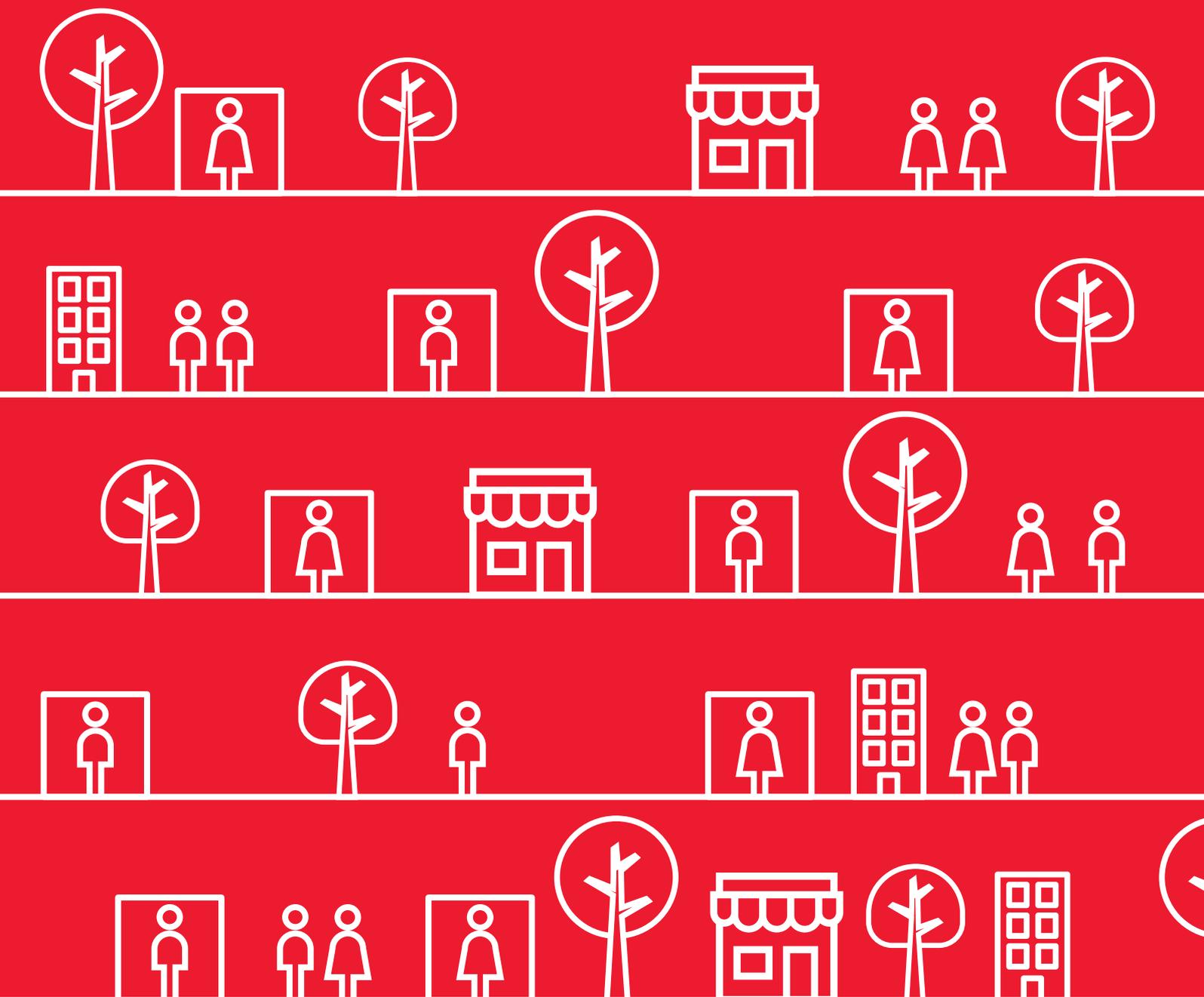


HIV in Ireland 2017

Findings from the:

Summary Report

1. National HIV Knowledge and Attitudes Survey 2017
2. People Living with HIV Stigma Survey 2017



HIV
Ireland

Contents

Preface	1
HIV Ireland and our work	2
Acknowledgements	2
Introduction	3
Methodology	4
Key themes	4
Young people know less	6
Stigma in Ireland	7
Stigma within the Health Service	10
Challenges and Opportunities	11
Conclusion	12

Preface

This research contains data from two surveys; the first is the National HIV Attitudes and Knowledge Survey and the second is the People Living with HIV Stigma Survey. These two surveys present us with valuable insights into the views and attitudes of the whole population as well as the lives of people living with HIV in Ireland in 2017. The story this data tells captures how people living with HIV are viewed within Irish society, and how HIV impacts on their everyday lives and experiences. This is not an insignificant issue - over 7,500 people have been newly diagnosed with HIV in Ireland since the 1990's. HIV Ireland estimate that approximately 4,000 people are knowingly living with HIV in Ireland today.

One of the key findings in this report is the continued existence of HIV related stigma within society, and the fact that this impacts in very real ways on the lives of people living with HIV. The stigma surrounding HIV is complex. Who stigmatises, how they stigmatise, and why they stigmatise are important questions. All of us working within the area of HIV and AIDS seek to challenge HIV related stigma. We believe that stigma can be removed from the equation when people better understand this chronic illness, and accept that HIV is fundamentally a health issue rather than a question of morality, culture, or lifestyle.

We know from this survey that the general population's knowledge of HIV transmission varies considerably depending upon the mode of transmission being discussed, and the age group people belong to. We know that younger people within the general population survey had higher levels of misinformation regarding HIV transmission than older people (e.g. 20% compared to 10% reporting that HIV can be passed by sharing a public toilet seat). However, they would also be more accepting if a friend or colleague were living with HIV than some people from the older generation would be.

We know stigma still exists within Irish society. We know it impacts on the feelings and experiences of people living with HIV in Ireland. This is particularly true in areas such as disclosure, shame and rejection, being outed by others, offensive language, being stigmatised by immediate family, health professionals or friends, because of a person's sexual orientation, being a member of a minority group, being a migrant worker or being an injecting drug user. For many people, they must contend with several layers of stigma on a daily basis. This impacts, and takes its toll. For some it becomes too much, and the prospect of suicide is considered.

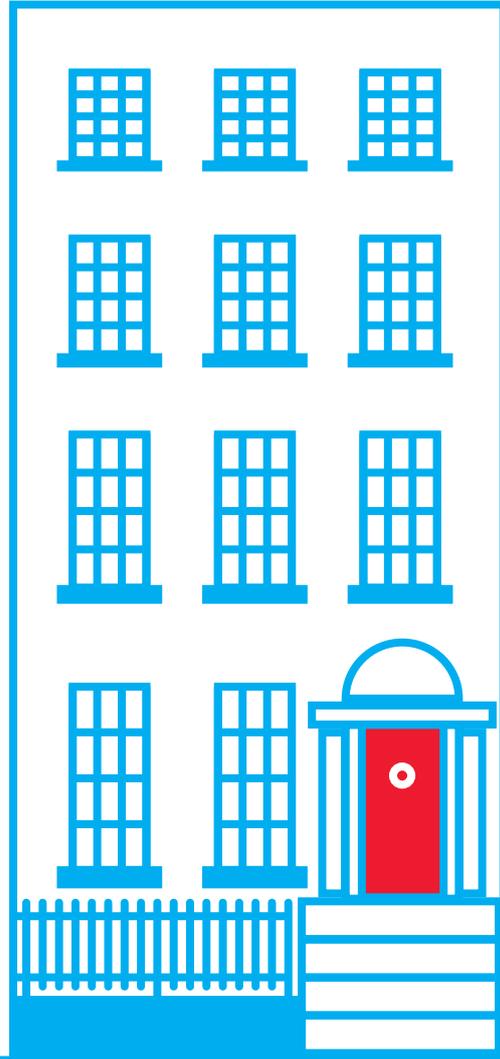
In many ways HIV is a hidden illness that will remain so for many people, until the stigma that surrounds it is challenged and removed. The findings from this survey offer insight and hope while at the same time challenging us to listen to experiences that are sometimes difficult to hear. Fundamental to this is accepting people living with HIV as equal human beings who have the same rights as all members of society and are not simply defined by their illness. Stigma creates many barriers to attaining those rights, and dehumanises people living with HIV. The responsibility lies with all of us to break it down.

Niall Mulligan
Executive Director
HIV Ireland

September 2017

HIV Ireland and our Work

HIV Ireland (HIVI) is a registered charity operating at local, national and European levels. The principal aim of the organisation is to contribute towards a significant reduction in the incidence and prevalence of HIV in Ireland and towards the realisation of an AIDS-free generation. We are working towards an Ireland with a significantly reduced incidence of HIV, reduced new HIV infections and HIV-related stigma and discrimination. Our approach broadly reflects a harm minimisation model which emphasises practical rather than idealised goals. For more information, visit www.hivireland.ie.



Acknowledgements

HIV Ireland would like to thank everyone who supported this National HIV survey. In particular, we would like to thank all those who took the time to complete the survey, our many partner organisations and individuals across Ireland who worked alongside us in promoting and facilitating the survey, members of the steering group (Dr Patrick Murphy, Mr. Lysander Preston, Mr. Alan Mackin, Ms. Susan Donlon, and Dr Erin Nugent), Quality Matters and Empathy Research, as well as Claire Connaughton. Thanks to Dr Patrick Mallon, Mater UCD, and Positive Now for facilitating two focus groups to support the design aspect of the questionnaires. We are indebted to both Janssen Ireland and Dublin Frontrunners Athletics Club for providing us with the funding for this project.

Introduction

Medical advances now mean that people living with HIV can have long and healthy lives if the illness is diagnosed and managed. Nonetheless, getting an HIV diagnosis can be a devastating experience. HIV remains heavily stigmatised and this stigma causes many people to fear a diagnosis of HIV, or feel shame if they have been diagnosed with it.

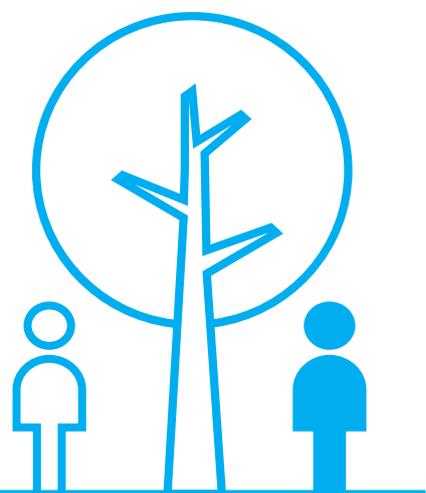
HIV related stigma can be something that people experience - negative judgements, cruelty, denial of care, and support. It can also be something that people witness – negative attitudes in wider society towards the illness or those living with it. People can also stigmatise themselves; thinking of themselves negatively, as less worthy. People living with HIV commonly experience stigma and shame, and are likely to feel unworthy and unvalued. They are more likely to have negative self-perceptions, lower self-compassion and self-esteem than the general population. HIV is a physical illness; however the nature of HIV related stigma means that it can cause mental health difficulties such as depression and anxiety. HIV stigma not only impacts on people's mental health, but it can also affect their physical health too: people who experience stigma are less likely to comply with their HIV treatment.

HIV stigma also affects the wider community. The negative attitudes to HIV and those who live with it creates such fear around it that people may avoid getting tested – this means that people may be living with HIV but not know that they are, and could unknowingly transmit it to other people.

Having a good understanding of stigma, and finding ways to address it whether it is experienced, witnessed or internalised stigma, is a key element of international strategies to eliminate HIV. In Ireland, as diagnoses are on the rise, understanding public attitudes and experiences of stigma for people living with HIV has become increasingly important. The last national research on this issue was undertaken ten years ago in 2007.

The research summarised in this report was undertaken to identify current levels of knowledge and attitudes to HIV within the whole population, as well as recording the experience of people living with HIV. With 1,013 people from the whole population participating and 168 people living with HIV, this research is one of the most significant pieces of research on stigma and knowledge within Ireland.

The findings provide valuable data on people's knowledge, attitudes, and experiences of living with HIV. Aspects of the research are also comparable to the U.K. HIV Attitudes and Knowledge survey undertaken every two years, which provides an international context for the findings. The overall focus of this report is on Irish attitudes to stigma, as well as how stigma is impacting on people's lives.



Methodology

The study involved the development of two surveys. The first survey aimed to measure knowledge and attitudes within the general Irish population. The second survey measured stigma and the experiences of those living with HIV. This study, partly funded by Janssen and Dublin Frontrunners Athletic Club, was approved by the research ethics committee of the Mater Misericordiae University Hospital, Dublin.

The general population survey was developed by Quality Matters, with guidance from a multiagency research steering group and drew substantially on similar research undertaken in the U.K by the National AIDS Trust in their National HIV: Public Knowledge and Attitudes Survey . The survey was disseminated by Empathy Research as part of an omnibus survey amongst members of their proprietary research panel and was representative of gender, age, and location in Ireland. Survey respondents were required to be 18 years of age or older and the survey was completed by 1,013 people sampled randomly from Empathy Research's omnibus list. The sample size produced a margin of error of +/- 3.2%.

The People Living with HIV Stigma Survey was designed by Quality Matters, in conjunction with the research steering group and drew substantially on feedback from focus groups of people living with HIV and a review of relevant international surveys. The survey was disseminated through various social media channels through HIV support agencies and health services . Survey respondents were required to be at least 18 years of age and to have received a diagnosis of HIV infection. The survey was completed by 168 respondents.

For a more detailed analysis on this study please see the full report on www.hivireland.ie

Key Themes

Knowledge in the General Population is Good but there is Room for Improvement

The findings of this report indicate that while knowledge regarding HIV transmission in the general population is good in the majority of areas, there is still room for improvement.

Almost all adults (98%) correctly thought that HIV can be transmitted by sharing needles and syringes. A similar proportion correctly thought that HIV can be transmitted by a man and a woman, or a man and a man, having sex without a condom. These figures compared positively with the U.K. potentially highlighting the good work that has been done in relation to HIV awareness in Ireland. However, myths in relation to HIV transmission remain,

particularly in relation to routes of transmission such as biting, kissing, coughing, sharing a glass, or using a public toilet seat. Arguably, of most significance is that over half of people believe HIV can be transmitted through a blood transfusion, while theoretically possible is not a reality given the safeguards and screening used in Ireland. This assumption may negatively affect their experience of health services.

Other false perceptions persist in the general population; the majority of respondents reported incorrectly or did not know that there is a low risk of HIV transfer through sex if a person is taking effective HIV treatment. There was also significant misinformation or lack of knowledge in relation to the effectiveness of methods to prevent HIV being passed from mother to baby during pregnancy.



In the general population, knowledge of HIV transmission varies considerably depending upon the mode of transmission being discussed, and the age group people belong to.

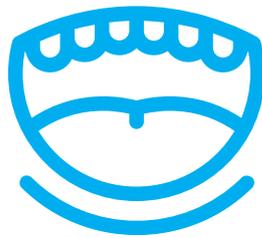
More than one in two people incorrectly think that HIV can be passed from person to person through a blood transfusion in Ireland.

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.

98% of adults correctly thought that HIV can be transmitted by sharing needles and syringes. A similar proportion correctly thought that HIV can be transmitted by a man and a woman, or a man and a man, having sex without a condom.

Common myths about transmission remain to varying degrees across respondents:

A



70%

of people believe HIV can be transmitted through a bite

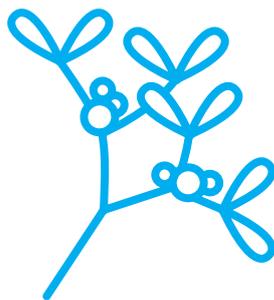
B



56%

of people believe HIV can be transmitted through a blood transfusion

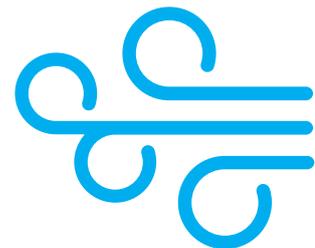
C



24%

of people believe HIV can be transmitted by kissing

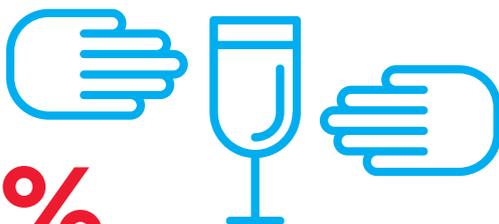
D



11%

of people believe HIV can be transmitted by coughing or sneezing

E



10%

10% of people believe HIV can be transmitted by sharing a glass

F



9%

9% of people believe HIV can be transmitted by sharing a public toilet seat

Young People Know Less

Young people had less correct knowledge than older people in relation to most methods of HIV transmission. For instance, 18 to 24-year olds were twice as likely than older people to think HIV can be transmitted by sharing a public toilet seat and almost a third more likely than older people to think HIV can be transmitted by coughing or sneezing. 18 – 24 year olds were also least likely to know that there are effective ways of preventing a pregnant mother with HIV from passing HIV on to her baby during pregnancy and childbirth compared with older people. 56% of young people under 24 didn't know this compared to 40% of people over 24 years old.

This study identified gaps and misconceptions in young people's knowledge in relation to HIV transmission. Addressing this issue, however, had clear support from the whole population. There was almost universal agreement (98%) that 'young people should be taught about HIV transmission during secondary school'.



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

20% 18 – 24 year olds



10% 24 or older



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% 18 – 24 year olds



13% 24 or older



There is a Significant Burden Caused by HIV Stigma in Ireland

Stigma and the fear of stigma affect the way that people living with HIV experience their lives. Many worry about the future and see stigma is a barrier to engaging in relationships, this translates into experiences of intimate relationships. Around two thirds of people feared being rejected in a relationship and around half of this number had actually been rejected. 54% of respondents were single compared to 38% in the general population:

“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”.

People living with HIV feared the effects that HIV stigma could have on them if their status was disclosed. They feared being rejected in a personal relationship (61%), being outed as HIV positive by other people (55%), and to a lesser extent, violence (17%). The majority of people living with HIV (61%) had not disclosed their HIV status at some point as they were afraid they would be judged or treated differently if they did. This suggests that even in the absence of discriminatory experiences, many people living with HIV were aware of negative societal attitudes about the HIV virus and those infected with it, and consequently lived with the burden of expecting to be discriminated against. Anticipated stigma is more frequent than experienced stigma, and can have a significant negative impact on an individual’s sense of safety and wellbeing. The stress that stigma can cause may explain why in the past year almost one in five people living with HIV have felt suicidal. More than a third also reported as having suffered from low self-esteem, anger, felt guilt or shame and blamed themselves for their HIV status.

“I am always wary of my status being found out, but the stigma, I believe, is worse... I think I am hardest upon myself. I am most angry at myself at this late stage in life and I hate myself for it. I have attempted to overdose, and I spent a week in hospital, soon after diagnosis”.

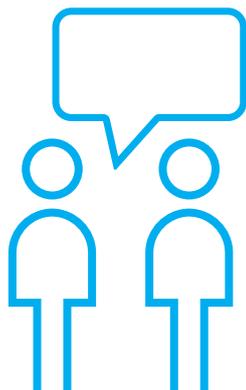
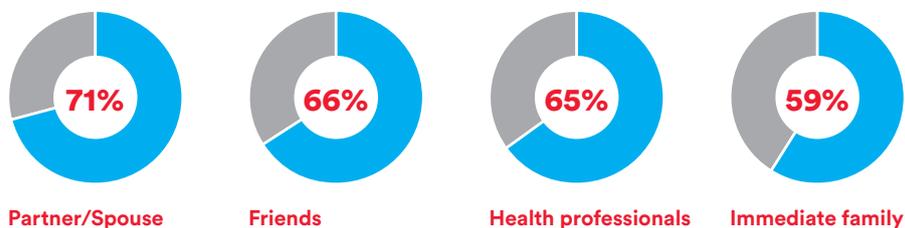
HIV stigma prevents people living with HIV from carrying out everyday actions that the general population take for granted. Stigma affects their ability to travel, to get a mortgage or loan, to get insurance or to get a job. Just under half of those surveyed were affected by at least one of these factors.

“It prevents me from applying for consultancy work in HIV hostile areas e.g. Middle East. If the authorities discover a person is HIV positive in these countries, it will result in either imprisonment or immediate deportation from the country”.

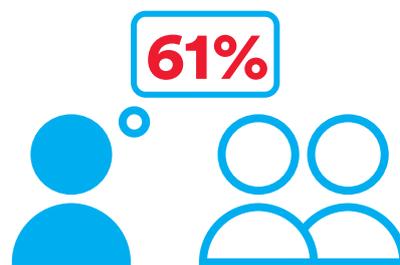
Stigma impacts – feelings and experiences of people living with HIV in Ireland

1. Disclosure

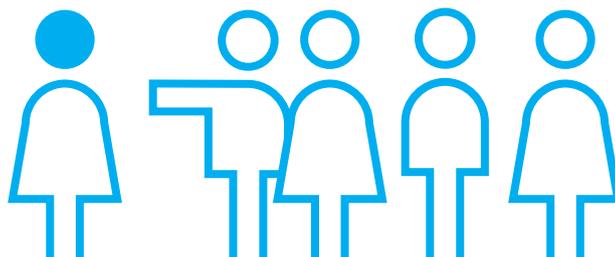
A) A majority of respondents disclosed their HIV status to one or more individuals i.e.



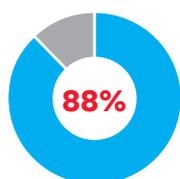
B) However, across those figures, 61% of respondents reported not disclosing their status to one or more people for fear of being judged or treated differently. People were most likely to share their HIV status when they trusted others, wanted to share information about themselves, and wanted to make sure that others are safe.



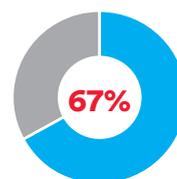
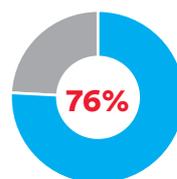
2. Shame & Rejection



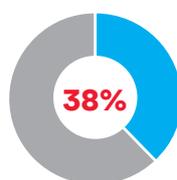
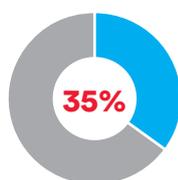
C) 88% of people living with HIV agreed that some members of the general population believe living with HIV is shameful.



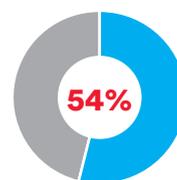
D) Respondents agreed it is more stigmatising to contract HIV through having sex (76%), and through injecting drug use (67%).



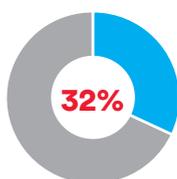
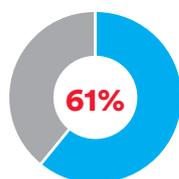
E) 35% of respondents agreed that some people do not want to associate with them because they are living with HIV, and 38% of respondents agreed that some people think they deserve to have HIV.



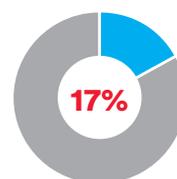
F) 54% of people living with HIV are single.

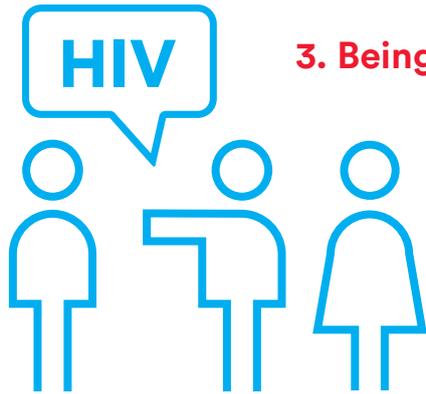


G) In the previous year, 61% of respondents feared being rejected in a personal relationship as a consequence of their HIV status, and 32% had experienced such rejection.



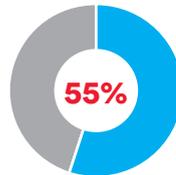
H) 17% of respondents reported having felt suicidal in the previous year (this compares with a range of 3.7% - 4% in the general population)



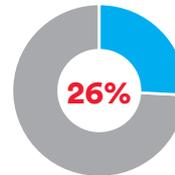


3. Being Outed

I) In the previous year, 55% of respondents feared having their HIV status outed by someone else, and 26% experienced being outed by someone else. 18% of respondents reported having had their HIV status disclosed by accident in a hospital setting.



Feared being outed



Were outed by someone else

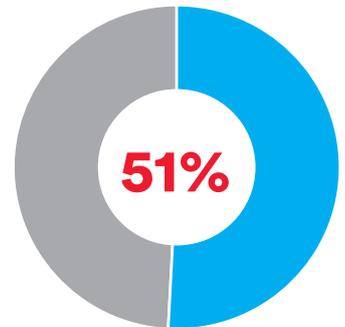


Outed in a hospital setting

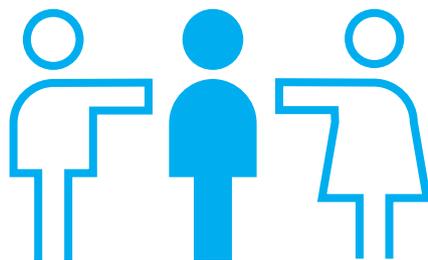


4. Offensive Language

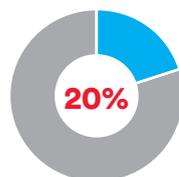
J) 51% of respondents are offended by language that is used on social media sites; use of the terms 'clean' and 'unclean/dirty' to describe a person's HIV status was noted as being particularly offensive.



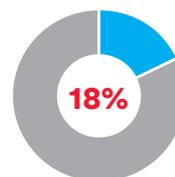
5. Being stigmatised



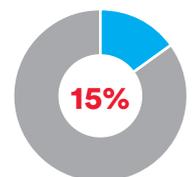
K) Respondents are most likely to have felt stigmatised due to their HIV status by...



Immediate family

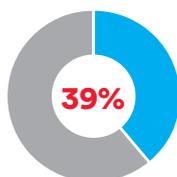


Health professionals

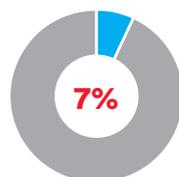


Friends

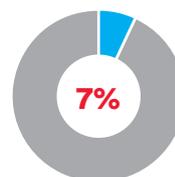
L) The main reason respondents felt stigmatised other than because of their HIV status was due to their...



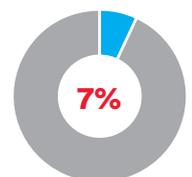
Sexual orientation



Being a member of a minority group



Being a migrant worker



Being an injecting drug user

Stigmatisation of People Living with HIV within Health Services

Though many people living with HIV describe positive experiences during their interactions with health services, there is room for improvement in how the health system provides services. Outside of close family and friends, this study found that health professionals were the group that people living with HIV were most likely to have disclosed their HIV status to. With the exception of their close family, people living with HIV also described groups within the health system (health professionals 16%, health services 18%, GP's 14%) as the groups they were most likely to feel stigmatised by.

“Having to disclose HIV status in hospital is difficult as I have felt staff gossiped about me.”

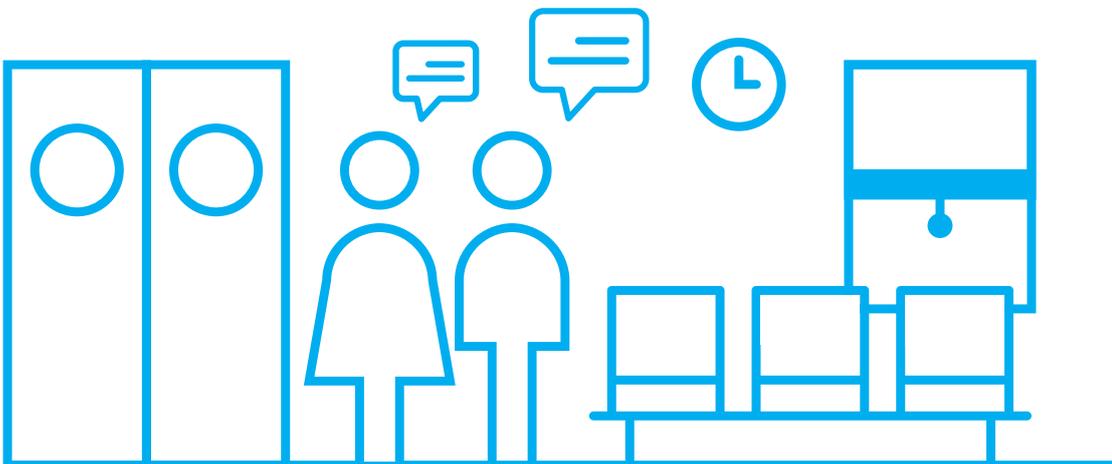
“Clinics and dispensing of medication are not to a satisfactory level. You cannot remain anonymous attending a HIV clinic.”

More than half of people living with HIV were fearful of being outed in any environment and for some people, this fear was realised; a hospital was the most common setting where people living with HIV were accidentally outed as being HIV positive, with 18% of people stating this had occurred. An example was provided within the focus group of this experience which involved a staff member in a hospital setting accidentally disclosing the patient's HIV status by discussing a known HIV specific medication while the person's visitors were present.



18%

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



An HIV Diagnosis Brings Challenges but also Opportunities

People living with HIV were asked about their most common feelings in the last year in relation to their HIV status. While acknowledging the challenges that living with HIV poses, people also spoke of opportunities for personal growth experienced since their diagnosis. The most common responses were that they felt more open minded and compassionate of others and that they were grateful for the people who had supported them in dealing with being HIV positive.

Well over half of people living with HIV are comfortable with their HIV status; this comfort is more pronounced the longer people have to get used to their status.

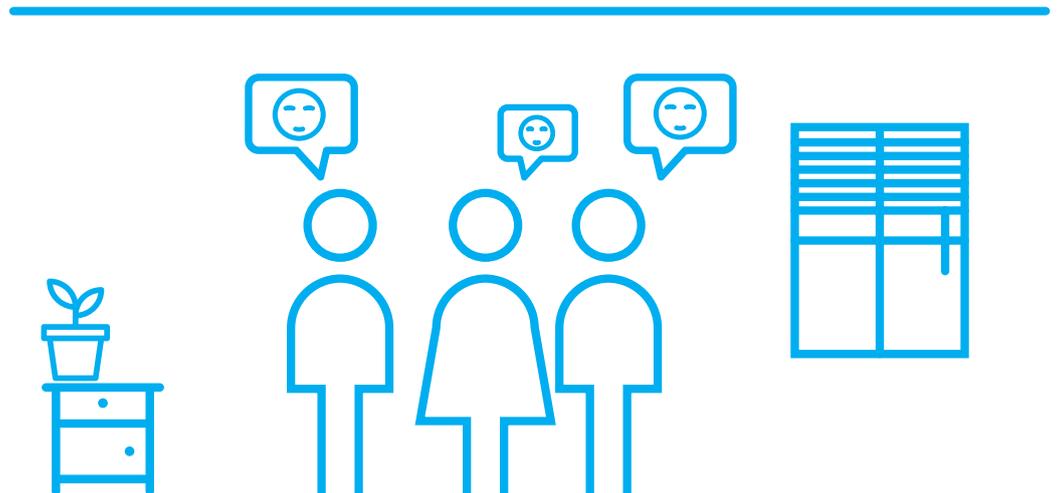
People living with HIV outlined high levels of supports provided to other people with HIV. In the last year just over half of people living with HIV have provided emotional and social supports to someone else living with HIV while 40% have provided information and advice on how to deal with being HIV positive.

“In general, there is still a lot of ignorance and stigma around HIV, and therefore a lot of shame. That’s why I decided to disclose my status almost immediately after my diagnosis. I felt there was nothing to be ashamed of. My goal was to give HIV a face; my face”.



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



Conclusion

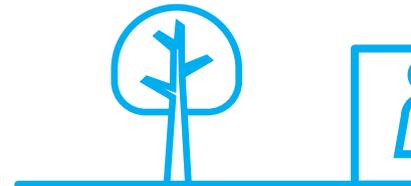
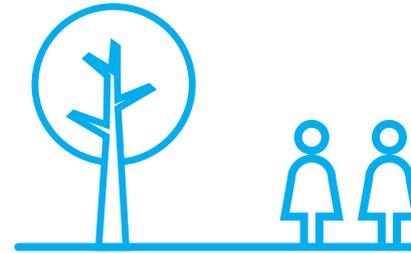
Despite knowledge in the general population regarding HIV transmission being relatively good, there is some room for improvement. Young people are more likely to have knowledge gaps and misconceptions about how HIV can be transmitted compared to their older counterparts. Conversely, young people are more likely to be accepting of people living with HIV than older respondents. These figures compared positively with the U.K., potentially highlighting the good work that has been done in relation to HIV awareness-raising in Ireland.

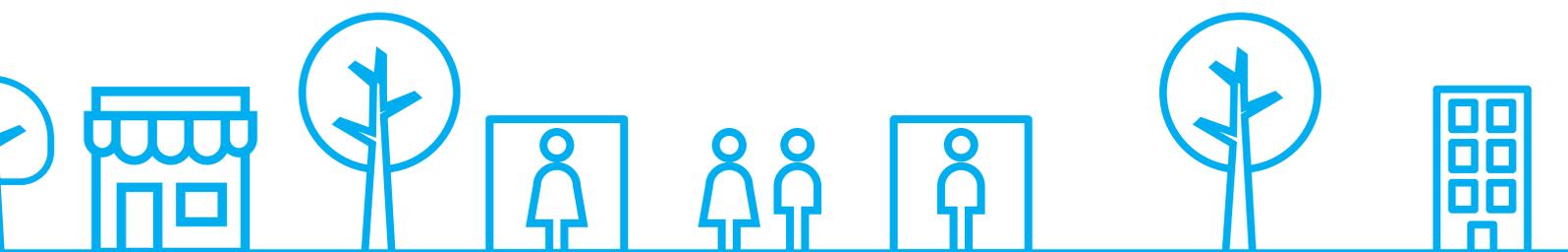
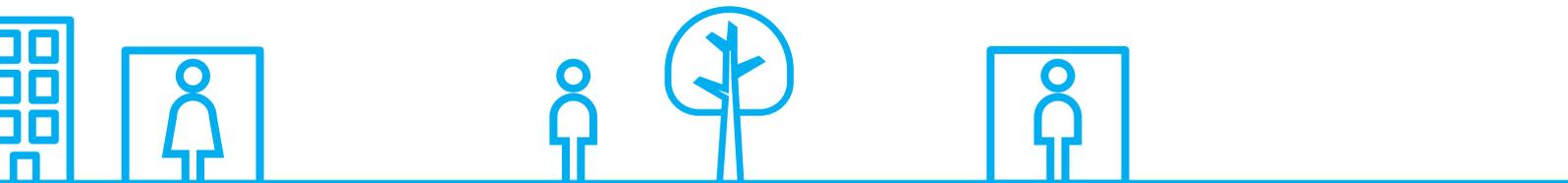
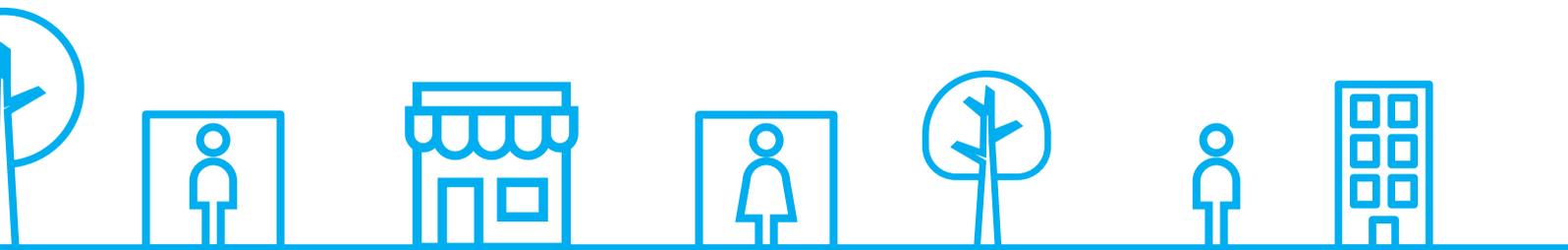
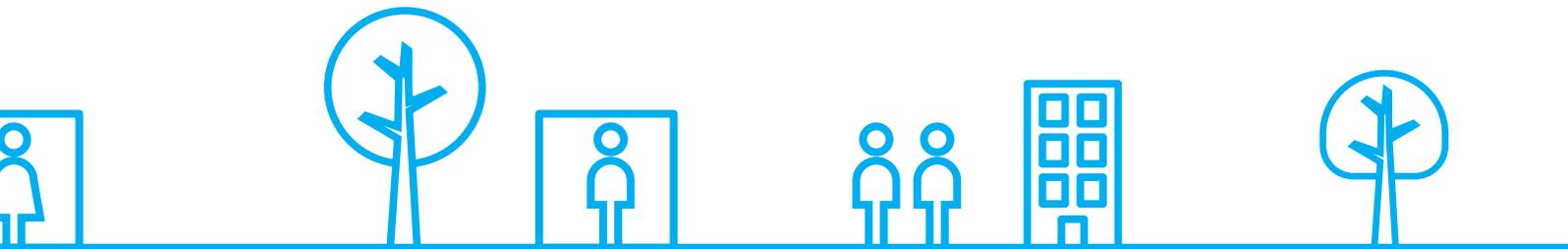
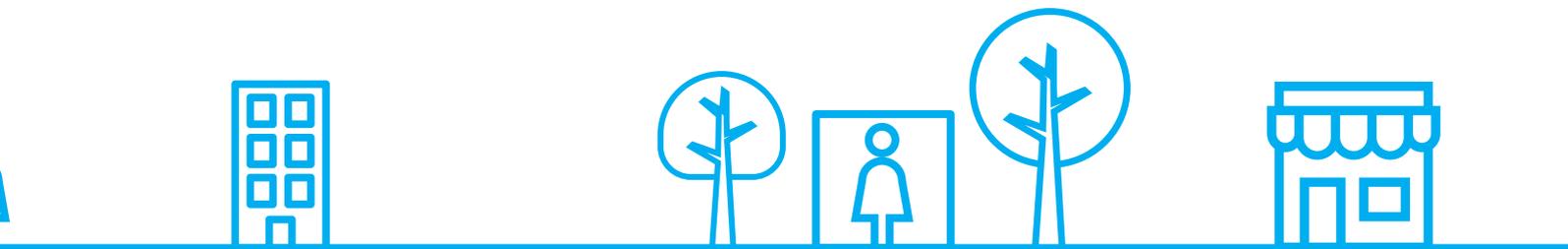
Stigma still persists and affects the everyday lives of people living with HIV. The majority of people living with HIV fear being judged and treated differently if they disclose their HIV status to others. The stress of HIV stigma may to some degree help explain why there is a high level of low self-esteem, and why suicidal thoughts were frequently reported by respondents living with HIV. People living with HIV identified that stigma affects their ability to travel, to get a mortgage or to get a job, actions which the general population take for granted.

People living with HIV also report that there is room for improvement within health services. Health services settings were one of the most likely settings to make people feel stigmatised because of their HIV status, and a hospital setting was the most common setting where people had been accidentally outed as being HIV positive.

Despite the stigma associated with living with HIV; people also saw opportunities to help others in dealing with their HIV status. The majority of people were comfortable with their status, and had provided social and emotional support to other people living with HIV in the past year.

Stigma has the potential to not only diminish the quality of life of the person living with HIV; it also impacts on their treatment outcomes and increases the risk of HIV transmission among the rest of the population. While stigma is most sorely felt by the person immediately impacted upon, society at large is not immune from the negative effects resulting from HIV-related stigma, as stigma can reduce the likelihood of people getting tested. It is hoped that this research will shine a light on this issue, and provide data to support informed education, awareness raising and effective policy development.







70 Eccles Street, Dublin, D07 A977
Phone: (01) 8733799
Email: info@hivireland.ie
Web: www.hivireland.ie

