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.

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 UK Stigma Survey 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. 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 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

In 2015, people living with HIV in the United Kingdom continue to feel stigmatised and experience HIV related discrimination.

The survey findings show that while two-thirds of 1576 participants felt overall positive about their life and in control of their health, in the past year around half reported feeling shame, guilt or self-blame in relation to their HIV status and one in five had felt suicidal. These feelings are more likely to affect people recently diagnosed with HIV.

Furthermore, in the past year, about a quarter of participants worried about being gossiped about in relation to their HIV status, about one in ten had avoided family or social gatherings and one in five were excluded from these because of their HIV status. Of even greater concern was the proportion of participants who reported sexual rejection (20%).

Experiences of stigma in the health care setting were common and one in eight participants had avoided seeking care in the past year. Similarly about one in eight people had decided not to apply for, or turned down, employment or a promotion due to their HIV status.

The findings also show that whilst most participants had shared their HIV status with partners, friends and family, only about half felt well supported when disclosing their status.

A considerable number of participants had sought support in the last 12 months, including from a local HIV support organisation. Participants believe that education and awareness campaigns are necessary to challenge the stigma and discrimination experienced by people living with HIV in the UK today.

1. Who took part?

1576 participants were recruited from community organisations and HIV clinics throughout the UK. Participants broadly represent the current demography of people living with HIV in the UK in age and geography.5

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HIV testing, diagnosis and treatment

Nine in ten participants had first been diagnosed with HIV in the UK. Over two thirds of these were diagnosed more than five years ago and 9% were diagnosed in the previous year (this is comparable to UK-wide surveillance data).

The large majority of those diagnosed in the last 5 years in the UK reported being tested voluntarily, however 52 participants (12%) reported feeling made or pressured to take a test. One reason given for this was mandatory screening for employment in the private healthcare sector.

Nine in ten (91%) participants were currently on antiretroviral treatment; 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 (93%) 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. Overall, 15% of participants had never told anyone about their HIV; more BAME and fewer MSM participants had not disclosed their status. Half of participants (46%) felt empowered after telling someone. Overall, over half who had told someone about their HIV felt well supported.

“I expect more negative experiences because of the negative experiences I have had so far” Man, 41 years old, white Irish ethnicity and living in Northern Ireland, diagnosed 2014

“You are living with a secret that in itself has an impact on your health. You are constantly trying to hold things back” Woman, 49 years old, white ethnicity and living in Bournemouth, diagnosed 2008

“We expect more negative experiences because of the negative experiences we have had so far” Woman, 55 years old, white ethnicity and living in Wales

Figure 2. Time since diagnosis in the UK

Figure 3. Decision to test for HIV among participants diagnosed in the UK in the last 5 years
Partners

Three quarters (76%) of people were sexually active in the last 12 months, 35% with one main partner. A high proportion of sexual partners were aware of participants’ HIV status. Two thirds (65%) of those with one main partner felt well supported upon sharing their status, with fewer of those with multiple sexual partners reporting good support.

Family and friends

Disclosure to family members and friends varied considerably, with around three in five feeling well supported when sharing their status (58% and 59% respectively).

“I spoke to family and friends pretty soon, they’ve all been super supportive”
Man, 27 years old, white ethnicity and living in Bath, diagnosed December 2015

“I then went on to disclose to my brother and his wife... that was a really positive experience, and they were just a bit puzzled as to why I hadn’t told them before, which I thought was lovely”
Woman, 44 years old, white ethnicity and living in London, diagnosed 2003

“I never at any point considered telling my family. And I’m really grateful that I decided not to. My parents are Muslim, my family are Muslim”
Man, 36 years old, Asian ethnicity and living in Brighton, diagnosed 2010

“It’s totally different when you are going to tell someone you are going to get intimate with that you are HIV+, it’s massive”
Woman, 49 years old, white ethnicity and living in Bournemouth, diagnosed 2008

Figure 4. Awareness of HIV status and support in sexual relationships

Figure 5. Awareness of HIV status and support among participants’ family members

Figure 6. Awareness of HIV status and support among participants’ friends
Faith

One in four of the 628 participants who were active in a religious community reported that someone in the community was aware of their status and over half (57%) felt supported. These proportions were similar among those active in the last 12 months.

Workplace

Almost half (47%) of the 1,059 participants currently working reported that someone in their workplace was aware of their HIV status, while two thirds (63%) felt supported upon telling a co-worker. However, in the last year, 190 (12%) out of all 1576 participants had decided not to apply for, or turned down, employment or a promotion due to their status.

Pressure to tell others

Despite reporting good levels of support, not all participants felt in control of telling others, with 11% and 7% of all 1576 participants reporting pressure from a family member and/or sexual partner respectively to tell others about their HIV in the last 12 months.

"There are certain places where I won’t talk about my status; I find it very difficult to talk about HIV in mainstream workplaces because they don’t know anything about HIV. I find it difficult because I am not being myself, I can’t talk about myself. I have this part of my life that I hide" Woman, 60 years old, black African ethnicity and living in Scotland, diagnosed 2003

“I actually told my boss. That made life much easier, so instead of inventing what I needed to when I needed to go to the hospital or clinic, I could just say where I was going. It makes a difference, it made me feel better” Man, 41 years old, white ethnicity and living in Southampton, diagnosed 2012
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. Many felt this was mainly due to their HIV status (rather than other factors).

In the last 12 months...

Although most participants felt well supported by their partners, relationships provided one of the most common sources of worry in the last year. A third of all participants feared being rejected by a sexual partner (35%) and had avoided sexual encounters (33%) in the last 12 months due to their status.

“I don’t feel positive about finding and maintaining a relationship because of my status”  Man, 37 years old, white British ethnicity and living in Wales, diagnosed 2006
4. Mental health and well being

Almost two-thirds of participants reported feeling positive about life (64%) and in control of their health (61%), with 58% reporting they felt as good as anyone else in relation to their HIV.

“[A] positive empowering experience” Woman, 48 years old, white British ethnicity and living in the South East, diagnosed 2008

Yet, around half of participants reported feeling shame, guilt, low self-esteem and/or self-blame in relation to their HIV status in the last 12 months. Negative feelings varied with time since diagnosis: 53% of those diagnosed in the last year had a negative self-image compared with 34% of those diagnosed more than 5 years ago. Overall, 18% of participants reported suicidal ideation (this was higher among those diagnosed in the last 12 months (28%)).

5. Healthcare

Of the 88% who reported that their GP practice was aware of their status, three in five (58%) felt well supported.

“I do not feel I require others’ acceptance or approval. I do not feel this status fundamentally changes the person I am but my willingness to believe in myself as undiminished has required of me to dig deep within and be courageous.” Woman, 54 years old, black British Caribbean ethnicity and living in London, diagnosed 1991

Fewer, (55%) reported that their dental practice was aware, however a similar proportion felt well supported.

Nevertheless, in the last 12 months, 32% and 39% of all participants worried about being treated differently to other patients at their general and dental practice respectively, 13% and 14% avoided seeking care in either setting when required, and 5% felt their treatment had been delayed or refused. A similar trend was found in other health care settings with the exception of sexual health clinics.

“Again it’s the whole thing of are we going to be treated any differently, is it going to create a situation or a problem, they might not want to see me or treat me. That’s the reason I want to avoid those situations. If you can avoid those situations, then for me that’s perfect.” Man, 40 years old, Asian ethnicity and living in London, diagnosed 2005-2006
In the last 12 months, one in 10 (11%) felt pressured by a healthcare worker to inform others of their status and one in seven (13%) reported hearing negative comments from a healthcare worker about themselves or other people living with HIV. A small number of participants also reported a healthcare worker had discussed their status with others without their consent.

6. HIV and the law

Challenging discrimination

Forty-one people (3% of all participants) reported losing their job or another source of income due to their HIV status in the last 12 months, while one in nine reported being denied insurance products (e.g. health, dental, life, or job protection) in the last year.

Most (59%) were aware of the Equality Act 2010, which provides protection against discrimination for HIV positive people in England, Wales and Scotland. However, the majority (117/160, 73%) 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 insufficient financial resources.

“Helping others with their diagnosis also helps me” Trans woman, 58 years old, white British ethnicity and living in London, diagnosed 1985

“I now work as a community representative in the HIV sector. I have been told that I have been an inspiration to others, this is extremely rewarding and empowering” Man, 58 years old, white British ethnicity and living in London, diagnosed 1997
Less than one in five (18%) felt able to influence legal or rights matters affecting people living with HIV. Despite this, one third (34%) of all participants had tried to address an issue of HIV-related stigma or discrimination while a fifth (20%) had been involved in a programme or project providing assistance to people living with HIV.

“In [was] unfairly dismissed and believe this was directly due to HIV. [The] equality act is weak protection” Man, 53 years old, white British ethnicity and living in London, diagnosed 1989

Investigation or prosecution relating to HIV transmission

Sixteen people (1%) had been investigated by the police in relation to their HIV status in the last 12 months (six in the South of England, two in Scotland, and one in Northern Ireland). One person from Yorkshire was prosecuted in relation to their HIV status in the last 12 months.

Overall, 85% of participants were aware that people have been prosecuted for recklessly transmitting HIV to a sexual partner. A similar number (87%) thought that both partners, regardless of HIV status, equally share responsibility for preventing transmission. However, one in five participants believed that transmission of HIV should be a criminal offence; 37% were not sure. Two in five (40%) reported that the risk of criminal prosecution relating to HIV transmission has influenced decisions to tell others they are positive.

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 (59%) of participants had reported seeking support and almost a third (30%) had received support from a local HIV support organisation; this proportion was higher among participants recently diagnosed (46%), who had felt suicidal (43%) and those who experienced HIV-related discrimination (37%).

“For me, you build a confidence that wasn’t there before, you learn what it’s like to be HIV positive, and you know you will live well. It’s a definite game changer, without a doubt” Man, 53 years old, white British ethnicity and living in London, diagnosed 1989

<table>
<thead>
<tr>
<th>Source of Support</th>
<th>Overall</th>
<th>Diagnosed in last year</th>
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</thead>
<tbody>
<tr>
<td>Local HIV support organisation</td>
<td>30%</td>
<td>46%</td>
</tr>
<tr>
<td>Online</td>
<td>16%</td>
<td>25%</td>
</tr>
<tr>
<td>Peer group</td>
<td>11%</td>
<td>17%</td>
</tr>
<tr>
<td>NHS patient support group</td>
<td>10%</td>
<td>11%</td>
</tr>
<tr>
<td>Local policy organisation</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Faith group</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>Community group</td>
<td>2%</td>
<td>1%</td>
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<tr>
<td>None</td>
<td>41%</td>
<td>33%</td>
</tr>
</tbody>
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Table 2. Sources of support in the last 12 month/s (participants could report more than one)
One in six (16%) sought support online in the last year, while only 10% of BAME individuals turned to online support.

Despite two in five reporting they had not sought support of any kind (a third of those diagnosed in the last year), half of all participants reported offering emotional support to other people living with HIV in the last 12 months.

Actions to address stigma and discrimination for which participants would most like to advocate include HIV education in schools, raising public awareness and knowledge, and providing emotional, educational and referral support to people living with HIV.

“People need to be brave and not hide, it’s the hiding that causes the stigma”
Man, 38 years old, white ethnicity and living in Suffolk, diagnosed 2013

Figure 14. Addressing stigma and discrimination for people living with HIV (participants could tick more than one category)
8. Conclusions

Overall, the survey findings show that stigma, and discrimination continue to impact the lives of HIV positive people in the UK today.

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. Around half 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. Fear of sexual rejection was reported by a third, with fewer (one in five) reporting a partner had rejected them due to their status in the last year. Knowledge of undetectability could impact highly on the stigma felt by people living with HIV 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 people living with HIV including the provision of psychological and peer support especially in the year after diagnosis.

A third of participants stated they had gone without food and/or struggled to keep up with financial commitments in the last 12 months; economic hardship was particularly pronounced among BAME participants and women. Further research on the linkages between poverty and at-risk populations, as well as the effect of poverty on adherence and health outcomes among people living with HIV, is recommended.

Despite widespread awareness of anti-discrimination laws, seeking redress for discrimination was uncommon among participants. Meanwhile, survey findings indicate on-going discrimination. Organisations should ensure they have up-to-date non-discrimination policies in place.

Survey participants believe that stigma needs to be addressed across society, with public awareness campaigns and better HIV education in schools. 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.
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.

Three-quarters (75%, n=1182) were men and 82% (n=970) identified as men who have sex with men (MSM); 23% (n=359) were women, 96% (n=325) of whom identified as heterosexual, and 2% (n=31) identified as transgender or non-binary. There were comparatively more UK-born men and fewer women from black, Asian and other minority ethnic (BAME) communities among participants. Almost two thirds of participants were born in the UK and of white ethnicity. Overall, 63% (n=989) identified as white British or Irish, while 71% (n=269) of women identified as black, Asian or minority ethnic (BAME). Of the 583 (37%) people who identified as belonging to an ethnic minority group, 310 (53%) were born in an African country. About half (54%, n=799) were between the ages of 35 and 50. Overall, 217 people (14%) had ‘ever’ injected recreational or performance enhancing drugs with 33% (71) of these having injected in the last 12 months. 32 (2%) had been paid for sex in the last year.

Hardship was not uncommon among people living with HIV; almost a quarter (23%) had sometimes, and 9% had often, gone short of food in the last 12 months. Furthermore, 15% struggled constantly to keep up with bills and 12% reported falling behind on financial commitments in the previous year.

Seven out of ten participants (71%) were working at the time of the survey and 12% had been a volunteer in the last 12 months.

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 (35%) were in the lowest SES group, 23% were in the middle group, and 41% were in the highest SES group. Almost half (46%) of BAME participants and 28% of MSM were in the low SES group, while 50% of women compared to 31% of men had a low SES. Those who had been diagnosed less recently were more likely to be in the lowest SES group.
Two in five participants (41%, n=628) had been active members of a religious community, (60% of BAME individuals and 60% of women). One in five (n=326) were currently active members. Of those who had ever been an active member of a religious community, 78% identified as Christians (Figure 4). 15% of ever-active members (11% of men and 23% of women) had become more active in their faith since their diagnosis. Overall, 13% had become less active and 7% had left their faith group completely.

About half (52%) of participants were in a relationship at the time of the survey. Almost a quarter (23%) of participants did not have a sexual partner in the last 12 months.