The landscape for people living with HIV in the United Kingdom (UK) is dramatically different from what it was ten or twenty years ago. Advances in treatment mean the life expectancy of HIV positive people can be the same as that of the general population. Living with HIV in the age of undetectability and reduced risk of transmission should mean a better quality of life for people living with HIV.

However, despite some shifts in public attitudes, a considerable number of people in the UK still hold stigmatising attitudes towards people living with HIV. Consequently, stigma remains a significant obstacle for many people living well with diagnosed HIV.

The People Living with HIV Stigma Survey aimed to provide an evidence base of the HIV-related stigma and discrimination experienced by people living with HIV in the UK. Building on the experience of the 2009 People living with HIV Stigma Index, the 2015 survey was a collaborative, cross sector, community-led initiative that captured participants’ feelings and experiences with partners, family and friends, at work, in faith and in healthcare settings related to their HIV within the previous 12 months.

1576 participants were recruited from community organisations and HIV clinics throughout the UK. This report card focuses on the experiences of the 28 participants living in Northern Ireland. This report is one of eleven covering key findings of the UK Stigma Survey 2015. The reports were developed by community for community. We thank Public Health England for assistance in the data collection and analyses of the survey.

All of the report cards and survey methodology can be downloaded from the UKStigmaSurvey website.

HIV-related stigma is commonly understood as a process of devaluation and may constitute:

Self or internalised stigma: the acceptance of negative self-beliefs associated with being HIV positive

Anticipated or perceived stigma: the awareness of negative beliefs and expectation of negative treatment amongst people living with HIV

Discrimination: the negative and devaluing treatment of people due to their status. These may fall within the purview of the law.

These different types of HIV-related stigma were measured in a number of ways in the survey. Participants were asked about negative and positive feelings in relation to their status to assess levels of self or internalised stigma. They were also asked if they had worried about or avoided situations in relation to their HIV to assess levels of anticipated or perceived stigma and, finally, whether they had experienced different treatment in relation to their HIV to capture discriminatory treatment.

With the understanding that a person’s experience of stigma may be different in their personal, social and working life, participants were asked to describe their experiences of stigma with partners, family and friends, and in their workplaces, faith communities and healthcare settings over the past 12 months.

1 Undetectability means a person’s viral load, or the amount of virus in the blood of an HIV+ person, is lower than the amount a blood test can detect. A person with undetectable virus is extremely unlikely to transmit the virus to another person. See: http://www.aidsmap.com/No-one-with-an-undetectable-viral-load-gay-or-heterosexual-transmits-HIV-in-first-two-years-of-PARTNER-study/page/2832748


3 In order to further explore how people living with HIV experience stigma, 40 semi-structured interviews were conducted with a representative sample by a community researcher. Many of the quotations used in the report cards come from these interviews.

Summary of findings in this report

- Awareness of HIV status and support varied across social settings, with fewer people feeling supported by family and faith groups, compared to friends or co-workers.
- Anticipated stigma was most commonly reported, with many participants worrying about sexual rejection, treatment in the workplace and job security, and avoiding sexual encounters, due to their status.
- Half felt positive about life and in control of their health, yet three in five felt ashamed and blamed themselves due to their status in the last year.
- Half felt supported at their GP, and two thirds at the dentist, yet many feared being treated differently in primary care; more people had avoided dental care than in the UK overall.
- Most had sought support related to their HIV, with two in five consulting a local HIV support organisation in the last 12 months.

1. Who took part?

28 of the 1576 survey participants lived in Northern Ireland.

26 out of 28 participants in Northern Ireland were male, and 24 of these identified as men who have sex with men (MSM); 1 participant identified as trans. All participants in Northern Ireland identified as white British or Irish. Most were aged between 35 and 50.

Hardship was not uncommon among participants in Northern Ireland; 10 (36%) reported constantly struggling with or falling behind on financial commitments, while the same 10 reported sometimes or often going short of food in the last year.5

HIV testing, diagnosis and treatment

27 out of 28 individuals in Northern Ireland were diagnosed in the UK, 4 of these in the past 5 years. Of the 13 people diagnosed in the last 5 years, 10 reported being tested voluntarily, while 2 felt made to take an HIV test. 86% were currently on antiretroviral treatment (compared to 92% in the rest of the UK).
Changes and challenges

2. Telling others

25 of the 28 participants in Northern Ireland had informed someone in their social circle or at work about their HIV. While many felt supported after telling someone about their HIV, relatively fewer felt well supported by family members and in faith settings.

“How could I discuss it with someone and expect them to come to terms with it, when I hadn’t? I then realised that I wasn’t going to come to terms with it, unless I discussed it with someone else, but I didn’t want to, until I’d made some progress”
Man, 45 years old, white ethnicity and living in a rural area outside of Belfast, diagnosed 2008

Partners

27 participants in Northern Ireland were sexually active in the last 12 months, 18% (n=5) with only their main partner. Most reported their partners were aware of their HIV status; 80% (n=4) of those with one sexual partner felt well supported, with fewer of those with multiple partners reporting good support.

“I don’t actually, but I make sure, I know the rejection, I’ve talked to many people about this. Everything has to be safe sex, and I stick to that”
Man, 66 years old, white ethnicity and living in Belfast, diagnosed 2000

Disclosure to family and friends varied, with fewer than half (47%, n=9) feeling well supported upon telling a family member, and two thirds (65%, n=15) upon telling a friend.

“Over here, it’s completely different. People are wired differently, that’s probably the best way to put it. You say ‘HIV’ and they think ‘child molester,’ ‘paedophile.’ We must be 20 to 30 years behind the rest of the UK in terms of coming to terms with sexuality, let alone HIV”
Man, 45 years old, white ethnicity and living in a rural area outside of Belfast, diagnosed 2008

<table>
<thead>
<tr>
<th></th>
<th>Percentage of people</th>
<th>Percentage of partners aware</th>
<th>Percentage reporting good support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexually active with only main sexual partner</td>
<td>18%</td>
<td>100%</td>
<td>80%</td>
</tr>
<tr>
<td>Main and others</td>
<td>18%</td>
<td>100%</td>
<td>60%</td>
</tr>
<tr>
<td>Multiple</td>
<td>33%</td>
<td>71%</td>
<td>61%</td>
</tr>
</tbody>
</table>

Figure 3. Awareness of HIV status and support in sexual relationships
A third of participants (8) reported they were active members of the Christian faith, and 2 had told someone in their faith community about their HIV. 3 of the 8 participants had been active in the last 12 months, and 1 of these had shared their status. Only 1 participant reported feeling well supported in their faith group.

Workplace

Of the 18 participants working at the time of the survey, 8 (44%) reported that someone in the workplace was aware, while 9 (50%) reported that they hadn’t told anyone. 6 of the 9 people who had told someone felt well supported (67%). 2 people had decided not to apply for, or turned down, employment or a promotion due to their status in the last year.

3. Experiences of stigma and discrimination

Felt and experienced stigma are affected by many factors, including gender, sexuality, ethnicity and socioeconomic position, along with HIV status. The survey attempted to examine these “layers” of stigma and measure to what extent instances of worry, avoidance and discrimination could be attributed to participants’ HIV status.

A significant proportion had worried about being stigmatised, had avoided encounters or had experienced discriminatory treatment in the last 12 months (Figure 6). Many felt this was mainly due to their HIV status (rather than other factors).

Over half worried about sexual rejection, two in five had avoided sex, and a third had been rejected in the last year. Being gossiped about was also a common source of worry, and was experienced by a third of participants. Finally, around a third also worried about workplace treatment and job security due to their HIV in the last 12 months (Figure 6).
In the last 12 months...

**Have you worried about:**
- Sexual rejection: 53% (64% of all who answered yes)
- Gossip: 39% (64% of all who answered yes)
- Workplace treatment: 32% (64% of all who answered yes)
- Job security: 28% (64% of all who answered yes)
- Excluded - family gatherings: 21% (36% of all who answered yes)
- Excluded - social gatherings: 18% (25% of all who answered yes)
- Verbal harassment: 10% (21% of all who answered yes)
- Physical assault: 2% (7% of all who answered yes)
- Excluded - family gatherings: 14% (18% of all who answered yes)
- Excluded - social gatherings: 7% (14% of all who answered yes)
- Left a job / income source: 7% (7% of all who answered yes)
- Avoided sex: 42% (57% of all who answered yes)
- Avoided family gatherings: 14% (18% of all who answered yes)
- Avoided social gatherings: 7% (14% of all who answered yes)
- Left a job / income source: 7% (7% of all who answered yes)
- Avoided employment / promotion: 7% (7% of all who answered yes)

**Have you experienced:**
- Gossip: 35% (39% of all who answered yes)
- Sexual rejection: 35% (39% of all who answered yes)
- Verbal harassment: 10% (25% of all who answered yes)
- Excluded - family gatherings: 4% (11% of all who answered yes)
- Job change - consensual: 4% (7% of all who answered yes)
- Excluded - social gatherings: 4% (7% of all who answered yes)
- Job change - against wishes: 4% (7% of all who answered yes)
- Been refused employment / promotion: 4% (7% of all who answered yes)
- Physical assault: 4% (7% of all who answered yes)

Figure 6. Worry, avoidance and discrimination in the last 12 months

### 4. Mental health and well being

Half of participants in Northern Ireland felt positive about life and as good as anyone else, and 61% (n=17) felt in control of their health in the past year. Yet, three in five felt ashamed (61%, n=17) and/or blamed themselves (57%, n=16) due to their status; 2 of the 4 people diagnosed in the last year had a negative self-image. 14% (n=4) reported suicidal ideation in the past 12 months.

### 5. Healthcare

Most participants in Northern Ireland reported that their GP and dentist were aware of their status (79% and 61% respectively). Half felt well supported at their GP (n=11) upon disclosure, and three quarters reported good support at the dentist (n=13).

Figure 7. Awareness and support in primary care
Nevertheless, 10 individuals (36%) feared being treated differently at their GP, and 15 (54%) worried about discriminatory treatment at the dentist. 7 (25%) reported avoiding dental care when required in the last year due to their HIV.

In outpatient and inpatient care, 9 and 7 participants (32% and 25%) respectively worried about discriminatory treatment.

3 participants (11%) felt pressured by a healthcare worker to inform others of their status in the past year.

6. HIV and the law

One participant in Northern Ireland reported being denied insurance products (e.g. health, dental, life, or job protection) in the last year. One person reported being investigated by the police in relation to their HIV status in the last 12 months.

24 participants (86%) were aware that individuals had been criminally prosecuted for the reckless transmission of HIV. 24 (86%) also thought that both partners, regardless of HIV status, equally share responsibility for preventing transmission. Only 4 participants (14%) believed that transmission of HIV should be a criminal offence; 11 (39%) were not sure. More than half (n=16, 57%) reported that the risk of criminal prosecution relating to HIV transmission had influenced decisions regarding disclosure of their status.

7. Support and advocacy

Participants were asked whether they had sought support in relation to their HIV in the last 12 months. Overall over half (n=18) reported seeking support and more than a third (11) had received support from a local HIV support organisation, while 6 people had consulted online sources. No participants in Northern Ireland sought support from peer or faith groups.

<table>
<thead>
<tr>
<th>Source of Support</th>
<th>Northern Ireland (n=28)</th>
<th>Survey population (n=1576)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local HIV support organisation</td>
<td>39%</td>
<td>30%</td>
</tr>
<tr>
<td>Online</td>
<td>21%</td>
<td>16%</td>
</tr>
<tr>
<td>Peer group</td>
<td>-</td>
<td>11%</td>
</tr>
<tr>
<td>NHS patient support group</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>Local policy organisation</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Faith group</td>
<td>-</td>
<td>4%</td>
</tr>
<tr>
<td>Community group</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>None</td>
<td>36%</td>
<td>41%</td>
</tr>
</tbody>
</table>

Table 1. Sources of support in the last 12 months (participants could choose more than one)
Despite this, many (61%, n=17) provided emotional support to other people living with HIV in the last 12 months.

Actions for which participants in Northern Ireland would most like to advocate are raising public awareness and HIV education in schools.

“*It’s the one place where you can go, where you don’t feel like you have to talk about HIV. HIV is in the back of my mind every day, 7 days a week, but when I go to Positive Life, it doesn’t matter because we’re all HIV positive*” Man, 45 years old, white ethnicity and living in a rural area outside of Belfast, diagnosed 2008

Figure 9. Addressing stigma and discrimination for people living with HIV (participants could tick more than one)
Actions and Answers

8. Conclusions

Overall, the survey findings show that stigma and discrimination continue to impact the lives of HIV positive people in Northern Ireland today. Proportionally more participants in Northern Ireland reported experiences of stigma in the last 12 months than survey participants overall, although with a sample size of 28, comparisons should be treated with caution.

The majority reported someone in their social circle was aware of their status, while fewer than half of those currently working had told someone at work. Fewer participants reported good support following disclosure from family members compared to friends and co-workers. HIV-related stigma was most commonly reported in sexual relationships. Education targeted at the general public and people living with HIV on the reduced risk of transmission with an undetectable status could impact highly on the stigma felt and experienced by people living with HIV in sexual relationships and the lack of support reported from family members.

Over half reported negative feelings, or internalised stigma, related to their HIV in the last year. There is a need to improve support for people living with HIV including the provision of psychological and peer support especially in the year after diagnosis.

Most people in Northern Ireland had sought support in the last year. Two in five had sought support from a local organisation in the last 12 months; the majority reported providing emotional support to other people living with HIV. People living with HIV in Northern Ireland believe efforts to challenge HIV-related stigma and discrimination should focus on raising public awareness, education in schools and advocating for the rights of all HIV positive people. Additionally, efforts to promote third sector offers, emphasising interventions geared towards at-risk groups and factoring in access to care and services, could improve the quality of life of people living with HIV in Northern Ireland and the UK as a whole.

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6 See national report card for the experiences of people living with HIV in the UK as a whole.
Appendix: Methodology and demographics

Survey participants were recruited from over 120 cross-sector community organisations and 46 NHS HIV clinics throughout the UK; 25 of the 28 participants in Northern Ireland were recruited by community organisations. The survey was predominantly quantitative, with space for open comment after most questions where additional detail would help with clarification. Forty qualitative interviews were also conducted with a representative sample of people living with HIV in the UK.

Rates of employment for participants in Northern Ireland were broadly representative of the national sample; comparatively more participants were unemployed at the time of the survey, however (n=8 or 29%, compared to 17% of participants in the UK overall) (Table 1).

Participants were categorised into three socio-economic status (SES) groups according to education level, employment, size of residence and whether they had gone short of food or fallen behind on bills in the last 12 months. Overall about a third (29%, n=8) were in the lowest SES group, 42% (n=12) were in the middle group, and 29% (n=8) were in the highest SES group. This was broadly representative of the socioeconomic distribution of participants throughout the rest of the UK.7

8 participants in Northern Ireland reported living with a partner, 3 were in a relationship, and 17 stated they were single at the time of the survey.

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7 See national report card for comparison

Supported by a grant from ViiV Healthcare