HIV in the UK: Changes and challenges; actions and answers
The People Living With HIV Stigma Survey UK 2015
People who inject drugs

STIGMA SURVEY UK 2015
BYUS
FORUS

THE PEOPLE LIVING WITH HIV STIGMA SURVEY UK 2015
People who inject drugs

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.¹

However, despite some shifts in public attitudes, a considerable number of people in the UK still hold stigmatising attitudes towards people living with HIV.² Consequently, stigma remains a significant obstacle for many people living well with diagnosed HIV. HIV-positive people who inject drugs (PWID) may face a double stigma, based on both their HIV status and drug use.

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.³ 1576 participants were recruited from community organisations and HIV clinics throughout the UK.

This report is one of eleven report cards 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. This report card outlines the experiences of participants who injected recreational or performance enhancing drugs, focusing on the 71 people who had used in the last 12 months.

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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. Research has shown that when a person is undetectable they are not able 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).


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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.⁴

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.
Summary of findings in this report

- Most PWID had disclosed their status to someone, and people generally felt well supported
- Experiences of stigma and discrimination were more common among PWID than other participants, notably worry about sexual relationships and treatment in the workplace, and experiences of verbal and physical harassment
- Experiences of sexual rejection were more commonly reported by PWID compared to participants overall
- Half of PWID reported feelings of internalised stigma, comparable to the overall study population
- More PWID sought support from a local HIV organisation, online and from peer groups in the last year than participants overall

1. Who took part?

1576 participants were recruited from community organisations and HIV clinics throughout the UK. 217 participants (14%) had injected drugs with 71 (5%) using in the last 12 months. The majority of PWID were men (96% of those who used in the last 12 months and 90% of ever-users), and over two thirds were white British or Irish (72% of PWID in the last 12 months and 68% of ever-users).

HIV testing, diagnosis and treatment

87% of participants who had ever injected drugs were diagnosed with HIV in the UK, 7% of in the last year, comparable to the overall population accessing HIV care in the UK. The majority (83%) of those diagnosed in the past 5 years in the UK reported being tested for HIV voluntarily; 7 individuals (15%) felt made or pressured to take an HIV test, the reasons for which were not given.

Almost all (87%) of participants who had ever injected drugs were currently on antiretroviral treatment (compared to 91% of the study population). This was similar by gender and ethnicity and to the overall population accessing HIV care in the UK.
Changes and challenges

2. Telling others

Almost all participants who had injected drugs in the last year (96%) reported that at least one member of their family or friend group, a partner, or someone in their workplace or faith setting was aware of their HIV status. Most reported they felt well supported upon telling others about their status.

**Partners**

Most people who injected drugs in the last year were sexually active in the last 12 months (n=68). Almost all reported that their partners were aware of their status; people generally felt well supported, with more of those with only one main partner reporting good support.

**Family and friends**

Three in five (62%) reported that at least one member of their family was aware and a similar proportion felt well supported upon sharing their status.

The majority (89%) stated that at least one friend was aware, and two thirds felt well supported.

**Workplace**

Of the 55 people working at the time of the survey, around half (n=31) reported someone in their workplace was aware of their status, and the majority (61%) felt well supported upon informing someone.

14 participants (19%) who had used drugs in the last year had turned down employment or a promotion due to their HIV status, compared to 11% of participants overall.
A third of participants who used in the last year (n=21) had been active members of a religious community, 5 in the last year. No one reported they had told anyone in their faith community about their HIV.

Pressure to tell others

Despite high levels of support, not all people felt in control of telling others about their status, with some experiencing pressure to tell others in the past 12 months similar to participants overall.

3. Experiences of stigma and discrimination

Felt and experienced stigma are influenced by many factors, and people living with HIV who inject drugs may encounter stigma and discrimination related to both their HIV status and drug use. The survey attempted to measure to what extent the stigma and discrimination experienced by these participants could be attributed to their HIV status.

Many participants who had injected drugs in the last year had worried about being stigmatised, had avoided encounters or had experienced discriminatory treatment in the last 12 months (Figure 11); more PWID reported experiences of stigma and discrimination, HIV-related and generally, compared to study participants overall, primarily in sexual relationships (66% worried about sexual rejection, 54% avoided sex, and 54% experienced rejection in the last year), the workplace (46% worried about workplace treatment). Experiences of verbal (37%) and physical assault (15%) were also more common.5

“I was verbally abused in my property and threatened with physical harm” Woman, 44 years old, white British ethnicity and living in London, diagnosed 2003

5 See national report card for comparison

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Faith

A third of participants who used in the last year (n=21) had been active members of a religious community, 5 in the last year. No one reported they had told anyone in their faith community about their HIV.
4. Mental health and well being

The majority of people who injected drugs in the last year felt positive about life (68%) and in control of their health (65%), with half (54%) stating they felt as good as anyone else in the last 12 months. Fewer people who had ever injected drugs reported positive feelings compared to those who had used in the last year and participants overall (Table 1).

Yet, around half also felt ashamed, guilty, had low self-esteem and/or blamed themselves due to their HIV status in the last year, comparable to all study participants. A quarter reported suicidal ideation in the past 12 months, compared to 18% of the overall study sample (Table 2). 4 out of 9 PWID diagnosed in the past year experienced suicidal ideation in the last 12 months.

<table>
<thead>
<tr>
<th>Positive about life</th>
<th>Ever IDU (injecting drug use) (n=217)</th>
<th>IDU last 12 months (n=71)</th>
<th>Overall (n=1576)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>59%</td>
<td>68%</td>
<td>65%</td>
</tr>
<tr>
<td>In control of health</td>
<td>60%</td>
<td>65%</td>
<td>62%</td>
</tr>
<tr>
<td>As good as anyone else</td>
<td>49%</td>
<td>54%</td>
<td>59%</td>
</tr>
</tbody>
</table>

Table 1. Positive feelings in the last 12 months

Yet, around half also felt ashamed, guilty, had low self-esteem and/or blamed themselves due to their HIV status in the last year, comparable to all study participants. A quarter reported suicidal ideation in the past 12 months, compared to 18% of the overall study sample (Table 2). 4 out of 9 PWID diagnosed in the past year experienced suicidal ideation in the last 12 months.

<table>
<thead>
<tr>
<th>Ashamed</th>
<th>Ever IDU (n=217)</th>
<th>IDU last 12 months (n=71)</th>
<th>Overall (n=1576)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>49%</td>
<td>52%</td>
<td>48%</td>
</tr>
<tr>
<td>Guilt</td>
<td>43%</td>
<td>45%</td>
<td>45%</td>
</tr>
<tr>
<td>Self blame</td>
<td>43%</td>
<td>41%</td>
<td>43%</td>
</tr>
<tr>
<td>Low self esteem</td>
<td>53%</td>
<td>54%</td>
<td>48%</td>
</tr>
<tr>
<td>Suicidal</td>
<td>25%</td>
<td>25%</td>
<td>18%</td>
</tr>
</tbody>
</table>

Table 2. Negative feelings in the last 12 months

5. Healthcare

Comparable to the overall study population, 87% of people who injected drugs in the last 12 months reported their GP was aware of their HIV status and 60% of these felt well supported upon disclosure. Half (51%) said their dentist was aware of their status, and a similar proportion felt well supported.

“I’m more inclined to take better care of my health since diagnosis” Man, 39 years old, white British ethnicity and living in Yorkshire, diagnosed 2014

“It’s not HIV+ people who pose most risk, but those who are untested” Man, 31 years old, white ethnicity and living in the North West, diagnosed 2014

Figure 10. Awareness and support in GP practice

Figure 11. Awareness and support in dental practice
Compared to the overall study population, more people who used in the last year worried about discriminatory treatment at their GP (41%) and a similar proportion avoided care (15%) when required in the last year. Many also feared different treatment at their dental practice (42%) with 17% avoiding care. A similar trend was observed in other healthcare settings (Figure 12).

A minority (8%) felt pressured to disclose their HIV status in the last 12 months by a healthcare worker, comparable to the study sample.

6. HIV and the law

Challenging discrimination

Overall, 2 people who injected drugs in the last year (3%) reported losing their jobs mostly due to their HIV status in the last year. 12 individuals who injected in the last year (17%) reported being denied insurance products in the last year.

Most (64%) were aware of the Equality Act 2010, which provides protection against discrimination for people living with HIV in England, Wales and Scotland. However, the majority (5 out of 6) who reported instances of discrimination did not seek legal redress under the Act’s provisions. Reasons for not seeking redress included: lack of confidence that the outcome would be successful, feeling intimidated or scared to take action and/or the process of addressing the problem appeared too bureaucratic. Despite this, half (49%) reported addressing an issue of HIV-related stigma or discrimination in the last year.

Investigation or prosecution relating to HIV transmission

Of the 16 individuals investigated by the police in relation to their HIV status in the last year, 3 had injected drugs in the last year and 6 had ever injected drugs.

Overall, 87% of recent users were aware that people have been prosecuted for recklessly transmitting HIV to a sexual partner; 85% believed that both partners, regardless of HIV status, equally share responsibility for preventing transmission. 15% believed that transmission of HIV should be a criminal offence; 35% were not sure. Two in five (42%) reported that the risk of criminal prosecution relating to HIV transmission has 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 (56%) of participants had reported seeking support.

More PWID reported seeking support from a local HIV organisation, online and from a peer group in the last 12 months, compared to the overall study population (Table 3). Two out of five reported seeking no support yet the majority of PWID in the last 12 months (66%) reported providing emotional support to other PLWHIV, compared to half (50%) of the overall survey sample.

<table>
<thead>
<tr>
<th>Source of Support</th>
<th>IDU in last 12 months (n=71)</th>
<th>IDU ever (n=217)</th>
<th>Overall (1576)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local HIV support organisation</td>
<td>39%</td>
<td>32%</td>
<td>30%</td>
</tr>
<tr>
<td>Online</td>
<td>24%</td>
<td>23%</td>
<td>16%</td>
</tr>
<tr>
<td>Peer group</td>
<td>18%</td>
<td>15%</td>
<td>11%</td>
</tr>
<tr>
<td>NHS patient support group</td>
<td>10%</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>Local policy organisation</td>
<td>7%</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>Faith group</td>
<td>3%</td>
<td>3%</td>
<td>4%</td>
</tr>
<tr>
<td>Community group</td>
<td>1%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>None</td>
<td>44%</td>
<td>41%</td>
<td>41%</td>
</tr>
</tbody>
</table>

Table 3. Sources of support in the last 12 months

Actions to address stigma and discrimination for which people who had used in the last year would most like to advocate include HIV education in schools, raising public awareness and advocating for evidence-based media coverage of HIV (Figure 13).

“[We need to] express nationwide that living with HIV is not like the 80s. And diabetes or cancer can be worse” Man, 31 years old, white British ethnicity and living in the North West, diagnosed 2014

Figure 13. Addressing stigma and discrimination for people living with HIV

“I have done voluntary work, formed relationships from being HIV+ and a sense of belonging to an HIV+ sub-culture” Man, 63 years old, white British ethnicity and living in Wales, diagnosed 1996
8. Conclusions

The survey findings show that stigma and discrimination impact the lives of HIV positive people who inject drugs. More people who injected drugs reported experiences of stigma and discrimination, both overall and related to HIV.

Most people had told someone about their HIV status, yet there are still some who choose not to discuss their status; this is an area that warrants further investigation, as there are clear psychological advantages to discussing one’s status. Overall, the majority of participants reported good levels of support from those aware of their status.

However, many worried about negative treatment, and some experienced HIV-related discriminatory treatment. Findings indicate that sexual relationships are particularly difficult to navigate for people living with HIV who inject drugs. Fear of sexual rejection was reported by half. A third reported that a partner had rejected them due to their status in the last year; this was higher than other key populations and participants overall. Knowledge of undetectability could impact highly on the stigma felt by people in sexual relationships, and further education regarding undetectability targeted at community members and the general public is important.

Half of participants reported feelings of internalised stigma, and many had a poor self-image. There is a need to improve support for HIV positive people who inject drugs including the provision of psychological and peer support especially in the year after diagnosis.

More people who injected drugs had sought support from various sources in the last year than participants overall, yet more than 2 in 5 had sought no support. Participants believe that stigma needs to be addressed across society, with public awareness campaigns, better HIV education in schools and evidence-based media coverage of HIV. Efforts to promote third sector offers, emphasising interventions geared towards the most at-risk groups and factoring in e-literacy and access to care and services, could additionally improve the quality of life of people living with HIV in the UK.

“I am a much better person now in so many ways” Man, 54 years old, white British ethnicity and living in London, diagnosed 1997
Appendix: Methodology and demographics

Participants were recruited from over 120 cross-sector community organisations and 46 NHS HIV clinics throughout the UK. 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.

Nine out of ten participants who had used in the last year (90%, n=55) were working at the time of the survey.

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 of people who had injected drugs in the last year (27%) were in the lowest SES group, 21% were in the middle group, and half (52%) were in the highest SES group.

A third (n=21) had been active in a religious community, 15 of which were Christian.

Two in five (42%) were in a relationship at the time of the survey (Figure 5). 1 participant did not have a sexual partner in the last 12 months.

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full time</td>
<td>62%</td>
</tr>
<tr>
<td>Employed part time</td>
<td>7%</td>
</tr>
<tr>
<td>Casual work</td>
<td>1%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>20%</td>
</tr>
<tr>
<td>Volunteering</td>
<td>17%</td>
</tr>
<tr>
<td>Sick/disabled</td>
<td>11%</td>
</tr>
<tr>
<td>Looking after home</td>
<td>-</td>
</tr>
<tr>
<td>Retired</td>
<td>3%</td>
</tr>
<tr>
<td>Student</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 1. Employment status at time of survey (n=71)

Supported by a grant from ViiV Healthcare