reported that it had helped them to become more resilient, but most people did not agree with this.

Figure 1: Stacked bar graph illustrating the impact of HIV stigma



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Sharing Experiences of Stigma

The majority (82%) of people who had experienced stigma decided to tell at least one person about it. Of those who did this, 93% said they felt supported, whilst 7% were unsure.

People shared their experiences with a range of people, including friends (41%), family (24%) and work colleagues (6%). Some people shared their experiences with HIV organisations such as Blue Sky Trust (35%), Terrence Higgins Trust (6%), or with another person living with HIV (35%). Others spoke to their HIV medical team (35%) or another healthcare professional such as their GP (18%).

Stigma relating to characteristics other than HIV

Participants were asked whether they had ever experienced stigma relating to characteristics other than HIV. A total of 30% of participants had experienced another type of stigma, 25% were unsure, and 45% had not. Table 3 outlines the characteristics for which people had been stigmatised, with sexuality being the most common.

Table 3: Other types of stigma experienced

<i>Characteristic</i>	<i>Number</i>	<i>%</i>
<i>Sexuality</i>	5	83%
<i>Addiction</i>	1	17%
<i>Criminal record</i>	1	17%
<i>Neurodiversity</i>	1	17%
<i>Poverty</i>	1	17%
<i>Mental Health</i>	1	17%
<i>Being 'Southern' in the North East</i>	1	17%

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Addressing HIV Stigma

Participants were asked how HIV stigma should be addressed and who is responsible for this. Their suggestions have been captured in a word cloud, where larger words indicate more common responses (see figure 2). People shared different ideas, including promotion in public places (28%), education (22%), training (17%), improved sexual health education in schools (11%), and challenging and correcting outdated information (11%). One person suggested there is a need for 'strong' people living with HIV to talk openly about it and share their experiences. Another person indicated that it feels more challenging than ever to address HIV stigma, and they were unsure what else could be done.

Figure 2: Word cloud of suggestions for tackling HIV stigma.



Participants were asked where HIV awareness should be targeted.

Towards NHS staff was suggested by 30% of participants, 25% said the general public, and 20% suggested the Police. People also thought that employment agencies (10%) and social care services (10%) could be more aware of HIV.

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Interview Findings

Out of the twenty people who participated the survey, six went on to complete a follow-up interview. Interviews varied between 5 minutes and 1 hour in length. We identified four main themes, with associated sub-themes. These are shown in Figure 3.



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1. Diagnosis and disclosure

1.1 Adjusting to the diagnosis

Most of the people we interviewed had been diagnosed with HIV for years or even decades, and some had come to terms with the diagnosis.

“I came to terms with it a long time ago, I think since my diagnosis, obviously it was awful, it was awful but I adjusted quickly, that’s the way to put it and put it behind me and moved on” (Participant 3)

One participant, diagnosed a long time ago, struggled to adjust to the shift in how HIV is viewed medically.

“I find this U=U almost impossible to process. I don’t think I will ever accept it. It’s easier to live alone rather than face it” (Participant 5)

Someone we spoke to who was diagnosed recently recognised that they were still struggling to adapt, feeling as though their life was controlled by HIV.

“I’m living now, it’s like I’m on hot stones, you know sometimes, and then it calms down and I’m back on hot stones again, you know, so it has been not an easy time since I’ve been diagnosed” (Participant 4)

I’m not really living my life at the moment, the HIV is living my life for me, which is hard, you know, and it will get better, I understand that (Participant 4)

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1. Diagnosis and disclosure

1.2 Thoughts about HIV before diagnosis

The type of information and knowledge that people had access to before diagnosis impacted their adjustment. Being aware of modern medical treatments and seeing HIV stigma tackled on social media helped one participant to feel more knowledgeable. On the other hand, not knowing about medication, and viewing HIV as the same condition it was in the beginning, made adjustment more difficult.

“I was quite lucky to know quite a bit before, I just found a TikToker a couple of months before I got diagnosed and he basically tackles the stigma around HIV, so I knew quite a bit; I knew about the U=U. I didn't realise the medication though was so easy to take. I didn't realise it was that simple, I thought there was a lot more to it but yeah, apart from that I knew quite a bit” (Participant 6)

“I can't lie to you, I felt sorry for them, but again, I think I was like the other people as well I must admit, afraid of it, afraid of it, to go near them, I didn't even know about U=U, undetectable” (Participant 4)

1.3 Fear of others finding out

Several of the people we interviewed shared fears about having news of their diagnosis spread by others.

“Okay, well first of all they shouldn't know legally, they don't have to know but if they have known for whatever reason, it would be concerning” (Participant 3).

One participant was directly asked about their HIV status when they were accompanied to an appointment by their friend. This put them in an uncomfortable position where they experienced shame.

“During an assessment for mobility benefit- for income support, the GP asked me if I was positive. I felt ashamed because my friend was present and she didn't know my diagnosis. The GP did not need to ask” (Survey Participant)



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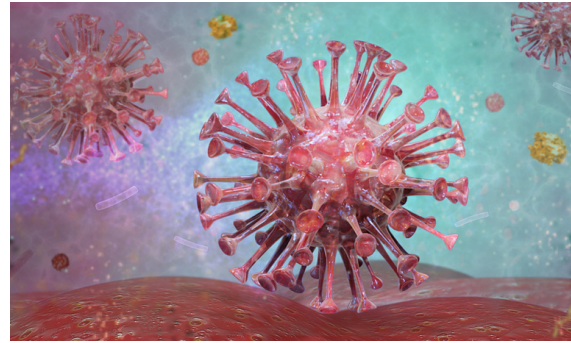
1. Diagnosis and disclosure

1.4 Public perceptions of HIV

Fear of others finding out about the diagnosis was linked to public perceptions of HIV. Participants talked about how difficult it was to disclose their diagnosis to people whose knowledge had not progressed from the 80s and 90s, who perceived it as 'the worst thing that could happen'.

"A lot of people act as if HIV is the be all and end all, it's like the worst thing that could happen so they've always used the phrase "oh at least it's not HIV," which isn't exactly nice to hear when you're diagnosed with it" (Participant 6)

"Imagine how hard it is as a mother or a father to hear the fact that their son or daughter has HIV, because again their mentality is still set back in the 80s and 90s seeing Rock Hudson and Queen and Freddie Mercury dying and straight away you know" (Participant 4)



Despite major advances in medical treatments and quality of life for people living with HIV, some participants felt that public perceptions had not caught up. There was a feeling that HIV is not documented so much by mainstream media, making it harder for the public to be well-informed of de-stigmatising messages.

"Felt like attitudes hadn't changed as much as I'd thought" (Survey Participant)

"You don't really hear much of HIV anymore, it's every so often there might be a little something, okay but they're not really talking about U=U, undetectable, they're not" (Participant 4)

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1. Diagnosis and disclosure

1.5 Anticipated stigma

The expectation of negative reactions or rejection caused participants to fear disclosing their HIV status.

“Of course, because again, rejection, the fear of what the person will say, how they’re going to treat you” (Participant 4)

“It made me a lot more anxious regarding how people would perceive me if they knew my status” (Survey Participant)

“That fear, I don’t know if its fear, if that’s the word, or if you don’t want to expose yourself to unexpected behaviour, to something that could happen, that could or ‘what if’” (Participant 3)



1.5 HIV disclosure

The people we interviewed had varying experiences when it came to disclosing their HIV status. Some people readily shared their diagnosis, while others kept it very private.

“I feel comfortable telling anybody cos for me it’s a normal thing” (Participant 1)

“I’ve told very few people” (Participant 6)

Deciding when and who to tell was a very personal decision, sometimes it was about confiding in someone to access social support.

“I told only one at the very beginning. He was the oldest and the wisest and I told him about my diagnosis when I first got diagnosed so at least he knows and umm he knows what I’m going through back then” (Participant 3)

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1. Diagnosis and disclosure

Participants strategically selected who to tell, hoping to reduce the risk of their diagnosis being spread or 'broadcast' more widely.

"Do you know why? Do you know why I chose my uncle? Cause if you think about it, if someone knows about my diagnosis, my uncle will get hurt too because he is related. Do you see how I associated these things? I didn't choose for example a friend" (Participant 3)

"I couldn't even tell them, not that I wanted to cos I don't want to broadcast it but yeah, dear friends I've had for thirty years of my life, I couldn't even sit down and talk like I'm talking to you" (Participant 4)

Some Participants talked about HIV disclosure at the start of a romantic relationship. Online platforms were commonly used for dating, and there was anxiety when it came to telling potential dates about HIV due to the fear of rejection.



"Obviously by talking on a chat or whatever to other people and then having the confidence to say look, before we meet, can we, can I be honest to you" (Participant 4)

"And then I found myself 5 years later, probably also because I'm also getting older, thinking to myself, "well, actually, it's the whole issue of disclosure, the effort, the whole training people almost to accept who you are that I can't be bothered with" (Participant 5)

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1. Diagnosis and disclosure

1.5 Consequences of disclosing

Some people found that once they had shared their HIV status publicly, they were no longer in control of how the information was spread.

“One of the things I did was to go on the television. I talked about being HIV positive, so people in my local community here found out. Once you're out, you can't take it back I suppose, so be careful” (Participant 5)

“I would have been diagnosed what, ooh, 97' so 11 years, so I was quite, not new to it, but I disclosed my status to the press and unfortunately they printed it” (Participant 2)

Other participants also described how their diagnosis had been shared without their consent.

“I know when someone came and told the department, the head of the department about my diagnosis and everything” (Participant 3)

“On top of this after visiting the GP in the village I was working/living they were already aware of my HIV diagnosis due to my employer going to the practice for advice” (survey Participant)

The people we spoke to described varying consequences of disclosure. Some felt relieved, while others felt burdened by the response from others.

“When you tell people for instance it's a weight off your head and I think it's made me a lot more open to people” (Participant 2)

“You also notice, some people that I have told, will constantly check in on me which they didn't do before, and I think that's because in their head their thinking oh he might have health problems, I'm going to talk to him and, which obviously isn't the case for the majority of people” (Participant 6)

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2. Source & Type of Stigma

Participants described stigma from a range of sources, including employment, insurance companies, the general public, friends, dentists, health services and on dating sites. This theme captures the nature of stigmatising experiences, including covert vs overt stigma, and stigma in different settings.

2.1 Overt Stigma

Participants' shared examples of overt discrimination that they had faced. Most of the people we spoke to had lived with HIV over a number of years, or even decades, and the examples below referred to stigma in the workplace that had occurred during an earlier stage of participants' HIV journey.

"I used to leave my tissue on the table and speak to tourists that came to me and I leave my tissue on that table and my co-worker made a like a *pushes away sign* don't touch this, don't touch this" (Participant 1)

"I went out and actually directly to their office and I went 'is there a reason that you're not coming to the café?' and they went, they said 'yeah we've seen some publicity about your HIV and we're concerned we might catch it from the sausages'" (Participant 2)

One recently diagnosed Participant talked about overt stigma that had occurred on an online dating website, and with a health insurance company.

"Rejection, number one. Obviously by talking on a chat or whatever to other people and then having the confidence to say look, before we meet, can we, can I be honest to you and then getting a response of being dirty, cheap and knocked down for six" (Participant 4)

"I'm calling for health insurance, okay and obviously talking to them on the phone I had to say to them, you know that I do have an illness I'm HIV positive [sigh] "oh no sorry we don't deal with that, goodbye", and put the phone down on me and I'm thinking "wow" that's, you know, an insurance company" (Participant 4)

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2. Source & Type of Stigma

2.2 Covert Stigma

Most experiences of stigma described by the participants were covert. This meant that others changed their behaviour or indicated negative views about HIV, but without explicitly directing this towards the person living with HIV. In the context of dating websites, abruptly cutting off contact without giving an explanation was common.

“If I'm talking to somebody, maybe on Grinder, although not so much, it was Gaydar in the early days, but any other platform which I dip into rarely, simply because if you're telling anybody the truth, then they'll mostly just instantaneously stop talking to you or block you” (Participant 5)

“The negative reactions was mostly not a direct exercise of stigma but it was rather strategic withdrawal does that make sense?” (Participant 3)

People also talked about how their careers had been adversely impacted. Some had lost their jobs shortly after informing an employer of their HIV status, and one participant saw a reduction in customers to their business.

“I had done a good job and I had a gay boss and I took him to the front porch and I still remember it like it was yesterday, I sat him down and we'll call him Alan, I said 'Alan, I'm HIV positive, is that gonna be a problem?' He said 'no, no, no, it's gonna be fine, you do an amazing job and we'll go from there' and so I carried on with work. Couple of weeks later, got fired” (Participant 2)

“It didn't bother me that they printed it however during the next couple of months I noticed just a decline in people coming to the café” (Participant 2)

Examples of covert stigma also occurred within friendships. People tended to give friends the benefit of the doubt, believing that there was no direct intention to hurt them, but this was nevertheless a consequence of their behaviour.

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2. Source & Type of Stigma

“They are a house of girls and they were talking about would they ever date a guy with HIV, and the majority of them were like ‘no, I would never do that, like that’s too risky, I would never do something with HIV” (Participant 6)

“It’s common that people sit on one plate and they eat together, and when you get invited, those things had stopped so they opted for putting plates out separate, they don’t make you feel like you are the only one who sits aside and eats, but they change the whole system, like it doesn’t take much to understand doesn’t it?” (Participant 3)

2.3 Stigma in healthcare

Participants talked about experiences of being segregated or discriminated against within healthcare settings.

“In truth, it’s happened so many times when they’ve isolated me off into rooms on my own when I’ve been admitted, and they tell me that they’re doing that because of the HIV they barrier nurse me half-heartedly. My greatest desire would be to have HIV removed from my medical records” (Participant 5)

“In retrospect I've been put at the bottom of dental appointment lists and hospital lists in the past too” (survey Participant)

In this latter example, stigma negatively impacted the quality of care that the person received. This occurred recently, during the Covid-19 pandemic.

“The one that happened at the hospital was when I was on admission due to Covid. My cannula removed during the night and blood was gushing out of my hand. I pressed the buzzer and a male nurse came but he wouldn't help me. When another nurse came to help me, he told her that she should be careful with my blood” (survey Participant)

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2. Source & Type of Stigma

2.4 Healthcare professionals not acknowledging stigma

Some participants had reported their experiences of stigma in healthcare. They felt that professionals had avoided taking responsibility, which left them feeling angry and powerless.

“They told me that it was Trust policy to isolate off anybody that had a blood born virus, and leave them isolated off in rooms and barrier nurse them. And this was only and I couldn't have been any more than 4 years ago. The whole experience led to total indignity and I left that ward once again crying and feeling like trash” (Participant 5)

“With the dentist again, [I was] angered by the way they dealt with it, especially the fact that the practice manager was the dentist seen for the initial consultation appointment. They tried covering up the breach of GDC guidelines” (Survey Participant)

I am these days almost indifferent, apathetic. It is a waste of time expressing anything as it always gets twisted by medical staff” (Survey Participant)

2.5 Medical needs overlooked

Although treatments for managing HIV have come a long way, most participants described ongoing concerns about their health and wellbeing. This could be related to the virus itself or to the medication.

“HIV can make me feel tired for instance and the medication sometimes, you don't know how both interact, depression, anxiety, all of these things. There's another aspect also, insomnia. I struggle to be honest, with my wellbeing more than stigma itself I would say” (Participant 3)

Some participants felt that the advancement in treatments and “normalising” HIV to view it as a manageable chronic illness meant that their symptoms and/or medication side effects were not taken seriously.

“When you're talking to people and doing assessments for benefits, we're saying that the HIV is a liveable disease that everybody can live. You know the reality is very different than you are living with something, and the medication has an impact on you as an individual rather than what usually happens to the majority of people” (Participant 4)

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2. Source & Type of Stigma

“You can ask nurses who are normal nurses, but it’s like “oh you have to ask the consultant or the senior”, the younger nurses don’t know much about HIV, they know that it’s in the body and that it’s undetectable but they don’t actually realise what it actually does to the person, you know” (Participant 4)

2.6 Multiple stigmas

HIV stigma can often intersect with other forms of stigma, for example sexuality or racial stigma. Some of the participants we interviewed described multiple stigmas, although this wasn’t relevant to everyone with HIV from a minoritised group.

“You know, you suddenly think, because as I said, being diagnosed with HIV in particular, it’s still classed as a gay, you know, disease amongst gay people and this type of thing” (Participant 4)

“Oh, she is African, she is a white African’. So, some stigma starts building from then to now” (Participant 1)

“Personally, I don’t, to the best of my knowledge, I never remember someone having highlighted the double prejudice against me no, but this is personal observation” (Participant 3)

One participant thought that breaking down the association between HIV and particular groups of people was necessary to reduce stigma.

“We need to disassociate these aspects, like the association with the LGBT community, the gay community, the African community, the association with practices, sexual practices and all of these things. This is also one of the ways that will take us towards the direction of not promoting stigma” (Participant 3)



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2. Source & Type of Stigma

2.7 Stigma from other gay men

Some participants highlighted HIV stigma coming from other gay men. Given the solidarity that was once offered, stigma from within the community felt particularly difficult for people to reconcile with.

“The number of cases of stigma by other gay men I've lost count of” (Survey Participant)

“I found that the attitude to HIV amongst the gay population in the north east is very negative” (Participant 5)

“There's this kind of ironic twist, because you know they're all taking PrEP, the youngsters are anyway these days. And yet, this seems to have created a kind of buffer, which means that they actually don't have to discuss or deal with the issue of HIV” (Participant 5)

2.8 Stigma from other countries

Some of the people we interviewed had experience of living with HIV in other countries and cultures. They reflected on how HIV stigma in the UK, and specifically in the North East of England was different to other places. One person thought that the individualism of UK culture meant that stigma was less problematic compared to their country of origin.

“First of all you have to understand that [my country of origin], it's a close net community by sociological terms. By close knit society, very connected and dense. It's not an individual-orientated society like here in the UK. With an aspect like HIV and stigma, it will spread like fire” (Participant 3)

However, other people with HIV experienced the UK, and specifically the North East of England, as more stigmatising than other places. Having a 'gossip culture' and HIV not being openly talked about were seen as ways in which stigma was perpetuated.

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2. Source & Type of Stigma

"I didn't know people with HIV don't talk with nobody, here, I used to meet people with HIV in a big big city in Portugal and speak to doctors there. And I knew a lot of people with HIV. More than here, I find it not normal, I thought England had open minds, but why they don't talk?"

(Participant 1)

"I find it extraordinarily difficult to cope with perhaps my perception of the way in which HIV is dealt with in the North East. I think it's much easier to deal with HIV in an urban setting, mostly because you've got more people, and you've got less of a gossip system going on. I don't see the North East as 'urban'"

(Participant 5)



2.9 HIV stigma has impacted the way I see myself

People talked about the ways in which experiencing HIV stigma had altered their view of themselves. Feelings of guilt, shame and internalised stigma were reported.

"It isn't easy for us saying "I'm gay". Well it's 2022, but it's the HIV again, I don't think that even today- it's the fear, as it's not talked about enough, and I do sometimes see a little advert where you see gay pride and the rush of guilt, the rush of fear and everything comes out of me in those few seconds, you know, because I am living that life, which in time I suppose will pass" (Participant 4)

"I think I am a tiny fragment of myself as I was in times gone by, and I don't know why that is, or what value I have anymore? And I blame the HIV for creating that scenario. So a lot of the stigma, a lot of the isolation, is probably self-imposed" (Participant 5)

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3. The Impact of Stigma

3.1 The impact of stigma on me and those around me

Participants discussed the personal impact that their experience of HIV stigma has had on them. There was a sense that stigma had negatively affected how people perceive themselves and the world around them.

“...and the words they used was just you know, made me feel dirty” (Participant 4)

“I find it very difficult navigating the world to be honest” (Participant 5)

“It damaged my faith in humanity and destroyed my self-worth” (Survey Participant)

The impact of stigma extends beyond the individual. Some people noted the impact HIV stigma can have on family because of being related to someone living with HIV. One person highlighted some concerns they once had about family members being stigmatised at their family dentist.

“I would say I am an over-analytical person and this dentist was the dentist that my ex and the children used to go to so I don't want her also to experience that stigma. Does that make sense? So if I don't know how they are going to react, I don't want my ex and the children to lose the dentist they are happy with. You see?” (Participant 3)

Another person shared their experiences of their partner losing their job at the same company from which they had previously been dismissed after disclosing they were living with HIV.

“Anger was a big factor, not only because my employer terminated my employment but they went on to sack my partner at the time for unfounded professional misconduct (guilt by association)” (Survey Participant)



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3. The Impact of Stigma

We identified a sense of loss amongst some people, due to termination of employment or personal relationships.

“Maybe there's the metaphor it's a bit like a Durham miner who certainly finds themselves without the mine, you know, I was working at the coal face, and I was working day in day out at the coal face where everything was happening and then all of a sudden, it feels as if the mine's been closed there's no coal face to go to anymore, because somebody's closed it down” (Participant 5)

“I lost family and friends. It has been financially devastating and made recovery (as much as I can) 100 times more difficult” (Survey Participant)

3.2 Feeling isolated or alone

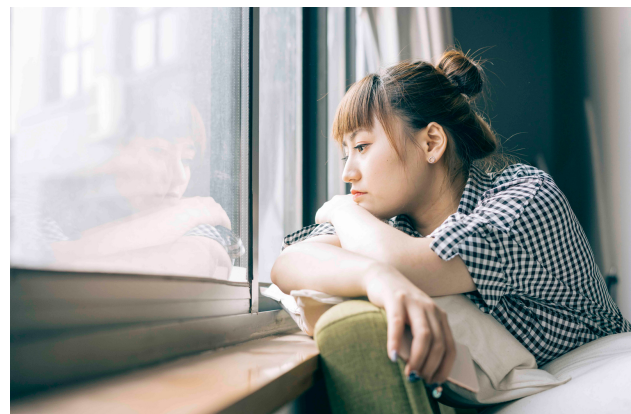
Some people described how isolated they have felt living with HIV and their difficulties adjusting to this.

“I've never experienced something like that before because I've been a person who gets on with everybody and erm obviously now it's sort of like I'm being trapped inside my own cocoon” (Participant 4)

“I think what's the most shocking thing is I find myself living up here like a hermit” (Participant 5)

One person described actively avoiding being around people, perhaps due to anticipated stigma.

“I just want to be by myself. I don't want to be close with people and meet people” (Survey Participant)



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3. The Impact of Stigma

3.3 Difficulty trusting others

People talked about how living with HIV can make it difficult to trust others who know about the diagnosis. One person referred to the possibility of this being used against them

“Forget about HIV or transmission or anything like that, think about if someone gets angry at you for whatever reason, it could be any trigger and they could use that aspect of you against you and that’s awful... if we say if you find someone who will truly love you then they shouldn’t practice these things against you or use such words, then you can’t ever be sure or guarantee that the other individual won’t opt for such tactics in difficult times” (Participant 3)

Another person spoke about their previous experiences of stigma within healthcare leading to a distrust of medical professionals.

“Sadly what can be done, I cannot remove my HIV from my medical notes so I expect to be squashed by someone in the medical profession. I have not a lot of trust” (Survey Participant)

3.4 My own reaction to stigma

People spoke about their own reaction to their experiences of stigma, whether this was heated, or calm and collected. One person described their reaction going against how they usually behave as a person. This instance highlights the toll that HIV stigma can take on individuals, particularly when feeling vulnerable.

“...and at one point I’m afraid I lost my temper. I don’t see myself as a particularly aggressive person, but when you’re in that amount of pain, that no one will take any notice of, you want to be seen by some extent by a specialist and listened to” (Participant 5)

Another person described being able to compose a polite text message to someone who was overtly rejecting them due to their HIV status.

“...and then the message he sent back was just- yeah [laughter] yeah I deleted it obviously straight away and I said well ‘thank you very much okay I respect that’, and I could’ve said a lot more, but I thought ‘it’s not worth it’” (Participant 4)

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3. The Impact of Stigma

3.5 Coping with the impact of stigma

People discussed their experiences of learning to cope with the impact of stigma on their daily lives. One person's early strategy was to try and ignore it.

“Personally, to be honest, although I was experiencing these things, I was just putting everything behind my back” (Participant 3)

Another person described turning to substances to help them to cope.

“Initially, taking drugs to escape the feelings” (Survey Participant)

However, people talked about the coping strategies they have developed over time, and this same participant described now being able to adopt healthier coping mechanisms.

“Subsequently, peer support and various talking therapies” (Survey Participant)

Another person reported finding benefit in listening to how other people living with HIV have coped with stigma.

“You meet here [at Blue Sky Trust], a lot of other people's stories and how they dealt with similar situations and then it kind of helps you manage it a bit more because you know how they dealt with and how other people reacted to it” (Participant 6)

3.6 Protecting myself from the impact of stigma

Although people reported being able to build coping skills to help deal with the stigma they are faced with, several people talked about further ways to protect themselves from the impact of stigma. One person discussed their idea of framing HIV stigma as a reaction from the perpetrator due to fear of the unknown rather than a personal attack.

“Addressing how the social dynamics can react to unknown things and showing people how it is not personalised but it is a 'reaction'” (Survey Participant)

Another person protected themselves from the impact of stigma by recognising their own limits in the fight against it and putting their health first.

“but in the end I was so ill and I thought 'I just want to get it over and done with' and I accepted the out-of-court settlement” (Participant 2)

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3. The Impact of Stigma

3.7 Growing 'used' to stigma

Several people mentioned longstanding stigma in their lives. One person discussed non-HIV related stigma and how this helped them to deal with any HIV stigma they have faced.

"I could deal with it so natural because I already felt stigma" (Participant 1)

The impact of length of time since diagnosis was also highlighted, and it was felt that the more time had elapsed since diagnosis, the more 'used to' stigma a person would be.

"I think the people who have been living with it a lot longer by twenty years and things like that they're not so bothered cos they've just got used to it" (Participant 4)



However, there were some people who felt they had experienced little or no stigma in the years they have been living with HIV.

"I definitely would say that personally I don't feel like I've been affected by stigma that much, I'm literally like trying to think of example" (Participant 3)

"I've been quite lucky that I've not been in a serious setting that I could, that I was trapped, you know, I couldn't get out of it" (Participant 6)

However, one person noted that it might be due to becoming accustomed to HIV stigma that they may have recognised instances of it less over time.

"...or at least maybe with me I'm so I so used to stigma that I don't notice anything, you know. Probably at the hospital some nurses or, I don't know" (Participant 1)

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3. The Impact of Stigma

3.8 Hearing others accounts of stigma

Whilst some people cited hearing about others' experiences and coping strategies as helpful in dealing with their own experiences of stigma, some people noted that listening to others' stories and experiences can have a negative impact and perpetuate a belief that everyone living with HIV experiences stigma

"Erm, in terms of downsides, whenever you have group sessions and you have everyone talking about their different scenarios that they've come across, sometimes that can be quite negative, it can have a negative effect because then it's almost like a wall of negativity, that you're facing, you're like oh everyone is just faced with negativity when they talk about their HIV" (Participant 6)

It was suggested that this may lead to the anticipation of stigma from particular sources.

"What feeds each other's stigma, by the way, is other people's experiences. I heard for example some awful experiences of some dentists that they actually practiced some unbelievable prejudice or stigma against some people with HIV" (Participant 3)

One person was reluctant to talk about their experiences of HIV stigma with people newly diagnosed as they thought that they might exacerbate worries about stigma.

"...at one point I used to talk to quite a lot of people who were just recently diagnosed, but if I was to do it now, I feel like I might be reinforcing the negatives" (Participant 5)

It was also noted that becoming more aware of stigma can lead to people becoming more likely to recognise it, perhaps even when others do not. One participant noted that as their understanding and awareness of stigma increased, they came to notice instances of HIV stigma more often.

"...and what made it more difficult, was my level of understanding. You know when you are like aware, it's like you see, you can't stop seeing these things" (Participant 3)

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4. Living Well & Responding to Stigma

This theme captures people's experiences of living well with HIV and often in the face of stigma, and highlights some of the suggestions made for responding to and tackling HIV stigma into the future.

4.1 Personal growth and achievements

People discussed their own personal growth since being diagnosed with HIV. One person discussed this in the context of forgiveness being helpful for them.

"Yeah, cause it's only acceptance that helps, being resentful will just make you stuck and make you not function maybe. I'm quite a positive person really in all this, I'm very positive, I move on with kindness, forgiveness because sometimes forgiveness is for you more than other individuals, it heals part of you" (Participant 3)

One person remarked that their experiences have increased their personal strength.

"The experiences I had have made me a much stronger person" (Survey Participant)

People also noted some of their personal achievements whilst living with HIV, with one person sharing his business success after being terminated by a previous employer due to his diagnosis.

"I was unemployed, and I decided I wanted to do something for myself so I started a business, I started a café...I've been a chef for like 35 years and I thought 'well, I could have a go at doing it on my own'...I got nominated for this Barclays business award. I was apparently in the top 10 finalists which I was amazed at because I had only been in the business probably four months and I was really chuffed" (Participant 2)



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4. Living Well & Responding to Stigma

4.2 Building confidence

There was a sense that being able to build confidence is an integral part of living well with HIV. A couple of people mentioned the need for formal work on this as a means of responding to stigma.

“What’s necessary is perhaps more work on building that confidence within life living with HIV. 30 years on, I feel I’ve gone backwards” (Participant 5)

“Just concentrate on building resilience to train positive people to put up with the shit they will face” (survey Participant)

One person shared that their experiences had led them to build enough confidence to be able to respond to stigma in a way they would not have been able to before.

“So now if you asked me ‘would you go to a different dentist?’, I’d say ‘ I can change dentists three times if you want, I don’t mind’, so there is this immunity you hold through time” (Participant 3)

4.3 Access to good healthcare

One thing that was cited to improve people’s experiences was access to good quality healthcare. People described their feelings of gratefulness for the healthcare they have received and continue to receive, particularly in terms of medical professionals and medication.

“I would say in the UK, I can’t say much, I’m grateful. For me, if you ask me personally, I am in debt, I will always be in debt for the medication I’m taking, for the consultancy I’m taking. For an individual like yourself who dedicates time and effort to make the life of people like us better, that’s just a purity, it’s beautiful and I’m grateful for that” (Participant 3)

“The help I’m getting is outstanding, with the medication and the doctors and that, it’s absolutely outstanding” (Participant 4)



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4. Living Well & Responding to Stigma

4.4 HIV isn't the worst health condition

Although people discussed difficult aspects about living with HIV, there was sense from some people that they could be living with 'worse' conditions. For instance, one person described being more concerned by another long-term condition, especially now that treatment for HIV is more advanced.

"Through the years, medication was bad, but it got better and better, and now I'm just ok with HIV and I'm much more concerned about diabetes" (Participant 1)

Meanwhile, another person recalled the moment they were diagnosed with HIV and at that time believed it was a terminal, life-limiting condition, based on knowledge about HIV before advances in treatment were made.

"I said 'I can't be, it can't be true, how long have I got?' and then they explained to me it's not like that anymore, you know cos I thought I only had like 6 months to live" (Participant 4)

People also mentioned beliefs of those around them about the condition, and there was a sense that medically, it has not had as much of an impact on their lives as other conditions might.

"My friends at the start treated me different, and whenever they realised I was getting on with my day as if it was normal, I think then then got used to the fact HIV is just a very normal thing that doesn't have to impact your life" (Participant 6)



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4. Living Well & Responding to Stigma

4.5 Social Support

Social support was discussed by people in various contexts as being a factor which makes it easier to live with HIV.

For instance, some people discussed people around them being directly supportive of them when they became aware of their diagnosis, whether this was family, friends or professionals.

“The support I had from family, friends and my HIV medical team, in time I felt empowered” (Survey Participant)

“I told people who I was in contact with, a lot of them acted really really nicely” (Participant 6)

“Through therapy and organisations that I’ve dealt with, I’ve not worried about it at all, I’ve always had someone to speak to” (Participant 3)

Others discussed more indirect sources of support, such as people who are aware of their diagnosis supporting them through tackling misinformation.

“...my friend who I told, is very, she’s a big part of my support network, she had discussions with her flat mates, where basically HIV came up in conversation, and my friend was just sat there like you guys really have no clue what you are talking about” (Participant 6)



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4. Living Well & Responding to Stigma

4.6 Feeling heard and supported

People reported it was helpful to be heard and supported and Blue Sky Trust was cited as a place where this is able to happen.

“Being able to talk about how I was feeling and what I was going through was really important” (Survey Participant)

“Blue Sky don’t judge us, you can be really how you feel, if you want to cry you can cry and if you want to laugh, you can laugh, but when I told them my story about the person rejecting me, they explained to me that this is going to happen and you might come across it a lot or not at all... it’s talking to someone who isn’t judging me or looking at me in a way of disgust, which I have experienced already” (Participant 4)

People also mentioned the benefits of connecting with others also living with HIV at Blue Sky Trust.

“Peer support, having a peer connection with whom you could share and discuss personal experiences” (Survey Participant)

One person also mentioned the role of psychology as something which could be helpful in containing and validating people and their experiences.

“I do think you mentioned a psychologist involved. I think that’s very good in terms of when people face stigma they automatically go to like a really dark part of their head where they think, even though they know it’s not true, they get taken back by the stigma and they get put down by it” (Participant 6)



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4. Living Well & Responding to Stigma

4.7 Being conscious of not stigmatising others

Some people talked about themselves not behaving in a stigmatising way towards others. One person described being aware that they would not stigmatise anyone.

“I wouldn't do that to someone else, it doesn't matter if they're rich, poor, on the streets, they're all the same to me... so” (Participant 4)

Another person mentioned being in a position where they would be able to stigmatise a perpetrator of HIV stigma but making a conscious choice not to do so as they do not behave in such a way.

“So for example if I'm gonna take the opposite position, I for example never stigmatised the other person about their mental health although they have been dealing with these difficulties” (Participant 3)

There was a sense that being on the receiving end of HIV stigma has made people more aware of other stigmas and evoked a desire to ensure they do not stigmatise other people.

4.8 Taking personal action against HIV stigma

People talked about things they have done to take a stand against HIV stigma. Some people described actively fighting against HIV stigma and making a contribution. For instance,

“...so a few weeks went by and I started a new job in a bowling alley in east London and I decided to take them, I looked on Google at unfair dismissal and I thought 'I'm gonna have to fight this' cause its nothing to do with my work, I think it's to do with my HIV” (Participant 2)

“I was there at the beginning. I've been involved in changing stuff. I've made a contribution. I've taken it from European work to international work, and I've made a contribution in treatment activism and education” (Participant 5)

Sometimes actively fighting against HIV stigma involved reporting it through official channels. This included a hospital complaint.

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4. Living Well & Responding to Stigma

“When I made the complaint, I said that I hadn't seen the doctor for three days, ‘is that normal?’ and I asked them why I was being barrier nursed. They flipped this, and I was made out to be a ‘problem patient” (Participant 5)

Others referred to their experiences of taking legal action against those who had discriminated against them for living with HIV.

“I reported this to the Terrence Higgins Trust, and their online legal support. They gave me lots of information, were quite appalled. In the end we agreed that I would not want to be involved with any organisation that was so badly run, and is unaware” (Survey Participant)

“...and over time felt strong enough to take my employer to court and hold them to account relating to the way they had treated me. The court case lasted 16 months and thankfully was successful” (Survey Participant)

People also described actively educating people around them about HIV to help reduce stigma.

“But I gave her some awareness that it's not the touch because the virus only survives seconds alive in the air so 18 seconds, so it's not worth thinking about those problems when they are not there” (Participant 1)

“...and at that point I smiled at them and I said ‘do you actually know anything about HIV?’ and so umm, I left their office and I went to the reception desk to the lady and I said ‘I'm wondering if you could do me a favour? Could you go on to Google and just find some HIV information and print it off for me?” (Participant 2)

In one instance, a participant used self-disclosure as a means of sharing their knowledge about the condition with their brother.

...“Are you not scared of the AIDS” and I said well “AIDS doesn't really exist anymore, years ago yes but fortunately now HIV doesn't get to that stage and if it does they've either stopped medication or that's down to them” and he goes, “oh you know so much about it don't you” and I turn round and say say “yeah cos I'm actually living with it” (Participant 4)

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4. Living Well & Responding to Stigma

4.9 Practical support

Some people talked about the importance of practical support for people living with HIV. One person described having a positive experience of this at Blue Sky Trust.

"I've been coming here [Blue Sky Trust] and if I hadn't, I'd be in a right mess but coming here they're so informed as well as what's going on out there, they let us know about new technology and insurances, and things I wouldn't have known about before, and how to make my life better as well, not to make it more difficult (Participant 4)

Others had some ideas about practical support that they would find helpful.

"Teach people how to deal with stigma, how to deal with negative relations, mindfulness" (Survey Participant)

"Advocacy and signposting where relevant" (Survey Participant)

4.10 Tackling stigma through open discussion

Being able to openly discuss HIV can go a long way towards tackling stigma, and people were in agreement that more open discussion is needed.

"Definitely in general there needs to be more open honest, human and humane conversation" (Participant 5)

One person reflected on their previous experiences of creating safe environments in which to have these conversations.

"You know what I used to do is I used to it's kind of like tried to create the environment which allowed people to be able to question or ask questions, because you know so I run the charity in Africa, so you know I used to talk about that in terms of kind of my interests and stuff, and it allows people to be able to talk to you about it" (Participant 6)

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4. Living Well & Responding to Stigma

4.11 Tackling stigma through education, training and research

Several people referred to the need for increased education around HIV as a means of tackling stigma. It was noted that where stigma is founded by lack of knowledge, education is the key to resolving this.

“The foundation, the foundation of negative things like stigma in HIV, the very ground for them is ignorance, so the more we educate people the more we develop understanding, empathy, sense of inclusiveness, the more we develop love for other people” (Participant 2)

It was also noted that teaching others about HIV is often done by those living with the condition who have experienced the effects of misinformation.

“Provide support to allow victims of stigma to use that experience as a tool to educate others about the facts around living with HIV in 2022” (Survey Participant)

It was noted that training workshops specifically around HIV stigma are helpful for those who then go on to educate others about HIV and HIV stigma.

“I was helped by training I received during the stigma taskforce sessions / workshops” (Survey Participant)

One person noted that when providing education or training around HIV, equal representation of the HIV community is important.

“...and I suppose presenting somebody who's HIV Positive requires not only to look after them as a person, but also to see them as a teacher. Blue Sky Trust have a woman going in and talking, because that presents one side of living with HIV, but it doesn't necessarily present all of the sides...so I suppose we have to look at in terms of visibility, that we create visibility that represents the whole group and not just part of the group” (Participant 5)

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4. Living Well & Responding to Stigma

The same participant cited research as being important in tackling HIV stigma, and there was also acknowledgement that research is worthwhile when those who have experienced stigma benefit from it.

“The stigma stuff requires more research. But then, I’m not sure what the research then passes back to the people. I’d like to know what value it’s had, or to see what practical changes have been made” (Participant 5).

4.12 Changing the language we use around HIV

Some participants highlighted the importance of thinking about the language we use when talking about HIV. One person shared their experiences of the word ‘clean’ and the connotations that come with this when using it to describe people who do not live with HIV.

“Are you clean?’ I say no, I am HIV positive. I say, well first of all clean has nothing to do with your physical, HIV has nothing to do with your physical hygiene and what do you mean by clean? So if they elaborate more... it is a reductive term in a linguistic sense” (Participant 3)

Another person discussed the connotations associated with the word ‘HIV’, and it was suggested that using a different word or acronym entirely may help to reduce stigma and that removing the word ‘virus’ may be helpful.

“H-I-V, that’s why I’m saying if they could change somehow those three letters into something that was not so spot on the actual virus, you know, like they changed coronavirus to the other word, what is it, covid” (Participant 4)

One way that we may reduce stigma by looking at our language choices, is to be aware of some of the negative associations with HIV-related language. One person referred to some work that Blue Sky Trust has been doing around this.

“Blue Sky Trust has highlighted such language, I think there is a sheet, I don’t know if you have seen it? It’s really useful because it breaks down some of the common negative associations about HIV” (Participant 3)

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4. Living Well & Responding to Stigma

4.13 HIV stigma and the future

There was a sense that HIV stigma has not lessened over the past few decades. This led some people to feel there is little hope in the way of tackling stigma today.

“Don't waste much time trying to change the outside world it won't change...it hasn't much changed after about 1995 it's unlikely to now” (Survey Participant)

“Well to be honest the way we're going at the moment, I don't think there is [much else we can do], I think we need to keep on going and focus on helping HIV positive people in dealing with their own stigma” (Participant 5)

However, there was some hope that with further advances in medical treatment and further reduced transmission rates, we will see a decline in HIV stigma.

“...which is not only a goal at the individual level, it is a goal on the collective level of society that by 2030 we'll reach the target on transmission that hopefully either by medication or vaccines that we will hopefully stop all this drama around HIV” (Participant 3)

There was recognition by one person that the fight against HIV stigma continue to require patience and time.

“I'm hopeful, look we can't expect change to happen overnight... What you guys do in the NHS and at Blue Sky Trust, they are doing amazing work already and that job is already going in the right direction... so I think we just need patience and we need time, both of them, for these things to get better” (Participant 3)



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Discussion

This project reflected the experiences of twenty BST members. The majority of participants had experienced HIV stigma, which was associated with a host of negative consequences including physical and mental impact, reduced self-esteem, anxiety related to disclosure, and feeling socially isolated. A minority of participants felt that experiencing stigma had made them more resilient. We saw in the interviews that repeated experiences of stigma could lead people to become 'used to' stigma. Building resilience could therefore be understood as a survival strategy, a way of protecting against the emotional impact of stigma. It is also possible that in sharing experiences of HIV stigma and feeling supported, people developed a greater sense of resilience.

The people we interviewed had varying experiences and attitudes about disclosing their HIV status. Some had told very few people, while others openly talked about their diagnosis. Predicting judgement or rejection deterred people from sharing their diagnosis. The people who openly talked about having HIV described personal benefits, such as feeling less burdened by secrecy. They had reached the conclusion that any judgement was a reflection of others and not of their personal character. Length of time since diagnosis seemed to be a factor in decisions about disclosure, with those diagnosed the longest appearing to more readily talk about their HIV.

The sample of people who took part in the project was skewed towards those who had been diagnosed for a long time (10+ years). This allowed us to gain a sense of experiences of stigma over time. Employment and dating websites were the most common sources of stigma. In the interviews, people shared examples of covert and overt stigma in the workplace, with the majority of these taking place a number of years (or even decades) ago. Legislation such as the Equality Act (2010) now protects people with HIV from experiences of direct stigma (such as being unfairly dismissed due to HIV), however, instances of covert stigma, where the change in behaviour is not directly linked with HIV seem more challenging to address.

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Discussion

Several participants shared recent examples of stigma on dating apps. This could be overt (such as use of derogatory language), or covert (being ignored, 'ghosted' after sharing their HIV status). The majority of people who took part in the project identified as gay men, and the interviews highlighted HIV stigma occurring from within this community. It could be helpful for BST and similar organisations to work with LGBTQ+ communities and dating websites. Participants thought that it was important to provide up-to-date information to address misconceptions about HIV. In the interviews, it was raised that current campaigning about HIV does not match the intensity and volume of the 80s and 90s, when stigmatising attitudes were perpetuated by the media. As a result, the general public remain largely uninformed about how medical treatments have advanced, and stigmatising views go unchallenged. A similar finding was reported by Hedge et al. (2021) who interviewed people living with HIV, activists, charity workers and health professionals to understand how HIV stigma had changed over time. They reported that public knowledge and attitudes towards HIV have changed over time, but not as much as they should have.

In Hedge et al.'s (2021) study, ongoing experiences of stigma and discrimination were reported within healthcare settings. Some participants in our study described stigma in medical settings, including inappropriate barrier nursing and poorer quality of care. This had a significant emotional impact for participants, and also has the potential to adversely impact their physical health if HIV is a deterrent to accessing healthcare.

Some research studies have highlighted intersections of stigma, such as the additional impact of homophobia, or racism on individuals with HIV from minority groups (Hedge et al, 2021; NAT, 2015). In our study, 30% of people reported experiencing multiple stigmas. Sexuality was the most common characteristic for intersecting stigmas. Interestingly, none of our participants reported an interaction between racism and HIV stigma. This is likely because the majority of participants were from White backgrounds. Struggling to recruit a diverse sample that reflects the HIV community is not a challenge unique to our project. However, since most of the people who took part were males who identified as gay, the findings more readily apply this group.

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Discussion

In terms of addressing HIV stigma, the people who took part in our project felt that promoting knowledge in public places was important in addition to training, education and more open discussions about living with HIV. Healthcare providers, police and the general public were suggested recipients of these interventions. In the interviews, the importance of language was highlighted, and it was suggested that dropping the association between HIV and other characteristics such as sexuality or race would help to reduce stigma.

People who had confided in others following an experience of stigma had largely found this supportive. Therefore, having access to a support network is an important aspect of talking stigma. Being connected with other people with HIV was largely considered helpful, however, some people indicated that hearing about others' experiences of stigma could create anxiety and apprehension, so this is something to be mindful of. For balance, it could be helpful for BST to share stories from people who have had positive experiences of sharing their diagnosis, as well as from those who have experienced stigma. Interview participants talked about how BST offered a place to be listened to, supported and to build confidence. It could be helpful for BST to routinely offer a space for people to share their experiences of stigma. Not only would this be supportive, but it would also allow data to be captured on an ongoing basis about locations where stigma is occurring to inform the intended targets of training and other interventions. Having access to legal and practical support was also important for empowering people to fight back against perpetrators of stigma; so signposting to available services such as Terrence Higgins Trust is helpful.

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Discussion

A summary of the main conclusions and recommendations from this project are shown in the box below:

Key findings and recommendations

- Of 20 people who took part, 85% had experienced HIV stigma. It was common for people to have experienced stigma on more than one occasion, in more than one place.
- Experiencing HIV stigma caused people to feel worse, physically and mentally. It was linked with increased isolation and worries about disclosing the diagnosis.
- Employment, dating websites and healthcare settings were the most common sources of stigma.
- Working with dating websites was suggested.
- People thought that promoting HIV knowledge in public places was important to address common misconceptions held by the general public.
- More open discussions about living with HIV, training, education (including sexual health education in schools) were recommended.
- Healthcare providers and police were recommended recipients of training.
- Routinely gathering experiences of stigma as they occur could be helpful for supporting members. This would have the additional benefit of providing ongoing data on the places in which stigma is occurring to inform interventions.
- Most of the people who took part were males who identified as gay, so the findings more readily apply this group.
- HIV stigma was reported from within the community of gay men. Collaboration with LGBTQ+ networks could be helpful.
- People who had confided in others following an experience of stigma generally found this helpful.
- Having access to a (personal, professional or peer) support networks is important.
- Hearing examples of stigma from other people with HIV can raise anxiety. Presenting a balanced view to include people who have had positive experiences of sharing their diagnosis as well as from those who have encountered stigma is important.
- Signposting to legal and practical sources of support (e.g. legal aid, or relevant legislation) is important for empowering people to take action against perpetrators of stigma.

References

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All Party Policy Group on HIV & Aids. (2020). Nothing about us without us: Addressing the needs of Black, Asian and minority ethnic communities in relation to HIV. Reports – All Party Parliamentary Group on HIV/AIDS (appghiv aids.org.uk)

Centers for Disease Control and Prevention. (2021). HIV stigma and discrimination. [Facts about HIV Stigma | HIV Basics | HIV/AIDS | CDC](#)

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.

Chambers, L. A., Rueda, S., Baker, D. N., Wilson, M. G., Deutsch, R., Raeifar, E., & Rourke, S. B. (2015). Stigma, HIV and health: a qualitative synthesis. *BMC public health*, 15(1), 1-17.

UK Government. (2010). Equality Act 2010. [Equality Act 2010 \(legislation.gov.uk\)](http://legislation.gov.uk)

Hedge, B., Devan, K., Catalan, J., Cheshire, A., & Ridge, D. (2021). HIV-related stigma in the UK then and now: to what extent are we on track to eliminate stigma? A qualitative investigation. *BMC public health*, 21(1), 1-10.

National Aids Trust. (2015). Tackling HIV Stigma: What works? Using the global evidence base to reduce the impact of HIV stigma. [Jun_16_Tackling_HIV_Stigma.pdf \(nat.org.uk\)](#)

National Aids Trust. (2022). [HIV in the UK statistics. UK HIV Statistics | National AIDS Trust](#)

Public Health England. (2021). Annual epidemiological spotlight on HIV in the North East 2018 data. [Annual epidemiological spotlight on HIV in the North East \(publishing.service.gov.uk\)](#)

Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., & Wilson, M., Logie, C.H., Shi, Q., Morassaei, S., Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ open*, 6(7), e011453.