



Survey of People Living with HIV 2017

National Knowledge and Attitudes Survey 2017



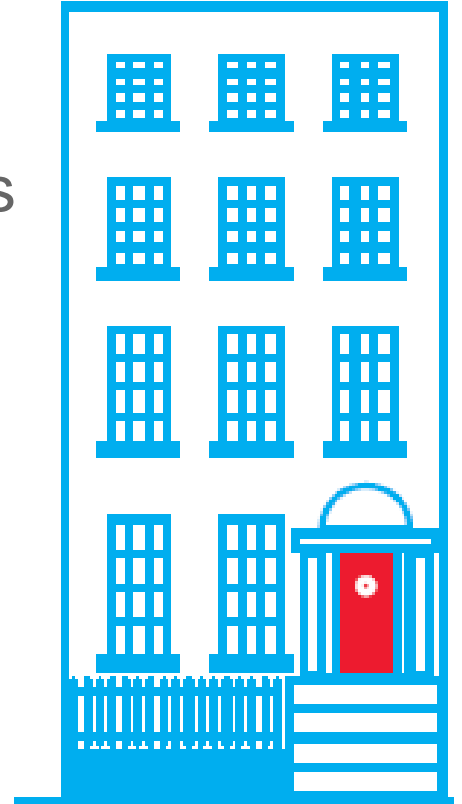
HIV
Ireland



Quality Matters
supporting improvement in social services

The presentation

- What we know about stigma
- Survey 1 - National knowledge and attitudes survey 2017
- Survey 2 - People living with HIV survey
- Summary - 6 key findings





1. What we know about stigma

Three types of stigma

- Stigma is the **devaluation of people**, or a mark of disgrace that sets people apart from one another
- HIV stigma related to societal attitudes to homosexuality, sex work, and drug use. Understood in 3 ways;
 - **Enacted Stigma** - rejection, isolation and... “microinsults and daily hassles or macroaggressions” (Bunn 2007).
 - **Perceived Stigma** - fear of stigma based on evidence of discrimination
 - **Internalised Stigma** - stigma that arises from a person devaluing themselves, usually arising from perceiving the stigma of others and accepting this about oneself.



The impact of stigma

- Stigma increases isolation and lowers self esteem (8, 11)
- Internalised stigma has been shown to have a worse impact on mental health than enacted or perceived stigma (8, 9)
- Internalised stigma is associated with depression, anxiety and hopelessness (3, 11, 12)

10x

- A person with a diagnosis of HIV is almost ten times more likely to develop depressive symptoms in comparison to the general population (11)

HIV stigma: individuals and society

For individuals HIV and stigma can mean:

- Lower quality of life (17)
- Poorer virological response to treatment (20)
- Reduction in adherence to treatment (22)

For society:

- Fear of prejudice can prevent individuals from getting tested and accessing treatment (18, 19)
- Fear of disclosure can put others at increased risk of contraction

Addressing stigma is key to national strategy

Target eight of the 2011 UN Political Declaration on HIV and AIDS reads:

‘Eliminate stigma and discrimination against people living with and affected by HIV through promotion of laws and policies that ensure the full realisation of all human rights and fundamental freedoms’.

Measurement of stigma is **an indicator** to achieving this target.



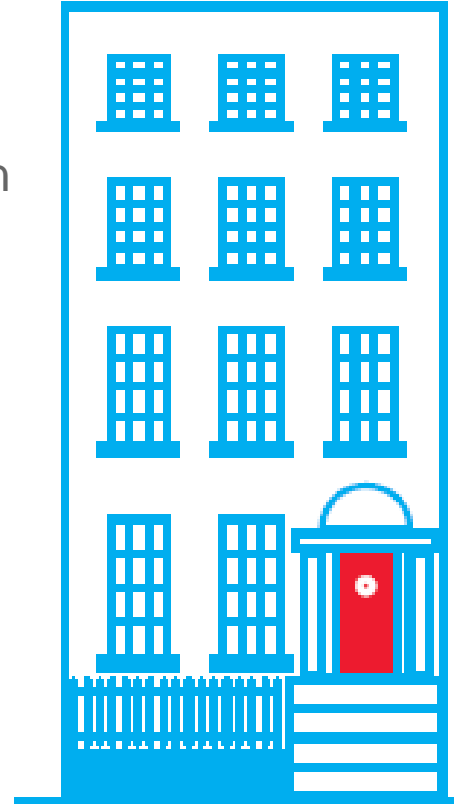


2. Findings: National Knowledge and Attitudes Survey

How we carried out the research:

Following Ethical Approval through Mater Misericordiae University Hospital, Quality Matters developed a survey based on the National AIDS Trust's *Public Knowledge and Attitudes* in the UK.

- Empathy Research distributed an online omnibus survey amongst their proprietary research panel
- 1,013 randomly sampled participants were over 18 years old and living in the Republic of Ireland
- Stratified by gender, age and region of the country with a margin of error of +/- 3.2%



Transmission of HIV

Generally, knowledge of routes of HIV transmission was good but common myths about transmission remain within a minority of respondents

A

70%

of people believe HIV can be transmitted through a bite



B

56%

of people believe HIV can be transmitted through a blood transfusion



C

24%

of people believe HIV can be transmitted by kissing



D

11%

of people believe HIV can be transmitted by coughing or sneezing



E

10%

of people believe HIV can be transmitted by sharing a glass



F

9%

of people believe HIV can be transmitted by sharing a public toilet seat



Young people

Younger people had higher levels of misinformation than older age groups

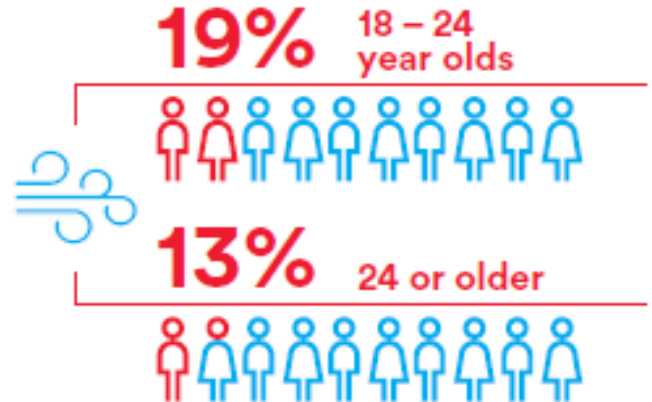
Indicates a lack of knowledge or uncertainty regarding routes of HIV transmission



One in five (20%) 18 – 24-year old's reported that HIV can be passed from person to person through the sharing of a public toilet seat compared to 10% of those over 24



Almost one in five (19%) 18 – 24-year old's reported that HIV can be passed from person to person through coughing or sneezing compared to 13% of those over 24



19%

Only 19% of respondents reported correctly that the risk of someone who is taking effective HIV treatment passing on HIV through sex is extremely low





Attitudes

83% believed that people with HIV deserve the same respect as people with cancer

93% agreed that all young people should be taught about HIV during secondary school to ensure they have a good understanding of the condition before they leave school

70%

Of respondents agreed that if they found out their neighbour was HIV positive it would not change their relationship with them. Young people were more likely to agree than older people.



72%

Of respondents felt that if someone in their family told them they were living with HIV it would not change their relationship





Comparison to the U.K.

Irish knowledge and attitudes to HIV
are broadly similar to attitudes to HIV
in the UK

Irish respondents are more likely
than British respondents to report
correctly that HIV is transmitted
through sharing needles and
unprotected sex

Irish respondents are more likely to
report incorrectly that HIV is
transmitted through spitting,
coughing, kissing and using a
public toilet seat

Summary

Knowledge of HIV transmission in the general population is relatively good, but there is room for improvement

Young people are more likely to have knowledge gaps about HIV transmission than older people

Young people are more likely to have accepting attitudes toward people living with HIV than older people

Stigmatising attitudes to HIV remain in the general population

Irish figures are broadly similar to those in the U.K.





3. Findings: People Living with HIV Survey

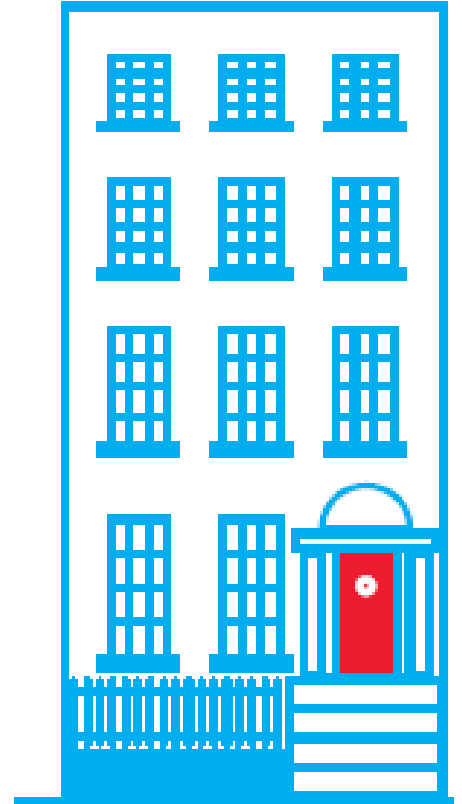
How we carried out the research

With steering group and based on literature we developed a draft survey. We ran 2 focus groups of 16 people in total to pull apart the survey and put it back together (co-design).

Online and paper options were provided via:

- Online invites
- Social media
- Gatekeeper services
- Posters

168 people took part.



Who completed the survey

Everyone was over 18 years and HIV positive:

- 61% under 44 years old
- 58% working / 21% unemployed
- Education - degree or higher 76%
- Born in Ireland 64%, EU 14%, Africa 9%
- Diagnosed in Ireland 75%, EU 10%, Africa 6%
- 52% living in Dublin
- Single 54%*, Married or in relationship 32%
- Approximately a third were diagnosed: 1) in the last 4 years, 2) between 5 and 10 years and, 3) 11+ years

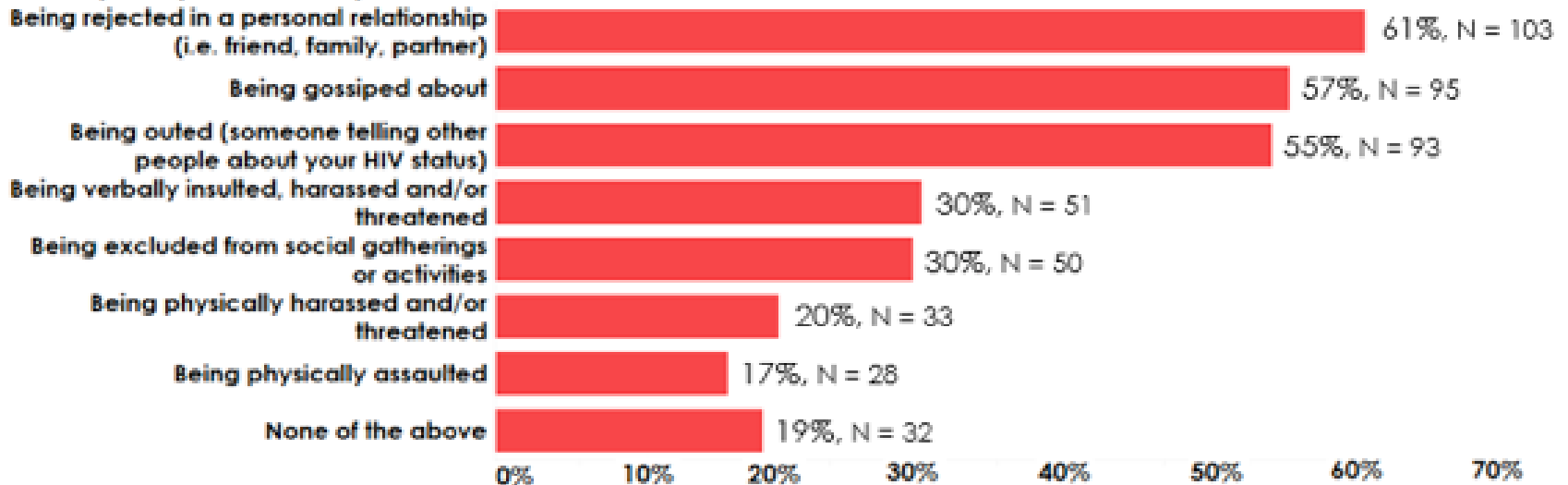
The Views of People living with HIV

35% of respondents agreed that some people do not want to associate with them because they are living with HIV.

- 88% agreed that **some people** think that having HIV is shameful.
 - 61% of people are comfortable with their HIV status. 26% are not and are most likely to be people diagnosed in the past 2 years.
-

Perceived Stigma

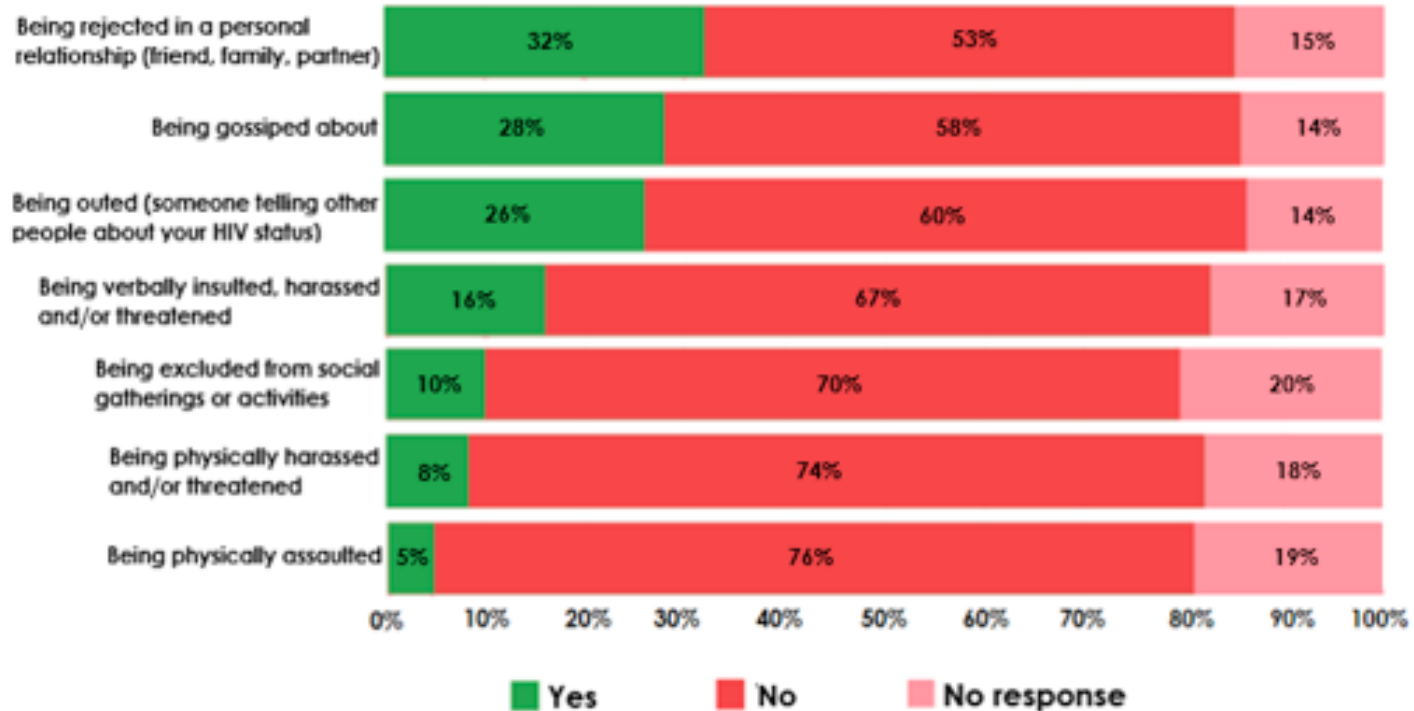
Fear of the following things happening in the last year.



Only one in five people had no fears about being stigmatised

Enacted Stigma

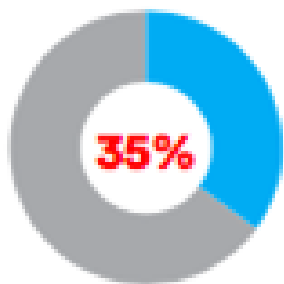
Experience of these things happening in the last year.



Rejection and isolation

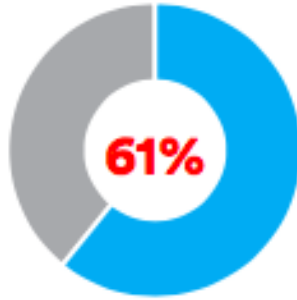
In the last year, **61%** of respondents feared being rejected in a personal relationship as a consequence of their HIV status, and **32%** of respondents actually experienced that rejection.

'It can leave you lonely and is very hard to discuss with some people. I blame it for the fact that I'm single and worry about old age: an odd thing for someone my (young) age'.



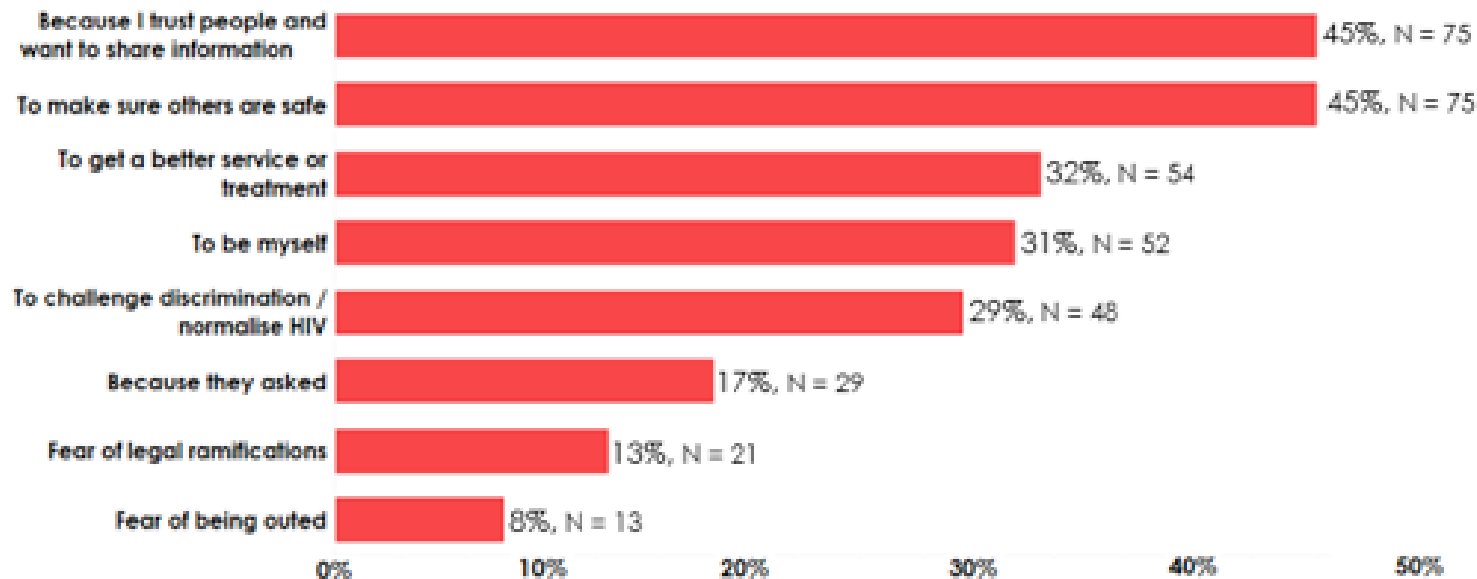
Respondents agreed that some people do not want to associate with them because they are HIV positive.

Disclosure



- 61% of respondents have not disclosed their HIV status as they are afraid they will be judged or treated differently if they do.
- 83% had not disclosed their HIV status to their neighbours.
- 76% had not disclosed their HIV status to work colleagues

Why people disclose



'There is a fear of people judging you and a fear of being rejected, even when your direct experiences haven't justified that fear. Entering a relationship or even engaging in a casual sexual relationship is fraught with anxieties over whether or when to disclose - you must weigh up your right to medical confidentiality and privacy against their right to be treated with honesty'.

Third party disclosure



18%

of respondents living with HIV have had their HIV status disclosed accidentally in a hospital setting

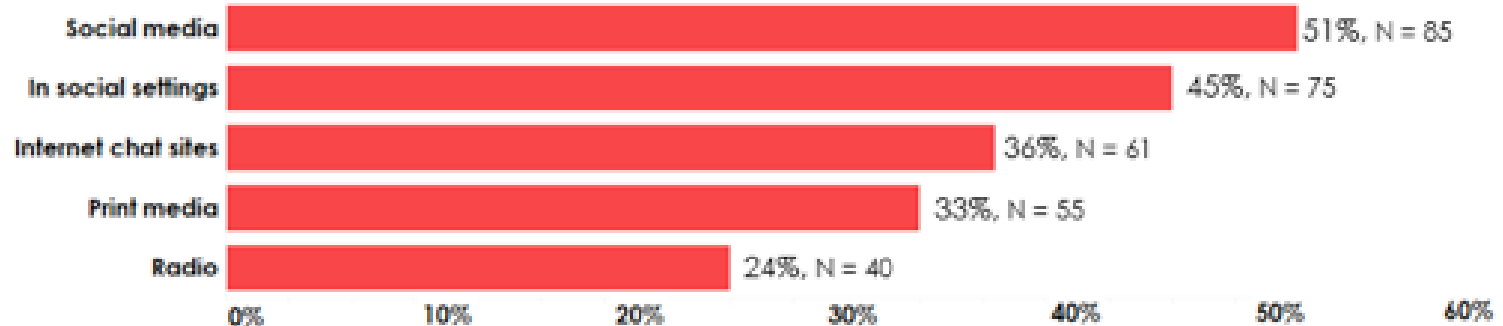


In the last year, **55%** of respondents feared having their HIV status outed by someone else, and **26%** experienced being outed by someone else.

Proportionally African respondents were around twice as likely than other nationalities to report being outed by a third party.

Offensive language

Percent of people offended at language used in the following settings:



Judgmental, defamatory and stereotyped language was considered most offensive

Views of the Media

'The idea that only those who are not careful get HIV, it can happen to anyone, also the idea that you must be sexually promiscuous to get HIV.'

'The use of the term "clean" on dating apps'

'A lot of the language I've heard in radio discussions about HIV has been offensive/prejudiced because it's been so poorly researched and understood – it seemed to be deliberately inflammatory.'

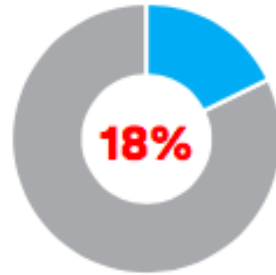


Who stigmatises

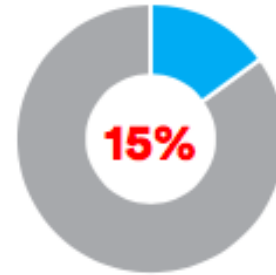
Stigmatisation occurs, most frequently in the the groups who people most often inform about their HIV status.



Immediate family



Health professionals



Friends

Layered stigma

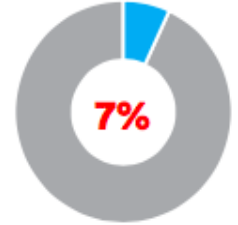
76% agreed that it is more stigmatising to have contracted HIV through sex or through drug use

18% also considered it more stigmatising to have contracted HIV through sexual violence.

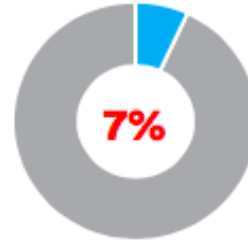
Reasons respondents experienced other discrimination:



Sexual orientation



Being a member of a minority group



Being a migrant worker



Being an injecting drug user

Mental Health

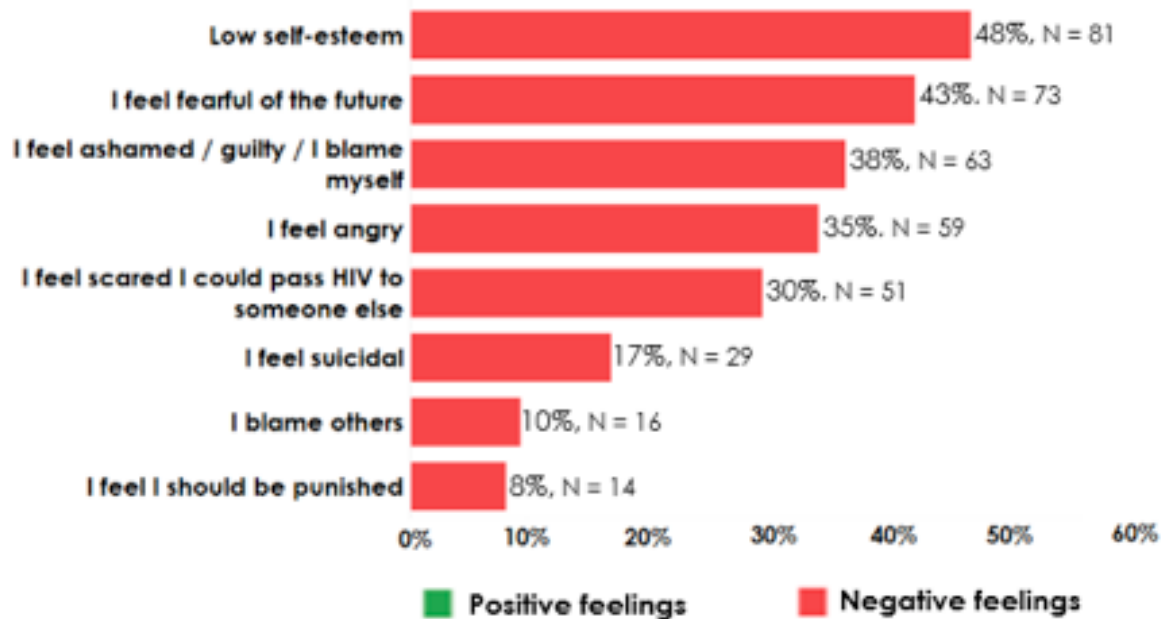
17%

Felt suicidal in the last year, this compares with a range of 3.7% - 4% in the American general population – where people were asked a similar question.



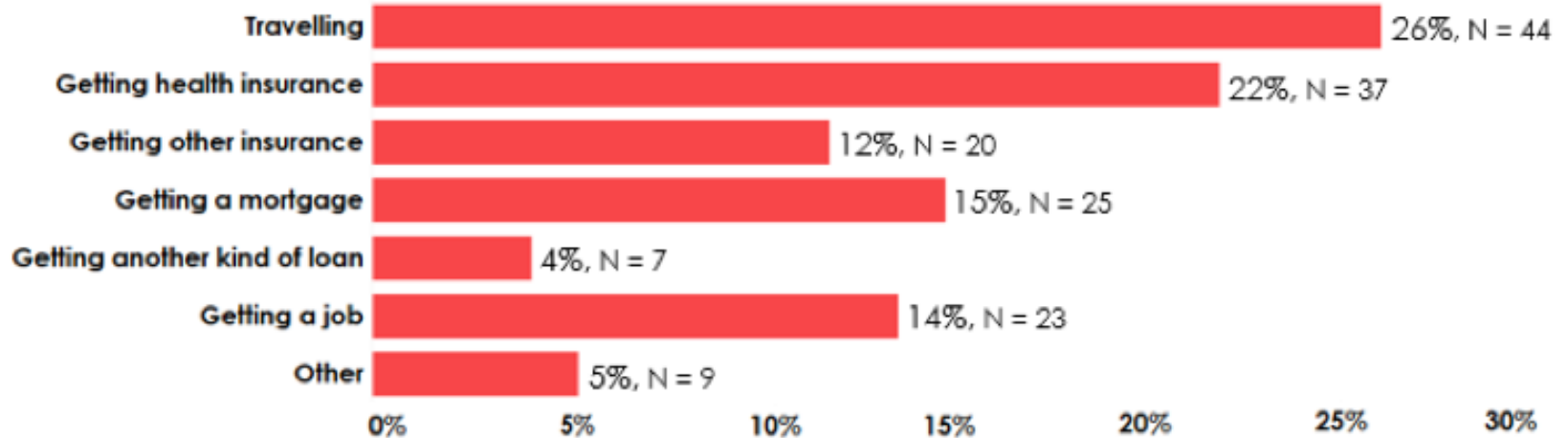
Other impacts of stigma

What feelings have you experienced in the last year



Impacts of HIV diagnosis and stigma

What have you been prevented from doing because of your HIV status



The impact of stigma on testing

33% agreed that their own fears about their health made them hesitate to get tested.

38% agreed that fears about how people would respond to a positive result made them hesitate to get tested.



Opportunities for growth

53% feel grateful for the people who they have met and who have supported them.

32% feel hope for the future



One in two (51%) people living with HIV in the last year have provided emotional and social support to someone else living with HIV

57% of people living with HIV feel more open minded and compassionate as a result of their HIV status





4. Summary

Summary

1. Knowledge in the general population is good but there is room for improvement
2. Young people know less
3. Four decades on from the AIDS Crisis, HIV stigma is still a reality
4. There is a significant burden caused by HIV stigma in Ireland
5. Stigmatisation of people living with HIV in health services
6. An HIV diagnosis brings challenges but also opportunities

‘HIV stigma affects my self-esteem and self-respect and has diminished me as a person. Confidence in myself, my future is shattered but I know I have a future, which I must face, including embracing my status fully’.



‘HIV stigma, is still a huge problem for many people with HIV. Working with my support group I am still affected when I hear how afraid, really terrified people are about others finding out their status. This is something I get upset about and am fighting hard to overcome.’



The full report will be available soon at:

www.hivireland.ie

For more information:

Caroline Gardner

Email: caroline@qualitymatters.ie

