

# HIV in Ireland 2017

## Findings from the:

# Full Report

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



HIV  
Ireland

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## To reference this report;

Gardner. C., O'Donoghue R., Dermody. A. *HIV in Ireland. Findings from the National HIV Knowledge and Attitudes Survey 2017 and People Living with HIV Stigma Survey 2017*. Dublin: HIV Ireland.

## Preface

This National Survey of People Living with HIV, Stigma and Public Attitudes presents us with a valuable insight into the lives of people living with HIV in Ireland in 2017. It captures a sense of how people living with HIV are viewed within Irish society, and how HIV impacts on their everyday lives and experiences. Over 7500 people have been newly diagnosed with HIV in Ireland since the 1990's, and we estimate that approximately 4,000 people are knowingly living with HIV in Ireland today.

One of the key findings arising from this report is the continued existence of HIV related stigma within society, and how this impacts 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 within the survey. However, they would also be more accepting of people living with HIV as a friend or colleague than some members of 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 & rejection, being outed by others, offensive language, being stigmatised by immediate family, health professionals, 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

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## 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 for the good work carried out by the National AIDS Trust U.K., the research tool for measuring the general populations knowledge of HIV transmission routes and attitudes toward people living with HIV was adapted from their Public Knowledge and Attitudes<sup>1</sup> survey. 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.

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<sup>1</sup> <https://www.ipsos.com/sites/default/files/migrations/en-uk/files/Assets/Docs/Polls/sri-health-hiv-public-knowledge-and-attitudes-2014-tables.pdf>

# 1 Executive Summary

## Introduction

Understanding, attitudes and treatment for HIV has changed radically over the last 20 years. The last significant research on attitudes and stigma was undertaken 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. The surveys support the issue of stigma to be understood from these two perspectives, that of the whole population and that of people living with HIV.

Getting an HIV diagnosis can be a devastating experience. Stigma plays a powerful role in how we think about ourselves and each other. Research shows that people who experience stigma are much more likely to feel unworthy and unvalued than those who do not. We know from past research that people living with HIV are more likely to have negative self-perceptions, lower self-compassion and self-esteem than the general population. Stigma, unnecessarily adds a mental health issue onto illness. However mental health is not the only thing at stake. HIV Stigma can also impact negatively on treatment outcomes, as people who experience stigma are shown to have less adherence to treatment regimes. Reducing stigma is considered a key element of National HIV prevention, as left unchecked, stigma has the effect of reducing people's likelihood to get tested, and this can in turn have an effect on rates of contraction.

With 1,013 people from the whole population participating and 168 people living with HIV, this research represents one of the most significant pieces of research on stigma and knowledge within Ireland. This executive summary outlines the key findings from these two surveys with a focus on Irish attitudes to stigma, as well as how stigma is impacting on people's lives. Key findings also outline existing knowledge in relation HIV contraction and treatment within the whole population.

## Findings from The National HIV Knowledge and Attitudes Survey

This whole population survey was completed by 1,013 people aged over 18 and who live in Ireland. The sample was selected using an omnibus survey<sup>2</sup> and was representative of sex, age and regionality in the Republic of Ireland. The sample size has a margin of error of +/- 3.2%.

### Knowledge of People Living with HIV

6% of adults knew someone living with HIV, almost 9 in 10 (85%<sup>3</sup>) did not know anyone with HIV.

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<sup>2</sup> An omnibus survey is a method of quantitative marketing research where data on a wide variety of subjects is collected during the same interview. It is a research in which multiple clients share the cost of conducting research. Subscribers usually receive the portion of the information that is collected specifically for them. Also called piggyback survey.

<sup>3</sup> Other categories: 'Don't Know' (7.54%), 'I'd prefer not to say' (0.43%) and 'I have HIV' (0.17%)

## Knowledge of HIV Transmission

Almost all adults (98%) correctly thought that HIV can be transmitted by sharing needles and syringes, a similar proportion correctly thought HIV can be transmitted by a man and a woman having sex without a condom (96%), or two men having sex without a condom (96%).

Common myths about transmission remain within a minority of respondents: 11% of respondents thought HIV can be transmitted by coughing or sneezing, with a similar proportion thinking HIV can be transmitted by sharing a glass (10%) or from sharing a public toilet seat (9%).

The majority of respondents (56%) thought incorrectly that HIV can be transmitted through a blood transfusion in Ireland.

24% of respondents reported that they thought HIV can be passed from person to person by kissing.

70% of respondents reported that they thought HIV can be passed from person to person through a bite. This view was more commonly held by men (76%) than women (64%).

Younger people had higher levels of misinformation than other age groups:

- a. 18 - 34-year old's (18%) were three time more likely to think that HIV could be transmitted by sitting on a toilet seat than 35+ year old's (6%).
- b. 18 - 34-year old's (14%) were more than one and a half times more likely to think that HIV can be transmitted by sharing a glass compared to 35+ year old's (8%)
- c. Almost double the proportion of 18 – 24-year old's (19%,) think that HIV can be transmitted through a cough or sneeze compared with those aged 25+ (10%,).
- d. 18 – 24-year olds are the most likely age group to believe that HIV can be passed to another person through a blood transfusion in Ireland, kissing someone and sharing a toilet seat.

A minority of respondents did not know if HIV was passable or not through the following routes: spitting (19%), coughing or sneezing (15%), biting (14%), kissing (14%), sharing a glass (14%) and using a public toilet seat (12%), indicating a lack of knowledge or uncertainty regarding routes of HIV transmission among the general population.

## Attitudes to People who are Living with HIV

83% of respondents agreed that people with HIV deserve the same level of support and respect as people with cancer.

66% of respondents agreed they would feel comfortable working with a colleague who is HIV positive.

70% of respondents agreed that if they found out their neighbor was HIV+ it would not change their relationship with them.

Women are more likely to be accepting of people who are living with HIV than men, measuring at least 5% higher on the four indicators of acceptance.

Younger people were also more likely to be accepting of people who are HIV positive than older people. The 18 – 24 age group were the most likely age group to agree that having someone in the family or a neighbour with HIV would not affect my relationship with them.

### Beliefs Regarding HIV

39% of adults mistakenly believed it is true that there is no effective way of preventing a pregnant mother with HIV from passing HIV on to her baby during pregnancy and childbirth.

5% of respondents mistakenly believed that if someone becomes infected with HIV they will probably die within three years. This view was more than three times as common in the 25 – 34-year-old age group (10%) as compared with an average of 3% at all other ages groups.

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

17% of respondents agreed they wouldn't have sympathy for people infected with HIV through unprotected sex.

There is almost universal agreement (93%) that *“Young people should be taught about HIV transmission during secondary school”*.

### Comparison to The U.K.

Irish attitudes to HIV are broadly similar to attitudes to HIV in the UK<sup>4</sup>. Irish respondents are more likely than British respondents to report correctly that HIV is transmitted through sharing needles and unprotected sex. However, Irish respondents are more likely to report incorrectly that spitting, coughing, kissing and using a public toilet are methods that facilitate the transmission of HIV compared with their British counterparts.

### Findings from The People Living with HIV Stigma Survey

The survey was completed by 168 people who are living with HIV, aged over 18 and who live in Ireland. The survey was developed in conjunction with HIV Ireland and people living with HIV and was disseminated through various social media channels<sup>5</sup> through HIV support agencies<sup>6</sup> and health services<sup>7</sup>. Interviewees were offered the opportunity to complete these surveys in a paper survey and online. All responses were undertaken in strict confidence and all identities have protected within this research.

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<sup>4</sup> <http://www.nat.org.uk/publication/hivpublic-knowledge-and-attitudes-2014>

<sup>5</sup> Twitter, planetromeo.com

<sup>6</sup> ACET, Safety Net, Balsecian, OutNow, Depaul, Uisce, Aids West, GOSHH (Limerick), Dublin Simon HIV Respite, Beaumont Connection, Trinity Court, HIV Ireland

<sup>7</sup> Dr Des Crowley, UCD School of Medicine, Cork University Hospital, Limerick STI Clinic, Galway University Hospital, Gay Men's Health Service, Sexual Health Centre (Cork)

## Disclosure

The majority of respondents have disclosed their HIV status to all or some of their partner/spouses (71%), their friends (66%), to health professionals (65%) or to their immediate family (59%).

61% of respondents have not disclosed their HIV status as they are afraid they will be judged or treated differently if they do.

Respondents are most likely to disclose their HIV status when they trust people and want to share information about themselves and to make sure that others are safe.

## Stigma & HIV

88% of respondents agreed that some people think that having HIV is shameful.

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

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

38% of respondents agreed that some people think that they deserve to have HIV.

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.

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

A small minority (5%) of respondents have been physically assaulted in the past year due to their HIV status.

A majority of respondents (51%) are offended by language that is used on social media sites and 33% are offended by language used in print media. The use of the terms 'clean' and 'unclean/dirty' to describe a person's HIV status was noted as being particularly offensive.

The main reason respondents felt stigmatised other than their HIV status was due to their sexual orientation (39% of respondents). Other reasons for stigmatisation included being a member of a minority group (7%), being a migrant worker (7%) and being an injecting drug user (7%).

Respondents are most likely to have felt stigmatised by immediate family (20%), health professionals (18%) and friends (15%) due to their HIV status

## Respondents Experiences of Being HIV Positive

In relation to their own HIV status, 57% of respondents reported they felt more open minded and compassionate of others, and 53% feel grateful for the people who have supported them.

18% of respondents have had their HIV status disclosed by accident in a hospital setting.



17% of respondents reported having 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.

The majority of people with HIV (51%) have supplied emotional or social support to another person with HIV in the past year.

## Conclusion

In conclusion, despite knowledge in the general population regarding HIV transmission being relatively good there is room for improvement. Young people are more likely to have significant knowledge gaps and misconceptions about how HIV can be transmitted compared to their older counterparts. Conversely, young respondents are more likely to be accepting of people living with HIV than older respondents. Irish attitudes and knowledge in the general population are broadly similar with their compatriots in the U.K.

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

Stigma has the potential to not only diminish the quality of life of the person living with HIV but 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 stigma target itself, society at large is not immune from the negative effects resulting from HIV-related stigma. It is hoped that this research will shine a light on this issue and provide data to support informed and effective policy making.

## 2 Introduction and Methodology

### Introduction

The purpose of this research was to explore attitudes and knowledge of HIV within the whole population, and attitudes to HIV and experience of stigma within the population of the people living with HIV in Ireland.

With 1,013 people from the whole population participating and 168 people living with HIV, this research represents one of the most comprehensive pieces of research on stigma and knowledge within Ireland. The findings provide valuable data on people's knowledge, attitudes and experiences related to HIV. Aspects of the research are also comparable to the U.K HIV Attitudes and Knowledge survey undertaken every two years, which provides a comparative international context for the findings.

This research was overseen by steering group, with representation from POSNOW, HIV Ireland, Mater Misericordiae University Hospital and Trinity College Dublin, who ensured that this process was methodically robust and informed by real experience and issues. Funding for this project was accessed through Jansen Pharmaceuticals and the work was Quality Matters in conjunction with Empathy Research, who were successful in a public tendering process. The research was granted ethical approval from the Mater Misericordiae University Hospital, Dublin, and undertaken to the highest ethical standards.

### 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 improve, through a range of support services, conditions for people living with HIV, their families and their partners while further promoting sexual health in the general population.

Our mission and vision 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 by advocating for individuals living with HIV, preventing new HIV infections and combating HIV-related stigma and discrimination.

Since 1987 HIV Ireland (formerly Dublin AIDS Alliance) has been pioneering services in sexual health education and promotion, and has consistently engaged in lobbying and campaigning in the promotion of human rights. Our approach broadly reflects a harm minimisation model which emphasises practical rather than idealised goals. For more information, visit [www.hivireland.ie](http://www.hivireland.ie).

### Methodology

#### Overview

The study involved the development of two surveys. The first survey aimed to measure knowledge and attitudes within the Irish population. The second survey measured stigma and experiences of living with HIV among the population living with HIV. This combined research, which was part funded by Jansen, had a number of objectives:

- Through structured focus groups, explore the relevance of the People Living with HIV Survey questions and bring suggestions into the survey design
- Identify issues affecting people living with HIV in Ireland relative to stigma and discrimination
- Gain a better understanding of the knowledge and attitude of members of the public towards HIV and people living with HIV in Ireland

## Ethics Approval

This study was undertaken by HIV Ireland in partnership with The Mater Misericordiae University Hospital and independent research company, Quality Matters. The Mater Misericordiae University Hospital and Mater Private Hospital Research Ethics Committee approved this study. This study was conducted in accordance with the ethical principles laid out in the Declaration of Helsinki (2013). The Principal Investigator, Quality Matters, was responsible for obtaining ethics committee approval of the protocol in compliance with the local regulatory requirements prior to entering any subject into the study. Ethics approval was based on a detailed research protocol.

## The National HIV Knowledge and Attitudes Survey

### Overview

In April of 2017 HIV Ireland commissioned an omnibus<sup>8</sup> survey to generate data on the attitudes of the Irish population to HIV and provide a snapshot of people's knowledge in relation to how HIV can be contracted. The survey was disseminated by Empathy Research amongst members of their proprietary research panel, aged over 18. The research was conducted between the 7<sup>th</sup> – 13<sup>th</sup> of April 2017. The general population stigma survey was adapted by Quality Matters under direction from the multiagency research steering group<sup>9</sup>. The survey drew substantially on similar research undertaken in the UK by the National AIDs Trust in their *National HIV: Public Knowledge and Attitudes* survey<sup>10</sup>.

### Recruitment and Data Collection

In order to be included in the survey participants were required to be 18 years of age or older and to have read and understood the survey information leaflet. The general population survey was completed by 1,013 participants, sampled randomly from Empathy Research's omnibus list and stratified by gender, age, region of the country. This stratification aimed to ensure that as far as possible the sample was reflective of the population as a whole. The sample size produces a margin of error of +/- 3.2%.

Empathy Research is affiliated with ESOMAR Corporate Member, the world organisation for market research, and abide by the ICC/ESOMAR International Code of Marketing and Social Research Practice. Participants received small rewards for their engagement. These rewards are in the form of credits which when combined

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<sup>8</sup> An omnibus survey is a method of quantitative marketing research where data on a wide variety of subjects is collected during the same interview. It is a research in which multiple clients share the cost of conducting research. Subscribers usually receive the portion of the information that is collected specifically for them. Also called piggyback survey.

<sup>9</sup> Membership included staff from HIV Ireland, Positive Now, Trinity College Dublin and the Mater Misericordiae University Hospital

<sup>10</sup> <https://www.ipsos.com/sites/default/files/publication/3697-03/sri-health-hiv-public-knowledge-and-attitudes-2014-report.pdf>

can be used to purchase gift tokens. The rewards for a survey of this size (i.e. seven questions) will be equivalent to less than one euro.

There were various methods employed to ensure that the completers of the survey were real people who engaged appropriately with the survey (i.e. not just hitting random answers). Methods include a software system to check the time taken to complete surveys, methods to ensure internal accuracy as well as ensuring that the survey could not be completed multiple times from the same person.

### Data Analysis

Data analysis was undertaken by the two companies, Quality Matters and Empathy Research to ensure accuracy of data. Descriptive statistics were developed using excel and tableau version 10.1. A number of cross tabulation calculations were carried out on each survey response. This was done with the intention of exploring whether factors like gender, age, and whether people live in rural or urban areas had any impact on attitudes or knowledge. In the interests of readability not all of this analysis has been included in published report, however when patterns were identified these have been outlined, for instance a certain view may be more commonly held by youth than older age group. More comprehensive cross tabulation analysis is available on request to HIV Ireland.

## The People Living with HIV Stigma Survey

### Overview

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 and a review of relevant international surveys. The survey generated data on the attitudes of people living with HIV regarding their perception of HIV stigma and provided a snapshot of their demographics and attitudes in relation to how HIV stigma. 168 people completed the survey.

### Focus Groups to Inform the Persons Living with HIV Stigma Survey

To ensure that the survey for people living with HIV asked the right questions in the right way, two focus groups of people living with HIV were held with a combined attendance of 16 people. These focus groups involved the review and further development of a survey tool designed solely for people living with HIV. The focus groups were recorded through notes and audio recording, and all records were managed in line with data protection.

In order to be included in a focus group, participants were required to:

- Be 18 years of age or older
- Be documented HIV1 antibody positive
- Consent to participate in a group discussion about HIV

Following eligibility screening, participants were provided with a Participant Information Statement and consent form. If patients met all inclusion criteria and study staff agreed they fulfilled the study requirements, they were invited to enrol in the focus group. In addition to a meeting with study staff where the information on the study, objectives, potential risks and harms were provided, they were provided with a Participant Information Statement to read and were asked to sign an informed consent form prior to participating.

The 16 focus group participants were recruited from the Mater Misericordiae University Hospital's out-patient clinic or through the HIV support group Positive Now. The focus groups consisted of one focus group meeting, which lasted for no longer than an hour and a half.

These focus groups resulted in significant changes and improvements to almost all questions in the draft survey and highlighted the importance of critical end user engagement in the survey development process.

### Participants and Data Collection

In order to be included in the persons living with HIV survey, participants were required to self-assess as being over 18 and documented HIV1 antibody positive. The survey was disseminated through various social media channels<sup>11</sup> through HIV support agencies<sup>12</sup> and health services<sup>13</sup> between May and June of 2017. Posters and flyers were made available to support this process. In all cases this involved informing the whole population accessing each media of the opportunity to anonymously participate in the survey.

Care was taken within the process to ensure that there were no risks to HIV positive people in relation to confidentiality and anonymity. Staff provided clients with paper surveys if requested and where this method was employed the survey was accompanied with a blank envelope in which the completed survey could be returned. Study sites were also instructed to provide clients with paper surveys only where confidentiality could be assured, i.e. they were not provided in a mixed service environment, where handing one client a survey could inadvertently inform people of their HIV status. Paper surveys were only provided to people in HIV specific services, where everyone had the opportunity to engage or in confidence within a 1-2-1 setting.

The main risk of harm to survey participants was a concern that participants could experience emotional upset as a result of the questions. Protective measures against this included ensuring participants were fully briefed on the content of the survey prior to participation and that relevant support helpline numbers were provided at the end of the survey.

### Data Analysis

Data was analysed through excel and tableau version 10.1. Any thematic analysis, i.e. of qualitative answers were reviewed by two staff to ensure considered and accurate thematic coding.

### Summary

This research was conducted to a high level of rigour and ethical standards. The research methodology provides a clear process which has potential to support future replicability should this be required.

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<sup>11</sup> Twitter, planetromeo.com, Facebook

<sup>12</sup> ACET, Positive Now, Depaul Ireland, Dublin Simon, UISCE, National Drug Treatment Centre, HIV Ireland

<sup>13</sup> Mater Misericordiae University Hospital, HSE/Thompson Centre, Cork University Hospital, Limerick University Hospital, Galway University Hospital, Gay Men's Health Service, Sexual Health Centre (Cork)

### 3 Literature Review

#### Overview

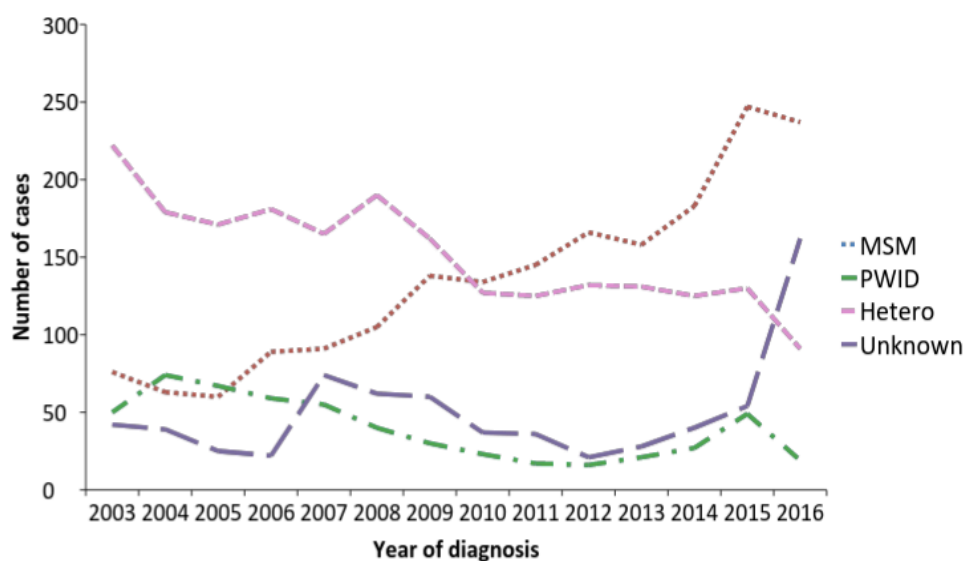
This literature review provides a foundation for this research report, highlighting what was known about HIV related discrimination and stigma at the time of this research, including: its impact on the individual and the community; stigma and discrimination in Ireland and in our closest neighbouring country, the UK; successes and strategies for addressing stigma and discrimination at national and international level. This chapter also highlights Ireland's international commitments in relation to HIV and HIV-related stigma and discrimination, and discusses the Sexual Health Strategy 2015 – 2020 in light of international strategy and research.

#### HIV in Ireland

Information on the diagnosis and prevalence of HIV/AIDS in Ireland is collected by the Health Protection Surveillance Centre (HPSC). It produces weekly, quarterly and annual reports on HIV diagnoses. At the time of developing this report, the headline data for 2016 showed 512 people were newly diagnosed with HIV in 2016; the highest number since national surveillance on HIV diagnoses began.

Since the early 1980's, approximately 8,350 people have been newly diagnosed with HIV in Ireland<sup>14</sup>. However, this number does not take factors such as death and migration into account, which means this is not likely to be an accurate number of people currently living with HIV in Ireland. In 2016, 512 new HIV diagnoses were notified in Ireland giving a rate of 11.2 per 100,000 population. This was an increase of 6% compared to 2015. The HSPC notes a steady increase in diagnoses since 1994, with particular spikes in diagnoses in 2003, 2008 and 2015. The graph below depicts trends in routes of transmission from 2003 to 2016.

Figure 1: Trends in HIV diagnoses by route of transmission 2003 to 2016



<sup>14</sup> The HPSC stated in their annual report that since the early 1980's, 7,353 people were newly diagnosed with HIV in Ireland, and in their 2015 report that 485 people were newly diagnosed in Ireland, and in 2016, that 512 were newly diagnosed

The HSPC note that sex between men remains the predominant mode of HIV transmission in Ireland, accounting for 46% in 2016 and 51% in 2015. From 2005 to 2015, the number of new diagnoses among MSM increased 4.5 times (from 60 to 237). This was particularly notable among migrant men, increasing from 85 in 2014 to 141 in 2015<sup>15</sup>.

Heterosexual contact was the second most commonly reported mode of transmission in 2016, (91; 18%). Injecting drug use as a route of transmission saw a significant 61% decrease from 2015 to 2016, with 19 diagnoses (4%) in 2016 and 49 in 2015. There was a spike in 2015 that was attributed to an outbreak of transmission among IDUs in Dublin in 2014/2015.

The HSPC data from 2015 highlighted key trends including higher rates of new diagnoses among men who have sex with men (MSM), and within that population, new diagnoses among migrant MSM.

## The Impact of Stigma on People with HIV

HIV related stigma refers to a devalued status arising from a socially constructed 'shared knowledge' about people living with HIV (2). This includes perceptions that the person is responsible for contracting the virus, and misconceptions about the virus itself (3). HIV stigma was first believed to have originated from its association with groups who are otherwise targets of discrimination such as homosexual men, sex-workers and people who use drugs (4).

For someone living with HIV, stigma can manifest in three ways:

- Enacted stigma relates to the actual and direct experiences of negative attitudes and behaviours of others towards the affected individual. This includes overt expressions of being deliberately isolated (e.g. loss of friendships) after disclosure of friendships, as well as "*more subtle expressions of stigma, such as microinsults and daily hassles or macroaggressions similar to those experienced by other marginalized groups*" (4).
- Perceived stigma relates to the evidence of discrimination and stigma that a person can see around them, targeted at people living with HIV generally or towards others, but not necessarily directed at them. It relates to how much a person believes that the public stigmatises someone living with HIV (5).
- Internalised stigma is the stigma that arises from a person devaluing themselves, usually arising from perceiving the stigma of others and accepting this about oneself (3); adopting the negatively held views held by society about oneself.

There is evidence to suggest that enacted, or experienced stigma, is not as prevalent as it could be. This may be because stigma and experience of negative impacts of it has been shown to be more prevalent among those who disclose their status (6), and avoidance of disclosure is a protective measure that people living with HIV may take

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<sup>15</sup> Detailed data for 2016 was not released by the HSPC at the time of writing this report, so the data for some of the section is taken from the HPSC's annual report for 2015 (1).

to protect themselves from perceived stigma (2), resulting in lower levels of perceived stigma than experienced stigma (7). This highlights an important points that needs to be considered in relation to efforts to address stigma; internalised stigma has been shown to have worse impact on mental health than enacted or perceived stigma (8,9), and measures to address stigma at a personal level may be a fast and effective approach to improving quality of live for those living with HIV, while slower-moving efforts to address wider society level discriminatory attitudes are implemented.

Stigma has a seismic impact on the lives of people living with HIV in terms of physical and mental health, personal and family relationships, employment, finances and the access to treatment options (10). In a summary of the literature on stigma and HIV/Aids, Mahajan and colleagues note:

*HIV/AIDS related stigma ... is invoked as a persistent and pernicious problem in any discussion about effective responses to the epidemic. In addition to devastating the familial, social, and economic lives of individuals, H/A stigma is cited as a major barrier to accessing prevention, care, and treatment services (10)*

The devastating effect of an HIV diagnosis on an individual's self-esteem, self-concept and mental health has been well documented in the literature. Internalised stigmas is associated with depression, anxiety and hopelessness (3,11,12). HIV stigma also appears to be particularly prominent among women living with HIV (13,14). This decline in self-worth may be exacerbated by the interpersonal distancing and social rejection from family or friends in the aftermath of a diagnosis disclosure (15,16)). Although protective factors such as social support tend to buffer the individual coming to terms with an HIV diagnosis (17), mental health difficulties are likely to emerge. Depression is listed as the most common mental health difficulty experienced by people living with HIV (12) followed by alcohol and drug abuse disorders (18). Research has shown that a person with a diagnosis of HIV is almost ten times more likely to develop depressive symptoms in comparison to the general population (11), with woman and transgender individuals most at risk (19). The knock-on effect of mental health issues is considerable with people who possess a dual diagnosis of HIV and depression becoming more likely to record poorer virological response to treatment (20), lower quality of life (17) and an increased likelihood of death (21). Stigma has also been shown to reduce the ability of individuals to adhere to their treatment (22).

The negative consequences of HIV stigma, however, are not limited to the individuals themselves. The wider community is affected by HIV-related stigma as the help-seeking behaviours of those living with HIV become minimised. Fear of prejudice can prevent individuals from getting tested and accessing treatment (e.g.18,19). Secondly, a person may transmit the HIV virus with sexual partners or fellow drug users either wittingly, or unwittingly, for fear of the disclosure attracting the negative reaction of the other party. Thirdly, it may discourage non-infected individuals from seeking pre-cautionary screenings and information about the condition. Thus, stigma has the potential to not only diminish the quality of life of the person living with HIV but also limit their treatment outcomes and increase the risk of HIV transmission among the rest of the population. Therefore, while stigma is most sorely felt by the stigma



target itself, society at large is not immune from the negative effects resulting from HIV-related stigma.

In a summary of the literature relating to stigma and its impact, it has been described as a fundamental cause of population health inequalities (24), and, arguments for the elimination of stigma as key to any effective response to the AIDS crisis are compelling in this regard (25). It has been argued that all drivers and facilitators of stigma, including social judgements, laws, policies and procedures, as well as supporting the alleviation of internalised stigma among people living with HIV, must be considered in any strategy to effectively address it (26).

## Public Attitudes to HIV and HIV Related Stigma Stigma, Discrimination and HIV

Given the devastating effect of stigma on people living with HIV/AIDS as documented in literature in the previous section, combatting stigma and discrimination has been a strategic priority in international HIV efforts in recent years. 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*

The indicator for countries to measure whether they are achieving target eight of the UN Political Declaration on HIV and AIDS is the measurement of stigma in its various forms. This includes discrimination experienced by people living with HIV/AIDS, as well as discriminatory attitudes among the general population towards people living with HIV/AIDS (27). UNAIDS argue that the value of collecting information on HIV related stigma is that it broadens collective understanding of the 'extent and forms' of stigma and discrimination. The information gathered, they argue, is a tool for advocacy in fighting for improved services and rights for people living with HIV (28).

The *People Living with HIV Stigma Index*<sup>16</sup> collects information in a number of countries on the stigma experiences of people living with HIV. UNAIDS notes the various benefits of doing this, including:

- Documenting the variety of experiences of people living with HIV regarding HIV-related stigma and discrimination.
- Comparing the situation of people living with HIV in one country or across different countries with respect to stigma and discrimination.
- Measuring changes over a period of time so that we can answer questions like, "Has the situation with respect to stigma, discrimination and rights of people living with HIV worsened or improved over the last couple of years in this community?"
- Providing an evidence base for policy change and programmatic interventions (28).

The value of collecting information on stigma is core to being able to respond and reduce it. The collection of this information is the norm in many of EU partner countries who participate in the United Nations data collection systems. The following section

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<sup>16</sup> <http://www.stigmaindex.org/>

illustrates Ireland's shortcomings in relation to collecting this particular type of information in relation to HIV/AIDS.

### Public Attitudes and Stigma in Ireland

The most recent research on public attitudes and stigma in relation to HIV in Ireland was undertaken in 2007. This involved a series of surveys which were undertaken and collated for the report *HIV Related Stigma and Discrimination in Ireland Today* (29). The ultimate objective of the report was to compare the experiences of people living with HIV with the perceptions and behaviour of other groups that have influence on them. It presents an understanding of stigma and HIV in relation to the following target groups: the general public, workforces (schools, unions, doctors and dentists, small businesses), and people living with HIV. The findings in relation to experiences of discrimination experienced by people living with HIV were in summary:

- 49% were discriminated against by friends.
- 43% by the local community.
- 37% by a doctor.
- 34% by a dentist.
- 28% by the family.
- 25% by social welfare.
- 21% by the workplace.
- 18% by school or college.

In relation to public attitudes, the research found that while there was a generally sympathetic attitude to people living with HIV in Ireland, the more personal the experience of HIV, the greater the perceived stigma and discrimination: 37% would want it to remain a secret if a member of their family contracted HIV, and 23% would be concerned about eating a meal prepared by a person living with HIV (29). Some of these concerning attitudes have also been found in research more recently in the UK, as detailed further in the next section.

This section highlights the concerning attitudes to HIV and levels of experience of stigma as documented in Irish research, as well as the dearth of recent, relevant information in relation to understanding public attitudes to HIV/AIDS or the experiences of stigma by people living with HIV/AIDS in Ireland.

### Public Attitudes and Stigma in the UK

As illustrated in the previous section, HIV related stigma and public attitudes has not been documented in Ireland since 2007, however, in the UK, the National Aids Trust undertake regular surveys of the population to assess people attitudes to HIV. In 2014, their survey on public attitudes and knowledge articulated that there was a strong association between good knowledge of HIV and of HIV transmission routes and more supportive attitudes to people living with HIV<sup>17</sup>.

In relation to knowledge on HIV, although it was noted there was some improvement in attitudes compared to those recorded in previous reports, some concerning findings in relation to knowledge of HIV transmission were highlighted:

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<sup>17</sup> The data to support this is not presented in the publically available report

- Only two in three (65%) of the public identify all three correct routes of HIV transmission; sex without a condom between a man and woman; sex without a condom between two men; and by sharing needles or syringes.
- 17% of the public are unaware that HIV is passed on through sex without a condom between a man and a woman.
- 19% are unaware that HIV is passed on through sex without a condom between two men.
- 16% of the public incorrectly think HIV can be passed on from kissing someone, compared with 9% in 2010.

In terms of attitudes to people with HIV found by the National Aids Trust, they note there are reasonably high levels of empathy for those with HIV:

- 79% of the public agree that people with HIV deserve the same level of support and respect as people with cancer.
- 72% agree that if a family member told them they were HIV positive it would not damage their relationship.
- 67% of the public agree they would be comfortable working with someone living with HIV.

However, there remains some potentially damaging attitudes, for example 38% of people felt their employer should inform them if a colleague was HIV positive, which would be a considerable breach of a person's right to privacy.

Another source of information on the levels of stigma in the general population in the UK is the abovementioned 2015 Stigma Index (30). This research reviewed the level of ongoing stigma and discrimination experienced by people living with HIV and found that around half of respondents reported internalised stigma (e.g. feelings of shame, guilt, low self-esteem, and self-blame) in relation to their HIV status. As well as that, comparable numbers of people experienced discrimination as that reported in Ireland eight years previously, although very specific examples of discrimination were provided in the UK, compared to the more general findings in the Irish research:

- One-fifth of all participants reported verbal harassment or threats.
- One in nine were denied insurance products.
- One in five felt pressure from employers or co-workers to disclose their status.
- One in three reported family members or friends had disclosed their HIV status without consent.
- One-fifth reported being treated differently to other GP patients.
- 

In addition to these enacted experiences of stigma, there was also evidence of avoidance behaviours potentially arising from internalised stigma including:

- Half of all participants reported avoiding sex.
- 41% have not sought any kind of support (30).

Despite decades of effort to inform, raise awareness about HIV, and tackle discrimination, addressing stigma remains a significant challenge in the UK. The

findings in the UK highlight the importance of continued efforts to gather this information in order to support and drive our efforts to address stigma here in Ireland.

### Commitment to End HIV/AIDS

Ireland, as a member state of the United Nations, has adopted the Sustainable Development Goals 2016 – 2030, successors to the Millennium Development Goals 2000 – 2015. These goals reflect the high level priorities of UN member states in relation to social, environmental, health, and economic outcomes for the world's population. The success of the Millennium Development Goals in relation to HIV/AIDS over the past 15 years is noted here by UNAIDS:

*In 2015, the world delivered on the AIDS targets of Millennium Development Goal 6 —halting and reversing the AIDS epidemic. This achievement marks the first time a global health target has been met and exceeded. (31)*

Building on this success, the Sustainable Development Goals for the next 15 years from 2016 – 2030 includes as a health and well-being target:

*Target 3.3: By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases. (32)*

As well as this, as a member state, Ireland is also signatory to the 2011 resolution adopted by the General Assembly of the United Nations *Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS*. This commitment includes 105 points covering all facets of prevention, treatment, and care, including national and international leadership, improving prevention and treatment efforts, reducing stigma, and provision of appropriate resources. Ten specific target actions from the 2011 Declaration were identified:

1. Reduce sexual transmission by 50% by 2015.
2. Reduce transmission of HIV among people who inject drugs by 50% by 2015.
3. Eliminate new HIV infections among children by 2015 and substantially reduce AIDS-related maternal deaths.
4. Reach 15 million people living with HIV with lifesaving antiretroviral treatment by 2015.
5. Reduce tuberculosis deaths in people living with HIV by 50% by 2015.
6. Close the global AIDS resource gap by 2015 and reach annual global investment of US\$ 22-24 billion in low- and middle-income countries.
7. Eliminate gender inequalities and gender-based abuse and violence and increase the capacity of women and girls to protect themselves from HIV.
8. Eliminate stigma and discrimination against people living with and affected by HIV through promotion of laws and policies that ensure the full realization of all human rights and fundamental freedoms.
9. Eliminate HIV-related restrictions on entry, stay, and residence.
10. Eliminate parallel systems for HIV-related services to strengthen integration of the AIDS response in global health and development efforts.

Ireland is collecting epidemiological data, which can be used to support monitoring of some of these targets and evidence outlined in the first section of this literature review shows that Ireland is not yet successful in meeting these. Ireland began submitting Global AIDS Response Progress Reporting to support monitoring of progress towards the Declaration targets in 2014.

There have been organised efforts to challenge HIV related stigma in Ireland in recent history, including for example the 'Stamp Out Stigma' campaign, which was a year-long campaign in 2007 which aimed to:

- Tackle the stigma associated with HIV while further challenging both direct and indirect discrimination experienced by people living with HIV in Ireland, while informing and learning from experiences in developing countries
- Promote an understanding of HIV while highlighting the irrationality of stigma and discrimination at home and abroad

The campaign was lead by a 'multi-stakeholder forum' consisting of civic organisations and relevant statutory organisations, and sought to achieve their aims through work with media, the Equality Authority and non-governmental organisations.

### Success Factors for Ending HIV/AIDS

Over the past 15 years, UNAIDS has provided considerable guidance to member states on how governments and society partners can progress effective responses to HIV. Principles applicable to all stakeholders in the country-level HIV/AIDS response were agreed at the International Conference on AIDS and STIs in Africa (ICASA) held in Nairobi, Kenya, in September 2003. These guiding principles for national authorities and their partners became known as the 'Three Ones':

- One agreed HIV/AIDS action framework that provides the basis for coordinating the work of all partners
- One National AIDS coordinating authority, with a broad based multi-sector mandate
- One agreed country level monitoring and evaluation system

The commitment and ownership of individual nations in tackling HIV/AIDS is noted as core to achieving high-level international goals, such as the Sustainable Development Goals. The key elements of country ownership<sup>18</sup> identified by UNAIDS are identified in the following illustration by UNAIDS (33):

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<sup>18</sup> Although 'country ownership' primarily relates to the promotion of ownership in low-middle income countries in receipt of international aid, this model depicts the core elements of a comprehensive response that can be equally applied to higher income countries such as Ireland.



Figure 2: Key elements of country ownership

In their position paper of 2005, *Intensifying HIV prevention*, UNAIDS note the following essential policy actions for the prevention of AIDS:

1. Ensure that human rights are promoted, protected and respected, and that measures are taken to eliminate discrimination and combat stigma.
2. Build and maintain leadership from all sections of society, including governments, affected communities, non-governmental organisations, faith-based organisations, the education sector, media, the private sector and trade unions.
3. Involve people living with HIV in the design, implementation and evaluation of prevention strategies, addressing the distinct prevention needs.
4. Address cultural norms and beliefs, recognising both the key role they may play in supporting prevention efforts and the potential they have to fuel HIV transmission.
5. Promote gender equality and address gender norms and relations to reduce the vulnerability of women and girls, involving men and boys in this effort.
6. Promote widespread knowledge and awareness of how HIV is transmitted and how infection can be averted.
7. Promote the links between HIV prevention and sexual and reproductive health.
8. Support the mobilisation of community-based responses throughout the continuum of prevention, care and treatment.
9. Promote programmes targeted at HIV prevention needs of key affected groups and populations.
10. Mobilise and strengthen financial and human and institutional capacity across all sectors, particularly in health and education.

11. Review and reform legal frameworks to remove barriers to effective, evidence-based HIV prevention, combat stigma and discrimination, and protect the rights of people living with HIV or vulnerable or at risk to HIV.
12. Ensure that sufficient investments are made in the research and development of, and advocacy for, new prevention technologies.

## Review of Current Strategy in Ireland

To evaluate the strategy that governs the area of HIV/AIDS in Ireland, a cross comparison was undertaken between Ireland's current strategy (the National Sexual Health Strategy) and three others: the previous national strategy (HIV and AIDS Prevention Plan 2008 - 2012<sup>19</sup>) and two current international HIV strategies (from the United States<sup>20</sup> and Australia<sup>21</sup>). All four strategies were measured against the UN's 'three ones' guiding principles for national authorities and their partners, and the 12 essential policy actions outlined in the UNAIDS 'Intensifying HIV Prevention' strategy(34). Overall, the current national strategy scored well in meeting the 15 items (the 'three ones and the 12 essential policy actions'), meeting 12 of the 15 criteria. All of the other strategies met 13 of the fifteen criteria. Where Ireland's current strategy falls down relates primarily to the overall approach, rather than the content of the strategy itself.

- The 'three ones' require that in each country there is an agreed HIV/AIDS action framework; in Ireland this has been subsumed into the National Sexual Health Strategy.
- Likewise, a 'National AIDS Coordinating Authority' is a requirement, however this structure does not exist in Ireland; the strategy states that an interdepartmental group, including NGOs, will be established to oversee implementation of the strategy generally, but no particular group is named as being established to oversee actions specifically relating to achieving commitments in relation to HIV/AIDS
- The strategy does not specify whether and how people living with HIV would be involved in the design, implementation and evaluation of prevention strategies, which is an 'essential policy action' identified by UNAIDS.

However, in all other areas, the content of the National Sexual Health Strategy addresses the other twelve criteria:

- One agreed country level monitoring and evaluation system
- Measures are taken to eliminate discrimination and combat stigma
- Leadership from all sections of society
- Involve people living with HIV in the design, implementation and evaluation of prevention strategies
- Address cultural norms and beliefs
- Promote gender equality and address gender norms
- Promote widespread knowledge and awareness of transmission / prevention
- Promote links between HIV prevention and sexual and reproductive health

<sup>19</sup> [http://health.gov.ie/wp-content/uploads/2014/03/HIVAIDS\\_educationand-pp\\_review-.pdf](http://health.gov.ie/wp-content/uploads/2014/03/HIVAIDS_educationand-pp_review-.pdf)

<sup>20</sup> National HIV/AIDS Strategy for the United States: <https://www.hiv.gov/federal-response/national-hiv-aids-strategy/overview>

<sup>21</sup> Seventh National HIV Strategy: <http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hiv>

- Support mobilisation of community-based responses throughout continuum of prevention, care and treatment
- Promote programmes targeted at HIV prevention needs of key affected groups and populations
- Mobilise and strengthen financial and human and institutional capacity across all sectors, particularly in health and education
- Review and reform legal frameworks to remove barriers to effective, evidence-based HIV prevention, combat stigma and discrimination, and protect the rights of people living with HIV or vulnerable or at risk to HIV
- Ensure that sufficient investments are made in the research and development of, and advocacy for, new prevention technologies

To what extent the National Sexual Health Strategy, and in particular actions in relation to HIV/AIDS will be implemented remains to be seen. However, the strategy provides a promising roadmap for Ireland to progress ambitious commitments to reduce HIV and HIV related stigma.

## Summary

People living with HIV experience significant levels of discrimination and prejudicial treatment. Stigma can manifest as an experience of prejudicial treatment by others, or it can be witnessed or perceived. Both enacted and perceived stigma have serious negative impacts on people living with HIV. HIV related stigma is associated with increased mental health difficulties such as depression and anxiety, and reduced access to social supports. Stigma can also exacerbate physical health difficulties and is associated with reduced adherence to treatment. Stigma is also associated with reduced rates of help-seeking behaviour; people may not go to get tested because of the shame associated with diagnosis, and where people are tested they may not seek help, again due to shame or fear of people finding out. This shows that stigma has the potential to not only diminish the quality of life of the person living with HIV but also limit their treatment outcomes and increase the risk of HIV transmission among the rest of the population.

Collecting information on stigma and discrimination in relation to people living with HIV has been consistently highlighted as crucial to combatting HIV by international bodies and national governments over the previous 30 years. Ambitious goals to combat stigma and discrimination have been included in numerous declarations, commitments and development goals. Ireland is among those nations formally committing to the achievement of these goals, and yet without information on the scope and nature of the problem of discrimination here, the achievement of our shared goal to combat HIV by 2030 and the crucial role understanding and tackling discrimination plays in achieving that goal, is undermined. This literature review draws attention to the immediate need for this research, and for the on-going collection of information on stigma and discrimination as a tool to combat discrimination, and a crucial factor in achieving our commitment to the Sustainable Development Goal to end HIV by 2030.



## 4 Findings from the Full Population Survey

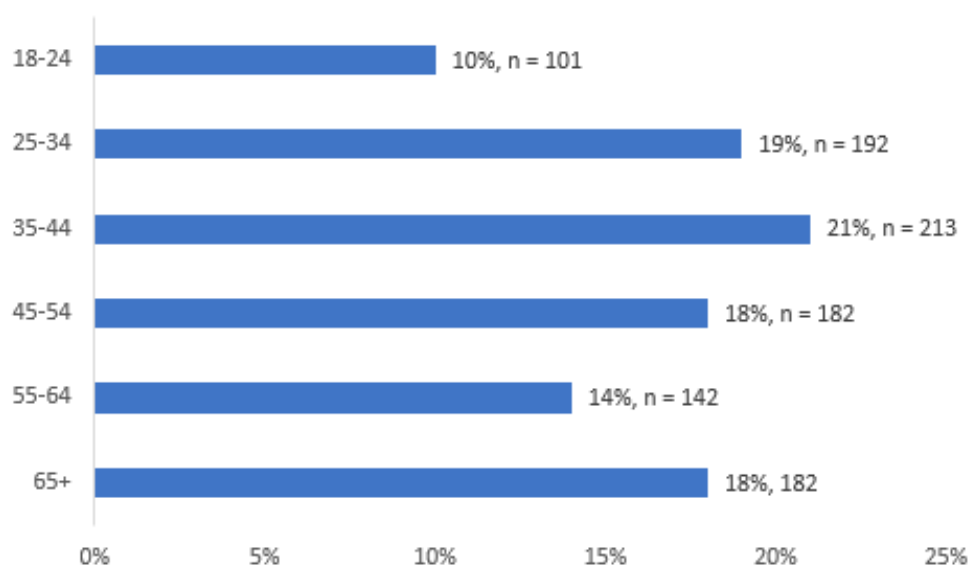
### Introduction

This section provides a brief profile of survey respondent demographics followed by a section asking respondents attitudes to HIV and how it is transmitted. Respondents are then asked whether they believe a number of statement regarding HIV are true or false and the full population survey finishes with a comparison of Irish attitudes regarding HIV compared to attitudes in the UK.

### Profile of the Survey Respondents

Survey respondents were sourced through an online survey across a nationally representative sample of 1,013 respondents, aged 18+ from within the Republic of Ireland. Quotas were placed on gender, age, social class and region with weighting applied to ensure the final sample was as representative as possible of the Irish population. The age distribution of the sample is generally reflective of the Irish population<sup>22</sup>. The majority of respondents fall between the ages of 25 – 53 with 58% of all respondents within this range. People aged 18 to 24-years account for the smallest proportion of respondents at 10%. The survey sample is roughly split equally between female and male respondents with 51% (n = 517) female and 49% (n = 496) male.

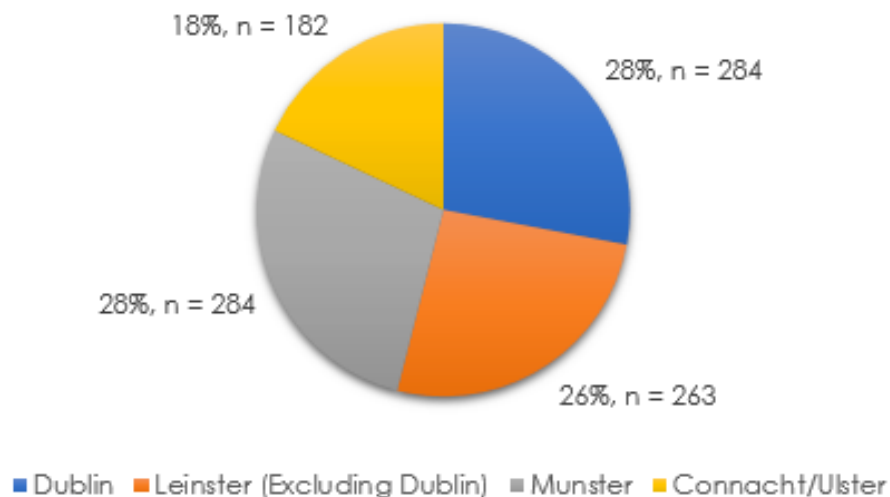
Figure 3: Age Distribution of Sample



<sup>22</sup> <http://www.cso.ie/multiquicktables/quickTables.aspx?id=pea01>

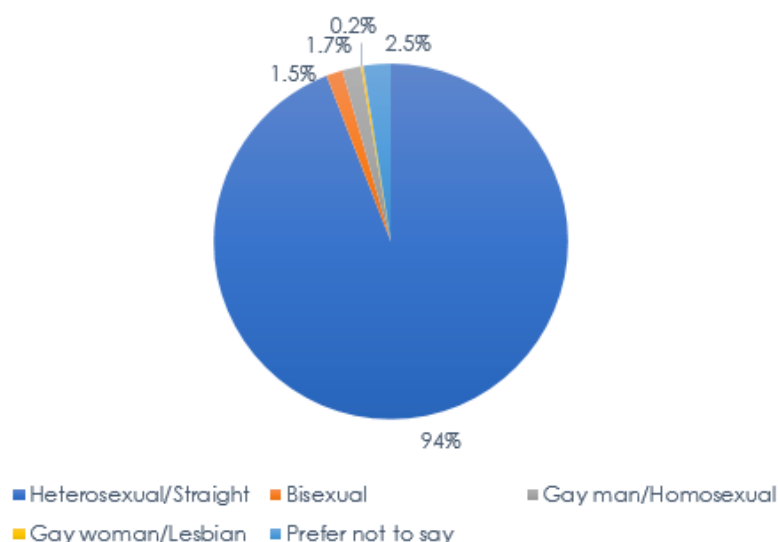
The regional representation is generally representative of the Irish geographic distribution<sup>23</sup>. The majority of respondents are from the Dublin/Leinster region with 56% of the total sample residing in the region. Connacht/Ulster accounts for the smallest proportion of respondents at 18%.

Figure 4: Regional Representation of Respondents



94% (n = 952) of respondents report as heterosexual, 3.5% (n = 35) of respondents reported as being gay or bisexual and 2.5% (n = 25) of participants preferred not to report their sexual preference. The proportions are generally in line with the Gay Britain<sup>24</sup> survey for the UK Office for National Statistics sexual identity in the general population, this is also generally in line with the most recent Irish research carried out by MRBI for the Irish Times on sexuality in the general population.

Figure 5: Reported Sexual Preferences of Respondents in the Sample



<sup>23</sup> <http://www.cso.ie/en/statistics/population/populationofeachprovincecountyandcity2011/>

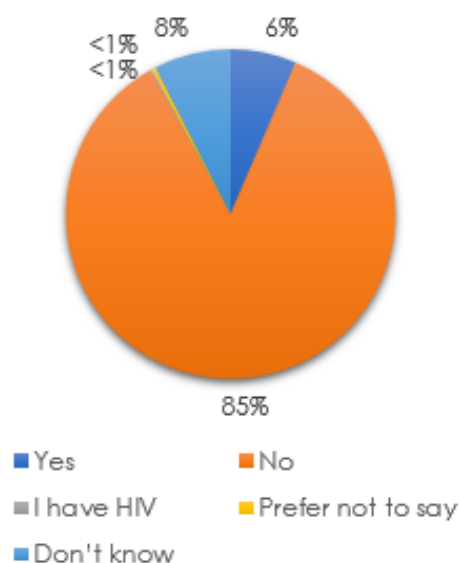
<sup>24</sup> [https://docs.google.com/spreadsheets/d/1Q\\_Fgszba3tS8fpoYxHcvJQO2VEcXpQP7v6ds0-PEFrQ/edit#gid=0](https://docs.google.com/spreadsheets/d/1Q_Fgszba3tS8fpoYxHcvJQO2VEcXpQP7v6ds0-PEFrQ/edit#gid=0)

## Findings of The Survey

### Knowledge of HIV Positive People

Respondents were asked did they personally know someone with HIV? 93% (n = 869) of respondents reported that they do not know or do not know if they know someone with HIV while 6% of respondents reported that they do know someone who has HIV. People living in the Dublin region were more likely to know someone with HIV (9% compared to 5% in the rest of the country).

Figure 6: Personal Knowledge of Someone Living With HIV



### Knowledge of HIV Transmission

Survey respondents were asked in which of a number of ways, did they think HIV could be passed from person to person? The following section outlines the frequency of responses based on people's belief in how likely each method was to transmit HIV.

#### Unprotected Sex and Sharing Needles

Almost all adults (98%, n = 993) believed HIV can be transmitted by sharing needles and syringes, with a similar proportion believing HIV can be transmitted by a man and a woman having sex without a condom (96%, n = 972), or two men having sex (96%, n = 972) without a condom. These figures are relatively similar across gender, age and region of the country.

Table 1: What is the Reality

<b>By sharing needles or syringes</b>	The risk of getting HIV is high if a person uses/shares unsterilised injecting equipment (e.g. needles, syringes, cookers, filters, water) after someone with HIV has used them <sup>25</sup> .
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<sup>25</sup> <http://www.aidsmap.com/HIV-transmission/page/3005817/>

<b>Sex without a condom between a man and a woman</b>	Vaginal sex without a condom with a HIV positive person is high risk. HIV can be passed to either the female or male partner although the female partner has the higher risk <sup>26</sup> .
<b>Sex without a condom between two men</b>	Anal sex without a condom with a HIV positive person is high risk. Receptive anal sex (bottoming) is riskier than insertive anal sex (topping) <sup>27</sup> .

**Standing on A Used Needle**

84% (n = 583) of respondents reported that they thought HIV can be passed from person to person by standing on a used needle. Younger people were more likely than older people to hold this belief. 91% (n = 267) of respondents aged 18 – 34-year old's think that HIV can be transmitted through standing on a used needle compared to 73% (n = 133) of 65+ year old's.

Figure 7: Can HIV be Passed from Person to Person by Standing on a Used Needle

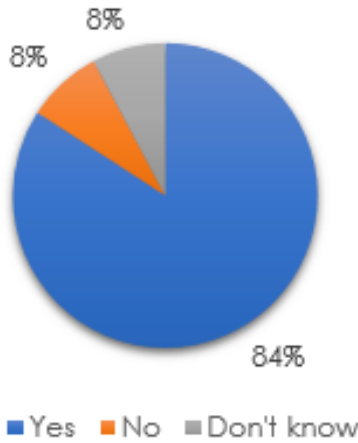


Table 2: What is the Reality

<b>Standing on a used needle</b>	Although theoretically possible, there have been no reported cases of HIV transmission from a needle stick injury outside of the healthcare setting <sup>28</sup> .
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**Biting**

70% (n = 708) of respondents reported that HIV can be passed from person to person through a bite. This view was more commonly held by men (76%, n = 376) than women (64% n = 322).

<sup>26</sup> <http://www.aidsmap.com/HIV-transmission/page/3005817/>  
<sup>27</sup> <http://www.aidsmap.com/HIV-transmission/page/3005817/>  
<sup>28</sup> <http://www.aidsmap.com/Discarded-needles/page/2124827/>

Figure 8: Can HIV be Passed from Person to Person by Biting

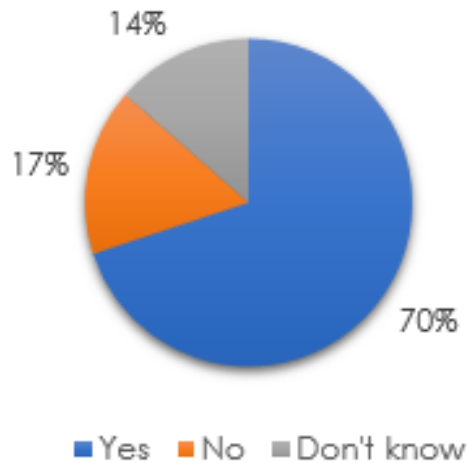


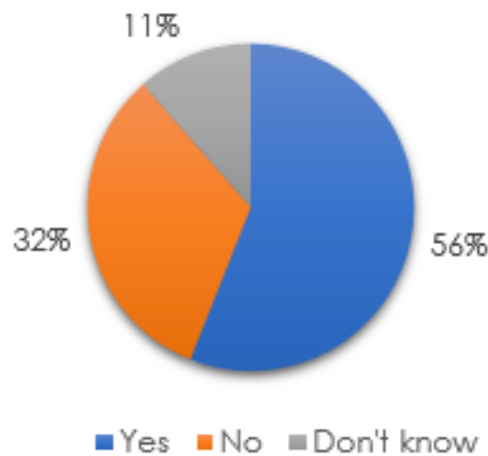
Table 3: What is the Reality

<b>Biting</b>	HIV transmission from biting is extremely rare and has happened only in cases where blood was present in the biters mouth. There is no risk of transmission if the skin isn't broken <sup>29</sup> .
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### Through a Blood Transfusion in Ireland

More than half of respondents (56%, n = 568) reported that they thought HIV can be passed from person to person through a blood transfusion in Ireland. This view was much more common among younger people than older people - 68% (n = 199) of 18 – 34-year old's think that HIV can be transmitted through a blood transfusion in Ireland compared to 48% of 55+ year old's (n = 154).

Figure 9: Can HIV be Passed from Person to Person Through a Blood Transfusion in Ireland



<sup>29</sup> <http://www.aidsmap.com/Biting/page/1322751/>

Table 4: What is the Reality

<b>A blood transfusion in Ireland</b>	It is not possible to contract HIV through blood transfusion in Ireland. All blood donated to the Irish blood transfusion board is tested for HIV <sup>30</sup> .
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### Kissing

24% (n = 243) of respondents reported that they thought HIV can be passed from person to person by kissing. 21% (n = 155) of 25 – 64-year old's think that HIV can be transmitted by kissing compared to more than 30% in the 18 – 24-year-old and the 65+ age groups.

Figure 10: Can HIV be Passed from Person to Person by Kissing

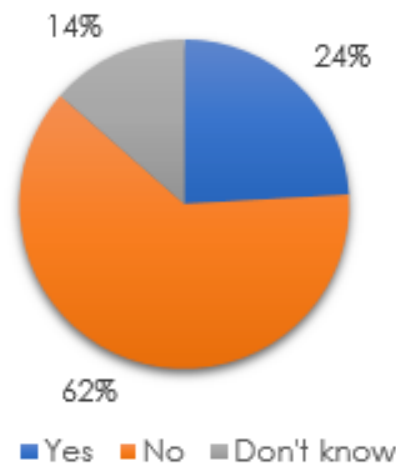


Table 5: What Is The Reality

<b>Kissing</b>	HIV cannot be transmitted through kissing. There have been no reported cases of HIV being transmitted from/by kissing <sup>31</sup>
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### Spitting

32% (n = 324) of respondents reported that they thought HIV can be passed from person to person by spitting. 36% (n = 95) of respondents in Leinster (excluding Dublin) were most likely to think that HIV can be passed from person to person by spitting and respondents from Connacht/Ulster (24%, n = 44) were the least likely. 34% of respondents from Munster thought that HIV could be transmitted through spitting, compared with 30% of Dublin respondents.

<sup>30</sup> [https://www.giveblood.ie/Become\\_a\\_Donor/Keeping\\_Blood\\_Safe/Safety/Safety.html](https://www.giveblood.ie/Become_a_Donor/Keeping_Blood_Safe/Safety/Safety.html)

<sup>31</sup> <http://www.aidsmap.com/Kissing/page/1323577/>

Figure 11: HIV be Passed from Person to Person by Spitting

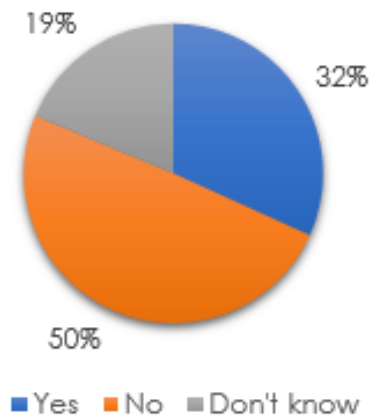


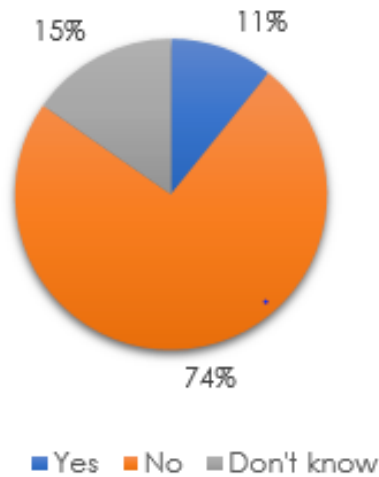
Table 6: What is the Reality

<b>Spitting</b>	HIV cannot be transmitted through spitting saliva <sup>32</sup> .
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**Coughing or Sneezing**

11% (n = 109) of respondents reported that they thought HIV can be passed from person to person through a cough or sneeze. Almost double the proportion of 18 – 24-year old's (19%, n = 19) think that HIV can be transmitted through a cough or sneeze compared with those aged 25+ (10%, n = 90).

Figure 12: Can HIV be Passed from Person to Person by Coughing or Sneezing



<sup>32</sup> <http://www.aidsmap.com/HIV-transmission/page/3005817/>

Table 7: What is the Reality

<b>Coughing or sneezing</b>	HIV cannot be transmitted through coughing or sneezing <sup>33</sup> .
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### Sharing a Glass

10% (n = 101) of respondents reported that they thought HIV can be passed from person to person by sharing a glass. A larger proportion of the younger 18 – 34-year old's (14%, n = 41) people have this misconception compared with for those over 35+ (8%).

Figure 13: Can HIV be Passed from Person to Person by Sharing a Glass

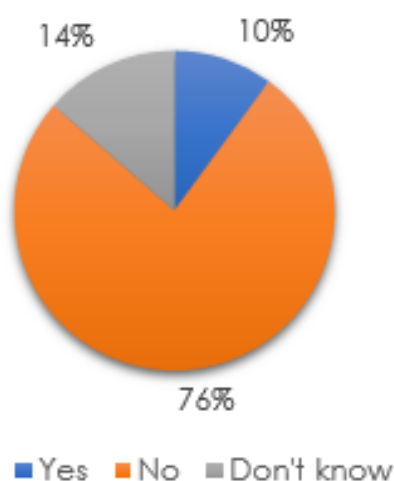


Table 8: What is the Reality

<b>Sharing a glass</b>	HIV cannot be transmitted through sharing a glass <sup>34</sup> .
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### Through a Public Toilet Seat

9% (n = 91) of respondents reported that they thought HIV can be passed from person to person through a public toilet seat. Three times the proportion of the younger 18 – 34-year-old age group (18%, n = 53) had this misconception compared with 6% (n = 40) of the older 35+ age groups.

<sup>33</sup> <http://www.aidsmap.com/Transmission-facts/page/2258343/>

<sup>34</sup> <http://www.aidsmap.com/Transmission-facts/page/2258343/>



Figure 14: Can HIV be Passed from Person to Person Through a Public Toilet Seat

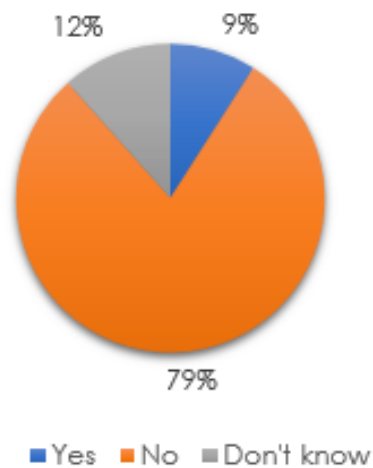


Table 9: What is the Reality

<b>From a toilet seat</b>	HIV cannot be transmitted through using a toilet seat <sup>35</sup> .
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### Attitudes to People Who are Living with HIV

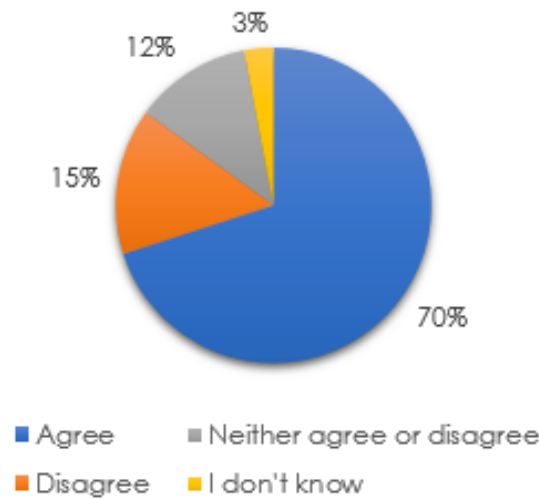
Survey respondents were asked whether they agree or disagree with a number of statements regarding people who are HIV positive.

#### Neighbour

70% (n = 709) of respondents agreed that if they found out their neighbor was HIV positive it would not change their relationship with them. Females (75%, n = 387) were more likely to agree with this than males (64%, n = 318). 18 – 24-year-old respondents (83%, n = 84) are also more likely to agree than 25+ year old respondents (68%, n = 622).

<sup>35</sup> <http://www.aidsmap.com/Transmission-facts/page/2258343/>

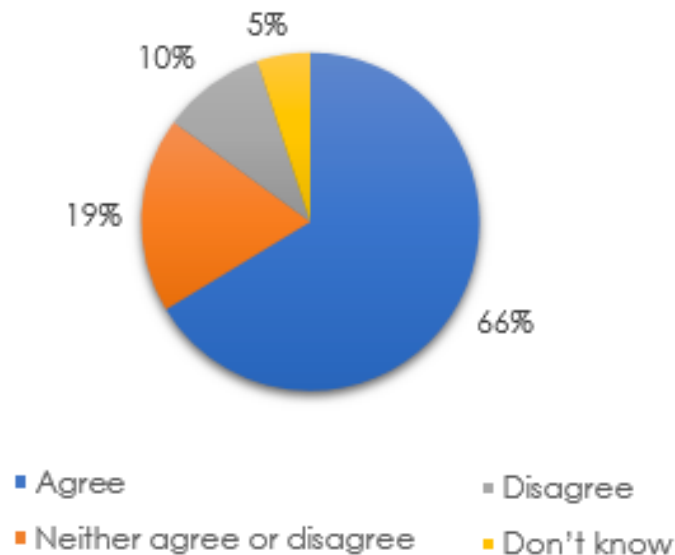
Figure 15: If I Found Out my Neighbour was HIV Positive, it Wouldn't Change my Relationship with Them



### Work Colleague

66% (n = 669) of respondents reported that they would feel comfortable working with a colleague that they knew was HIV positive. The 45 – 54 age group (77%, n =140) reported feeling the most comfortable working with a colleague that they knew to be HIV positive compared to the 65+ age group (55%, n = 100) who reported being the least comfortable. The 18 – 34-year-old age group reported as being generally around the average (66%) for being comfortable with a work colleague who is HIV positive.

Figure 16: I Would Feel Comfortable Working with a Colleague who is HIV Positive

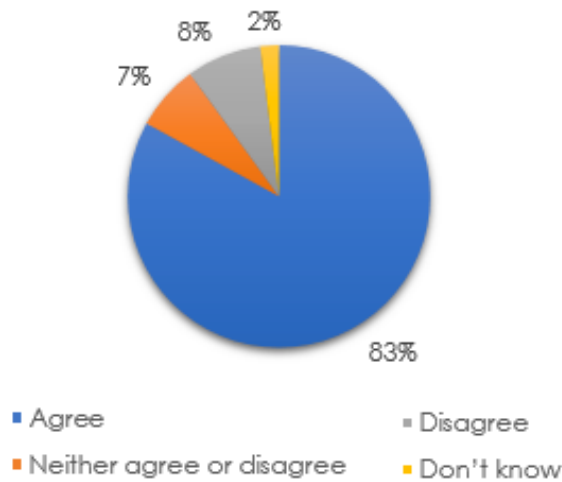


### HIV and Cancer Sufferer's Deserve the Same Respect

83% (n = 841) respondents agreed that they believed that people with HIV deserve the same level of support and respect as people with cancer. Respondents in

Connacht/Ulster (88%, n = 160) were the most likely to agree and respondents in Dublin (79%, n = 224) were the least likely to agree with the statement.

Figure 17: HIV and Cancer Sufferer's Deserve the Same Respect



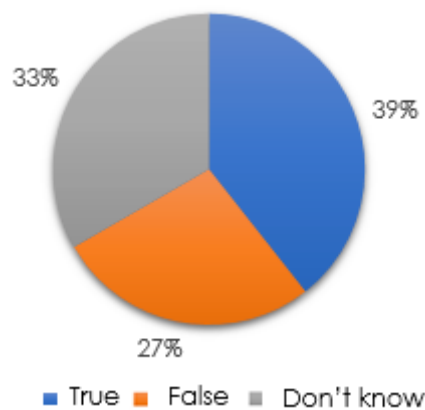
### Belief's & Attitudes Regarding HIV

Survey respondents were asked to rate whether they believed a number of statement regarding HIV were true or false.

#### Mother to Fetus HIV Transfer

39% (n = 395) of respondents responded that it is true that there is no effective way of preventing a pregnant mother with HIV from passing HIV on to her baby during pregnancy and childbirth. This view was held by 56% (n = 57) of respondents in the 18 – 24-year-old age group compared with 38% (n = 346) of respondents aged 25+.

Figure 18: There is no Effective Way of Preventing a Pregnant Mother with HIV from Passing HIV on to her Baby During Pregnancy and Childbirth

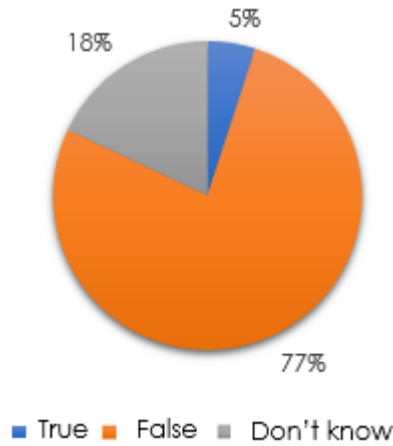


#### Life Expectancy on HIV Diagnosis

5% (n = 51) of respondents responded that it is true that if someone become infected with HIV they will probably die within three years. This view was twice as common in

the 25 – 34-year-old age group (10%, n = 19) as compared with an average of 3% (n = 25) at all other ages groups.

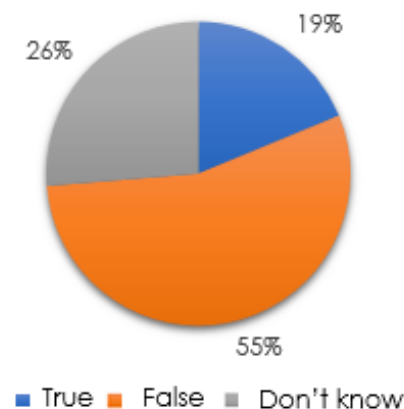
Figure 19: If Someone in Ireland Becomes Infected with HIV They will Probably Die within Three Years



### Risk of Transmitting HIV through Sex if Someone is Taking Effective HIV Treatment

Only 19% (n = 192) of respondents reported correctly that it is true that the risk of someone who is taking effective HIV treatment passing on HIV through sex is extremely low. This figure of 19% is relatively similar when compared across sex, gender and location.

Figure 20: The Risk of Someone who is Taking Effective HIV Treatment Passing on HIV Through Sex is Extremely Low

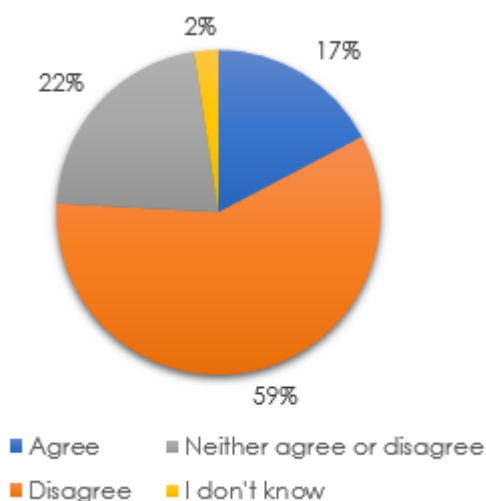


### Source of HIV Infection

Survey respondents were asked whether they agreed with two statements regarding HIV.

17% (n = 172) of respondents agreed that they don't have much sympathy for people with HIV if they were infected through unprotected sex. Survey respondents over the age of 55 were twice as likely to agree with this statement (26%, n = 85) than those between the ages of 18 – 54 (13%, n = 90).

Figure 21: I Don't Have Much Sympathy for People with HIV if They were Infected Through Unprotected Sex



### Sex Education Regarding HIV in Schools

There was almost universal agreement (93%) with the statement “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”. This agreement is relatively similar across gender and age groups.

### Irish Attitudes Compared to the U.K

This section provides a comparison between the total population responses between this survey carried out in Ireland and the HIV: Public Knowledge and Attitudes 2014 UK which was the last knowledge and attitudes survey carried out in the UK. The UK survey had 1992 respondents split across gender, age, social class and region, similar to the Irish survey, with weighting applied to ensure final data was as representative as possible of the UK population.

### Knowledge of People Living with HIV

Proportionally more respondents living in the UK (+4%) report that they know someone who is living with HIV than respondents from the Republic of Ireland.

Table 10: Personal Knowledge of Someone With HIV

Yes	Ireland	U.K
<b>Do you personally know someone with HIV</b>	6%	10%

## Knowledge of HIV Transmission

Irish survey respondents are more likely to think correctly that HIV can be transmitted from person to person by all stated means compared to British people. Proportionally more Irish respondents think that HIV can be passed from person to person by sharing needles (+23%), sex without a condom between a man and a woman (+13%), sex without a condom between two men (+15%), by standing on a used needle (+32%) and by biting (+34%) compared to British respondents.

Proportionally more Irish respondents than British respondents report incorrectly that they think it is possible that HIV can be passed between people from a blood transfusion in Ireland/UK (+12%). Double the proportion or more Irish people also think that HIV can be transmitted by spitting (+16%), sharing a glass (+5%), coughing or sneezing (+6%) and from a public toilet seat (+5%) compared to British people.

Table 11: Can HIV be Passed From Person To Person in the Follow Ways

<b>Yes (correct response to the question)</b>	<b>Ireland</b>	<b>U.K</b>
<b>By sharing needles or syringes</b>	98%	75%
<b>Sex without a condom between a man and a woman</b>	96%	83%
<b>Sex without a condom between two men</b>	96%	81%
<b>By standing on a used needle</b>	84%	52%
<b>Biting</b>	70%	36%
<b>Yes (<u>incorrect</u> response to the question)</b>	<b>Ireland</b>	<b>U.K</b>
<b>A blood transfusion in Ireland/UK</b>	56%	44%
<b>Spitting</b>	32%	16%
<b>Kissing someone</b>	24%	15%
<b>Coughing or sneezing</b>	11%	5%
<b>Sharing a Glass</b>	10%	5%
<b>From a public toilet seat</b>	9%	4%

## Attitudes to People who are Living with HIV

Attitudes toward people with HIV in Ireland and Britain are broadly alike with respondents in both countries agreeing with each of the statements at similar levels. Respondents in both countries agreed most strongly that people with HIV deserve the same level of support and respect as people with cancer and were least likely to agree that my employer should tell me if one of my work colleagues is HIV positive.

Table 12: Rate the Following Statements about People with HIV

<b>Agree</b>	<b>Ireland</b>	<b>U.K</b>
<b>People with HIV deserve the same level of support and respect as people with cancer</b>	83%	79%
<b>If someone in my family told me they were HIV positive, it would not change my relationship with them</b>	72%	72%
<b>If I found out my neighbour was HIV positive, it would not change my relationship with them</b>	70%	67%
<b>I would feel comfortable working with a colleague who is HIV positive</b>	66%	67%
<b>My employer should tell me if one of my work colleagues is HIV positive</b>	36%	37%

### Beliefs Regarding HIV

Irish and British people in general respond similarly in their beliefs regarding HIV. There is a small proportional difference in the belief that if someone becomes infected with HIV they will probably die within three years with almost twice the proportion of UK respondents reporting that they believed it to be true (+4%).

Table 13: Rate Whether the Following Statements about HIV are True or Untrue

<b>True</b>	<b>Ireland</b>	<b>U.K</b>
<b>There is no effective way of preventing a pregnant mother with HIV from passing HIV on to her baby during pregnancy and childbirth</b>	39%	36%
<b>The risk of someone who is taking effective HIV treatment passing on HIV through sex is extremely low</b>	19%	20%
<b>If someone in Ireland/UK becomes infected with HIV they will probably die within three years</b>	5%	9%

British respondents report a slightly higher level of agreement (+6%) when asked if they don't have much sympathy for people with HIV if they were infected through unprotected sex compared to Irish respondents. Although a large proportion of both nationalities agreed that all young people should be thought about HIV during school to ensure they have a good understanding of the condition before they leave school, Irish respondents were slightly more likely to agree with this statement than their British counterparts (+8%).

Table 14: Rate the Following Statements about HIV

Agree	Ireland	UK
<b>I don't have much sympathy for people with HIV if they were infected through unprotected sex</b>	17%	23%
<b>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</b>	93%	85%

## Summary

The findings of this survey produce a map of knowledge gaps and misconceptions in relation to HIV, and attitudes to people living with HIV in Ireland. With a detailed understanding of types of misinformation and knowledge gaps, and of who is most likely to exhibit them, comes an opportunity to target information and prevention initiatives and anti-stigma campaigns in the most effective way possible.

We know from this survey, that older respondents have more correct knowledge around what causes HIV with younger respondents more likely to think that HIV can be transmitted through kissing someone, coughing or sneezing, sharing a glass or sharing a toilet seat. Males and older respondents are less likely to feel comfortable interacting with a neighbour or colleague that they know has become infected with HIV compared to females and younger respondents. While younger respondents may be less informed regarding how HIV is transmitted, they are less likely to have stigmatising attitudes towards people who contracted HIV through unprotected sex. Knowledge of, and attitudes to HIV in Ireland are broadly similar to the UK. Irish respondents are more likely to correctly report that HIV is transmitted by sharing needles and unprotected sex but they are also more likely to report incorrectly that HIV is transmitted through spitting, kissing, coughing and using a public toilet seat compared to their British counterparts.

The need for a targeted, accessible and age-appropriate campaign is apparent in order to tackle misinformation especially among the younger cohort groups.



## 5 Findings from the People Living with HIV Stigma Survey

### Stigma Survey

#### Introduction

This section outlines the findings from the People Living with HIV Stigma Survey. Following a detailed demographic profile of the respondents to the survey are the following themes:

- Disclosure of HIV status, including how and why respondents disclose their status.
- Attitudes regarding stigma and HIV, where respondents provide feedback on their own attitudes and to their perception of others attitudes to HIV stigma.
- The section is completed with respondents providing feedback regarding experience that they have had as a result of living with HIV.

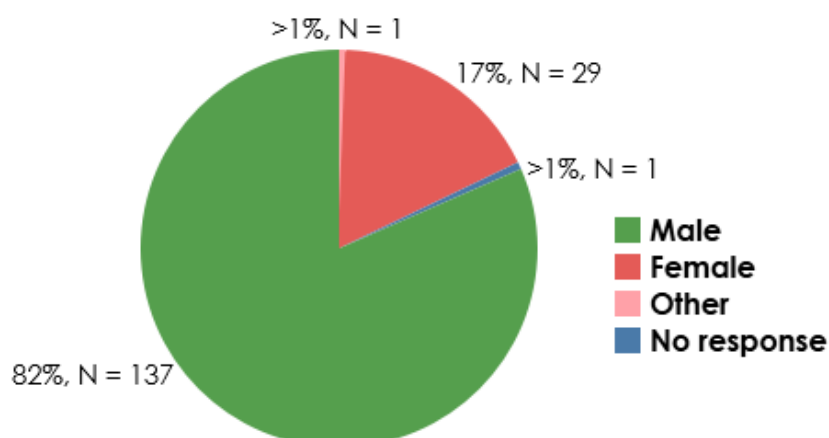
#### Profile of Respondents

The survey was undertaken by 168 people who were over the age of 18, living in the Republic of Ireland and who identified as being HIV positive.

#### Gender

Respondents were asked to identify their gender. Of those that completed the survey males accounted for 82% (n = 137) of respondents and females accounted for 17% (n = 29). One respondent reported their gender as other (>1%). This gender split roughly reflects the gender split within the general HIV positive population<sup>36</sup>.

Figure 22: Gender of Respondents



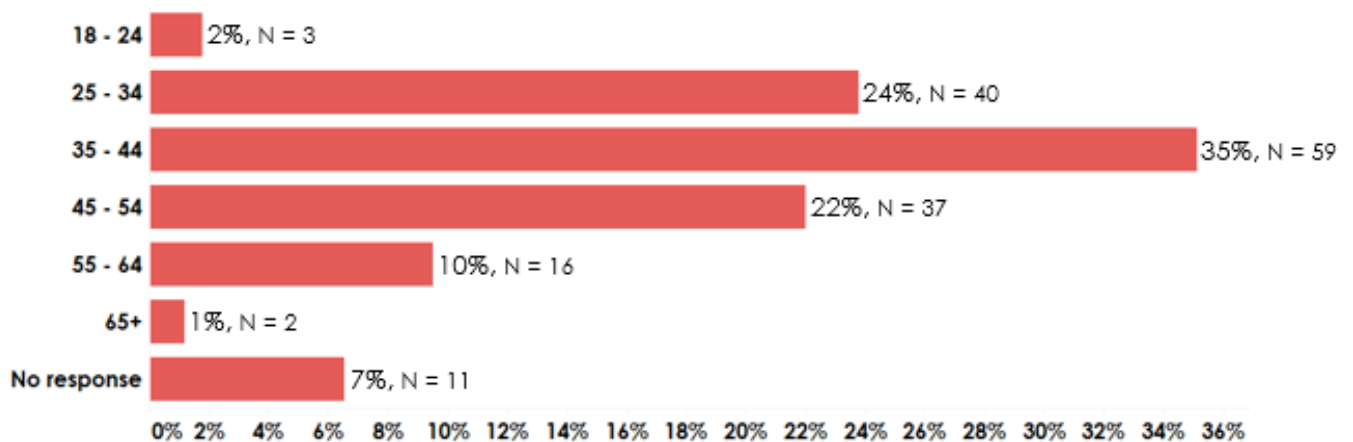
#### Age

A large majority of respondents fell between the ages of 25 – 54 (81%, n = 136), with a median age of 40 years for the sample. People aged 18 to 24-years (2%, n = 3) and 65+ (1%, n = 2) account for the smallest proportion of respondents. 10% (n = 16) of respondents are between the ages of 55 – 64 and 7% (n = 11) of respondents did not

<sup>36</sup> <https://www.hpsc.ie/a-z/hivstis/hivandaids/hivdata/File,15862,en.pdf>

report their age. The age range of respondents roughly reflects that found in the general HIV positive population<sup>37</sup>.

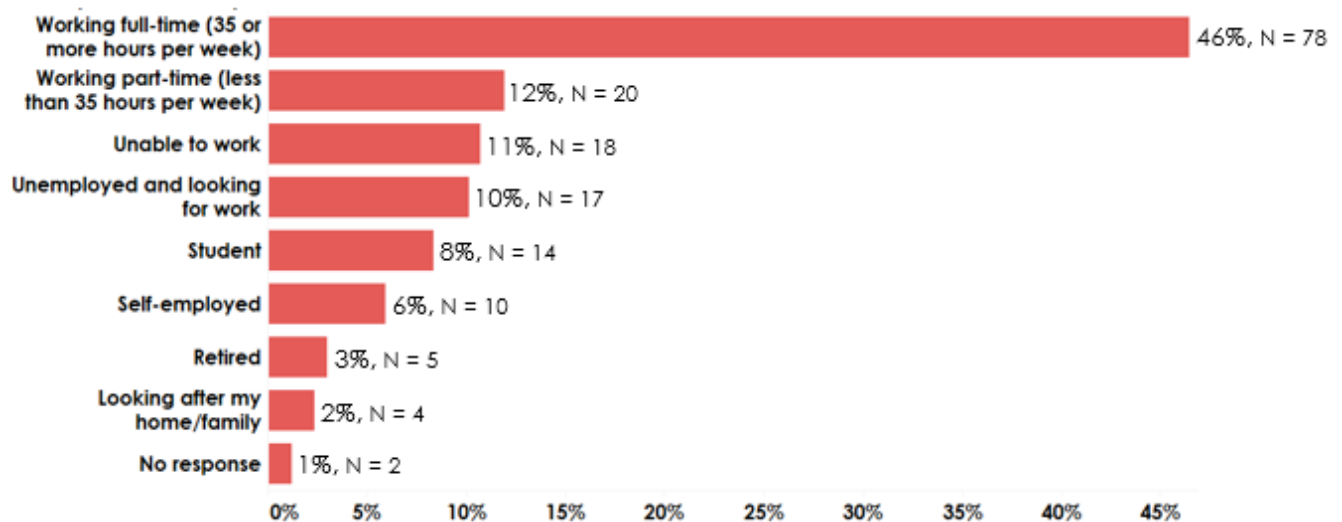
Figure 23: Age Range of Respondents



### Current Employment Status

The majority of respondents reported that they were working full time, part-time or were self-employed (64%, n = 108). 11% (n = 18) stated they were unable to work, 10% (n = 17) was unemployed and looking for work, while 8% (n = 14) were students. 5% (n = 9) were retired or looking after their home/family.

Figure 24: Respondents Current Employment Status

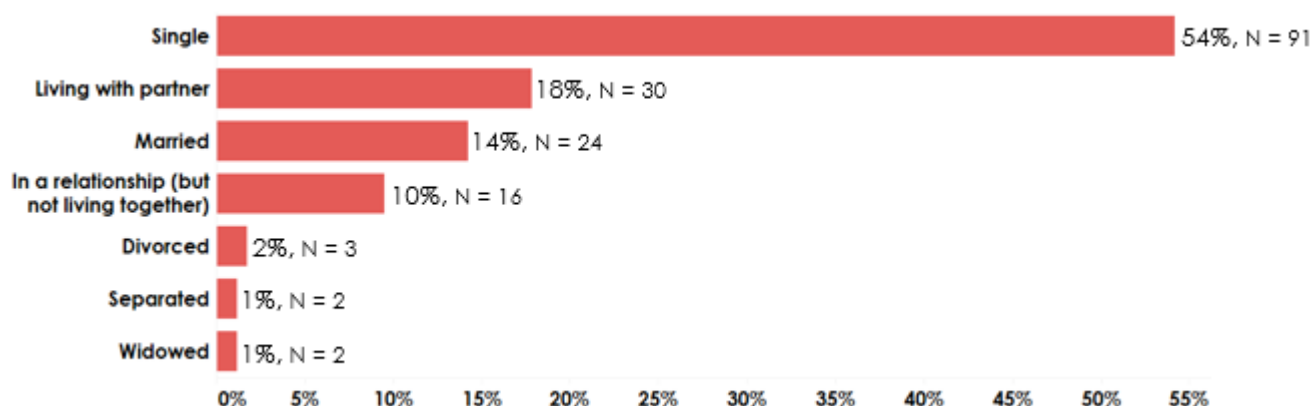


### Current Relationship Status

The majority of respondents reported that they are single (54%, n = 91) this compares with 38% of the general population over 18 years old in the 2016 census. 42% (n = 70) reported that they were in some form of relationship i.e. living with a partner, married, in a relationship, while 4% (n = 7) are divorced, separated or widowed.

<sup>37</sup><https://www.hpsc.ie/a-z/hivstis/hivandaids/hivdata/File,15862,en.pdf>

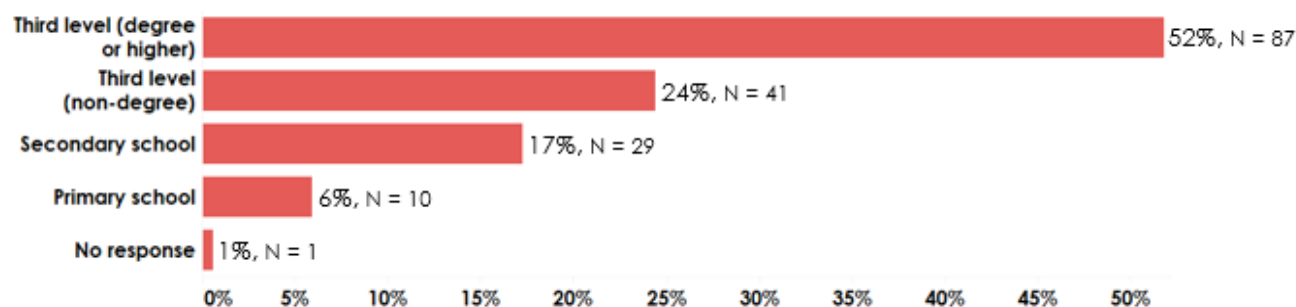
Figure 25: Current Relationship Status



### Educational Level

A large majority of respondents were educated to third level or higher (76%, n = 128), 17% (n = 29) educated to secondary school level and 6% (n = 10) were educated to primary level.

Figure 26: Respondents Current Level of Education

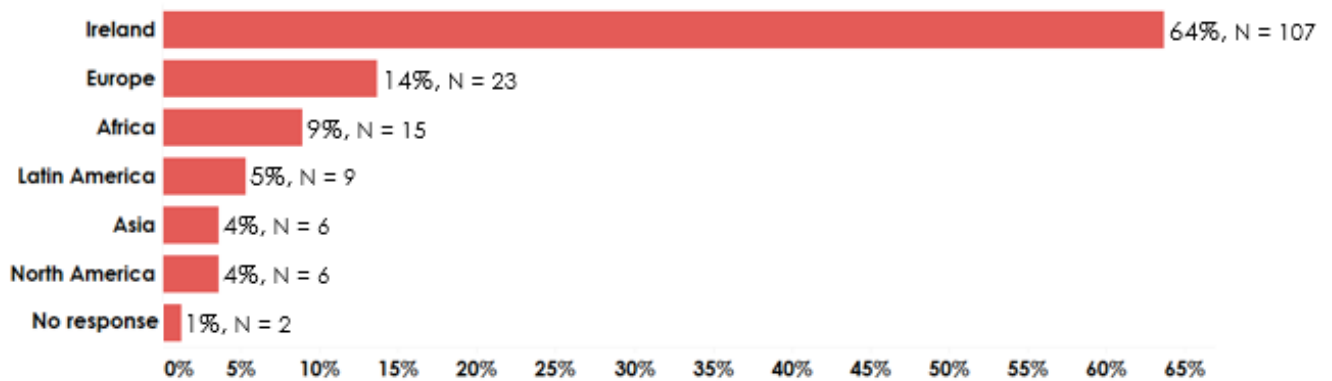


### Place of Birth

The majority of respondents were born in the Ireland (64%, n = 107) with 14% (n = 23) born in Europe and 22% (n = 36) coming from the rest of the world<sup>38</sup>.

<sup>38</sup> This differs from birth place data on the whole population - the 2011 census (cso.ie) reported that nationalities living in Ireland were: Irish (87%), European (9%), African (1%), Latin American (>1%), North American (>1%), Asian (1.5%).

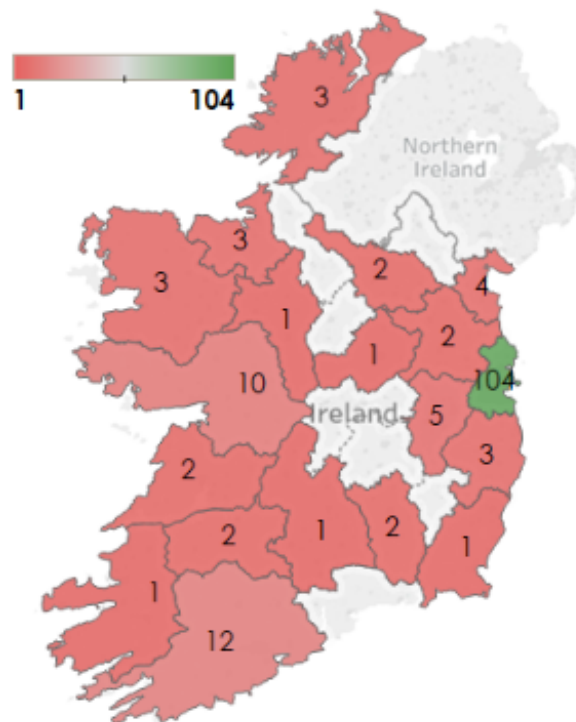
Figure 27: Respondents Place of Birth



### County of Residence

The majority of survey respondents come from Dublin (62%, n = 104). The remaining respondents come from various counties around Ireland as shown below. 4% (n = 6) of respondents choose not to divulge their county of residence.

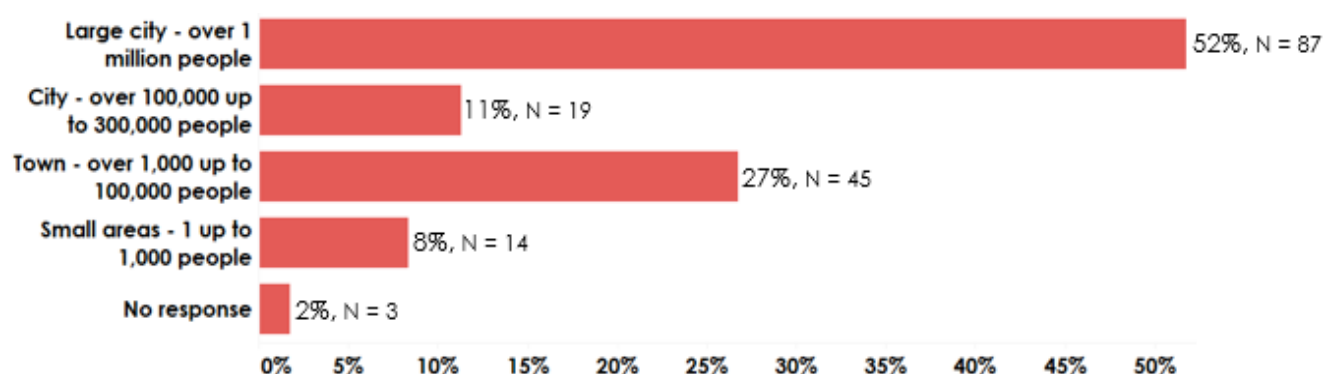
Figure 28: Respondents County of Residence



### Where Respondents Live

More than half of respondents reported living in a large city with over a million people (52%, n = 87). 38% (n = 64) reported living in an area with between 1,000 and 300,000 residents and 8% (n = 14) reported living in small areas of between one and 1,000 people.

Figure 29: Description of Respondents Area of Residence

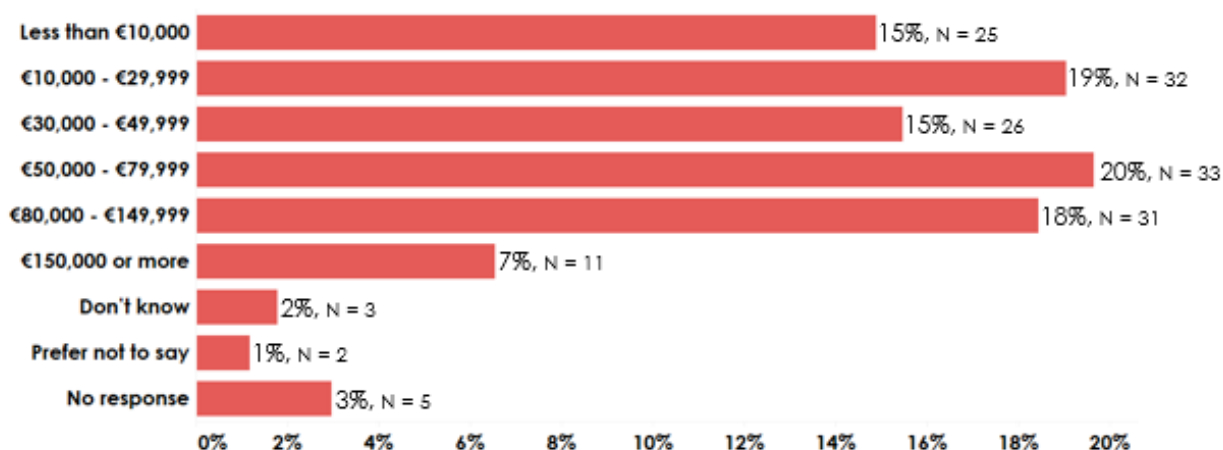


### Household Income

Respondents were asked in which of the following bands would they place their household's combined yearly income. Household income is the combined incomes of all people sharing a particular house. It includes every form of income, e.g. wages, benefits etc. before tax. A third of respondents reported that their household annual income was less than €30,000 (34%, n = 57). 35% (n = 592) of respondents reported that their household income was between €30,000 and €79,999 and 25% (n = 42) reported their annual household income was €80,000 or more. Average household income was €40,000 - €49,999.

Figure 9 illustrates that at least 15% (n = 25) of respondents are living in households at risk of poverty<sup>39</sup> as they reported their household income as less than €10,000.

Figure 30: Household Income



### Personal Income

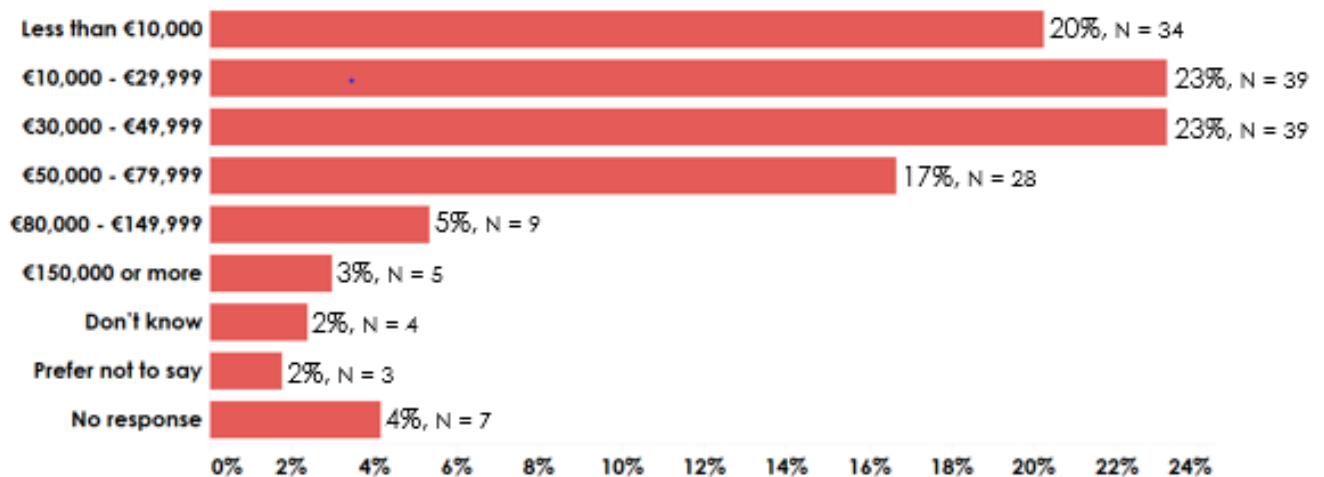
Respondents were asked about their personal Income. Personal income includes every form of income, e.g. wages, benefits etc., before tax. 43% (n = 73) of respondents reported that their personal annual income was less than €30,000. 40% (n

<sup>39</sup> People or households are considered to be at risk of poverty when their income is less than a particular threshold. In the EU, the threshold has been set at 60% of the median income. In 2015 median income reached €20,000 per annum, this means that the poverty threshold in 2015 was €12,000. <http://www.eapn.ie>

= 67) reported that their personal income was between €30,000 and €70,999 and 8% (n = 14) reported their personal income was €80,000 or more. Average personal income was €30,000 - €39,999, this compares to €28,500<sup>40</sup>, the median personal income in the general Irish population in 2015.

Figure 10 suggests that at least 20% (n = 34) of respondents are at risk of poverty<sup>41</sup> as they reported their personal income as being less than €10,000.

Figure 31: Personal Income



## HIV Diagnosis

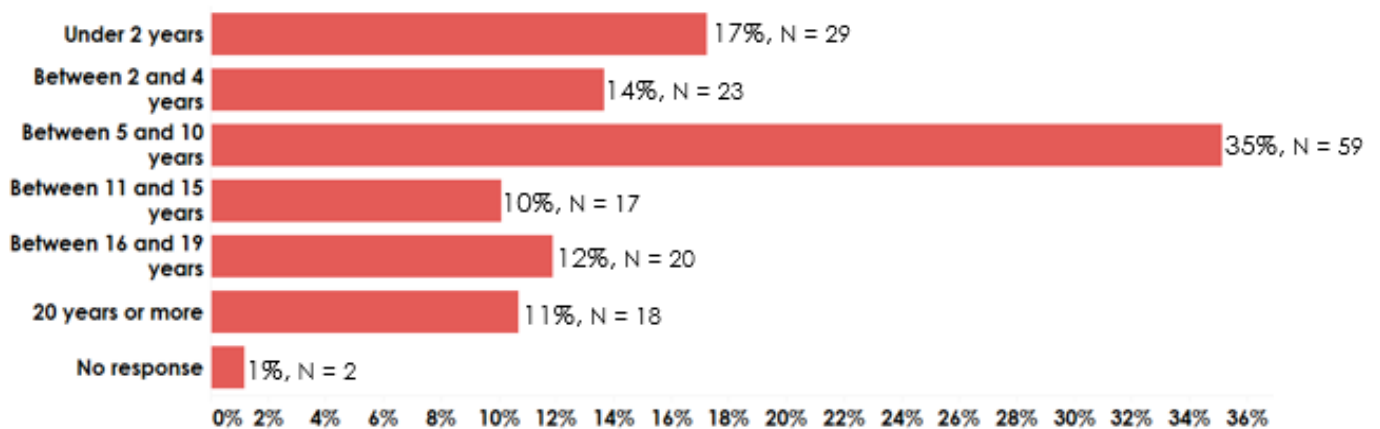
### When were Respondents Diagnosed with HIV

Almost half of respondents were diagnosed with HIV between two and ten years ago (49%, n = 72). 17% (n = 29) were diagnosed under two years ago. 33% (n = 55) were diagnosed 11 years ago or more. The median for which time-band for respondents were likely to be diagnosed in was between five and ten years.

<sup>40</sup> <http://www.cso.ie/en/statistics/earnings/>

<sup>41</sup> People or households are considered to be at risk of poverty when their income is less than a particular threshold. In the EU, the threshold has been set at 60% of the median income. In 2015 median income reached €20,000 per annum. This means that the 60% at risk of poverty threshold in 2015 was €12,000. <http://www.eapn.ie>

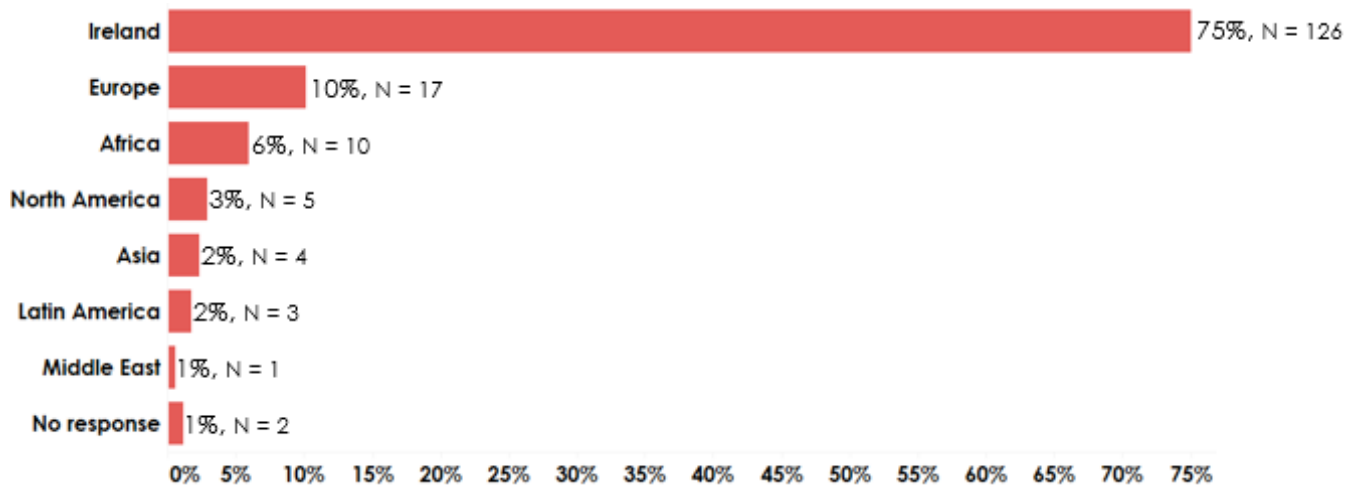
Figure 32: When were Respondents Diagnosed With HIV



### Place of Diagnosis

Three quarters of respondents were diagnosed in Ireland (75%, n = 126). 10% (n = 17) were diagnosed in Europe, 6% (n = 10) were diagnosed in Africa and 8% (n = 13) were diagnosed in the rest of the world with 1% (n = 2) not providing a response to where they were diagnosed.

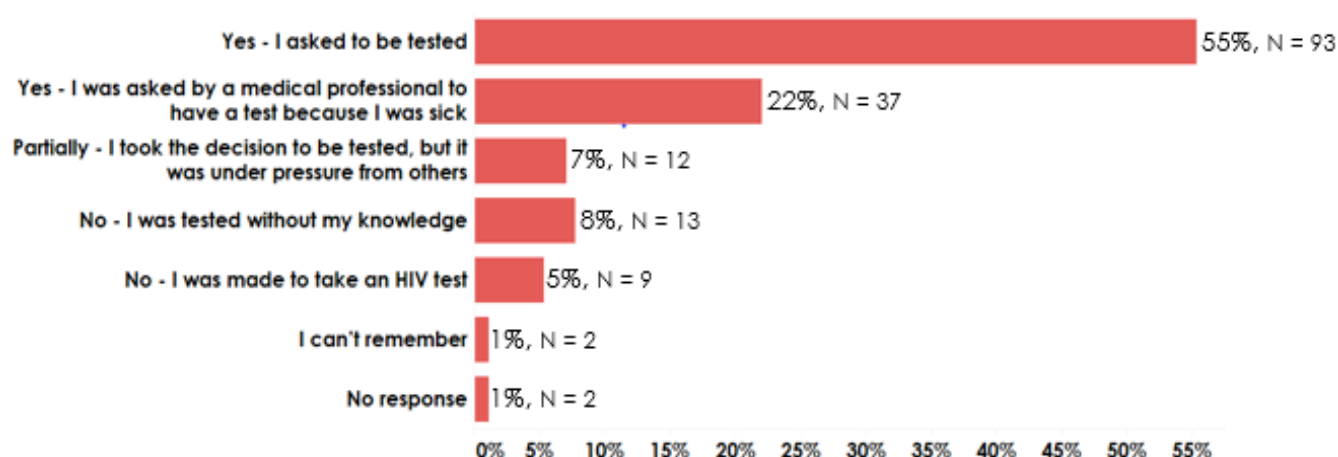
Figure 33: Where Respondents were Diagnosed With HIV



### Whether Respondents Chose to be Tested for HIV

A large majority of respondents reported that they asked to be tested themselves or were asked to take a test by a medical professional because they were sick (77%, n = 130). 13% (n = 22) were either tested without their knowledge or made to take a HIV test. Out of a total of 13 people who were tested for HIV without their knowledge, 10 were diagnosed in the Republic of Ireland and one was diagnosed in Africa, Europe and the Middle East respectively. Out of a total of nine people who were made to take a HIV test, six were diagnosed in Ireland, two were diagnosed in Africa and one was diagnosed in Europe.

Figure 34: How Respondents Choose to be Tested for HIV



## Disclosure of HIV Status

### Have Respondents Disclosed their HIV Status?

Respondents were asked whether had they told people about their HIV status? The vast majority of respondents (92%, n = 119) to whom the question was applicable<sup>42</sup> reported that they had disclosed their status to all or some of their partners/spouse/boyfriend or girlfriend. 88% (n = 110) to whom the question was applicable had disclosed their HIV status to all or some health professionals, 79% (n = 112) had disclosed to all or some friends and 68% (n = 99) had disclosed to some or all of their immediate family (children/parents/guardians).

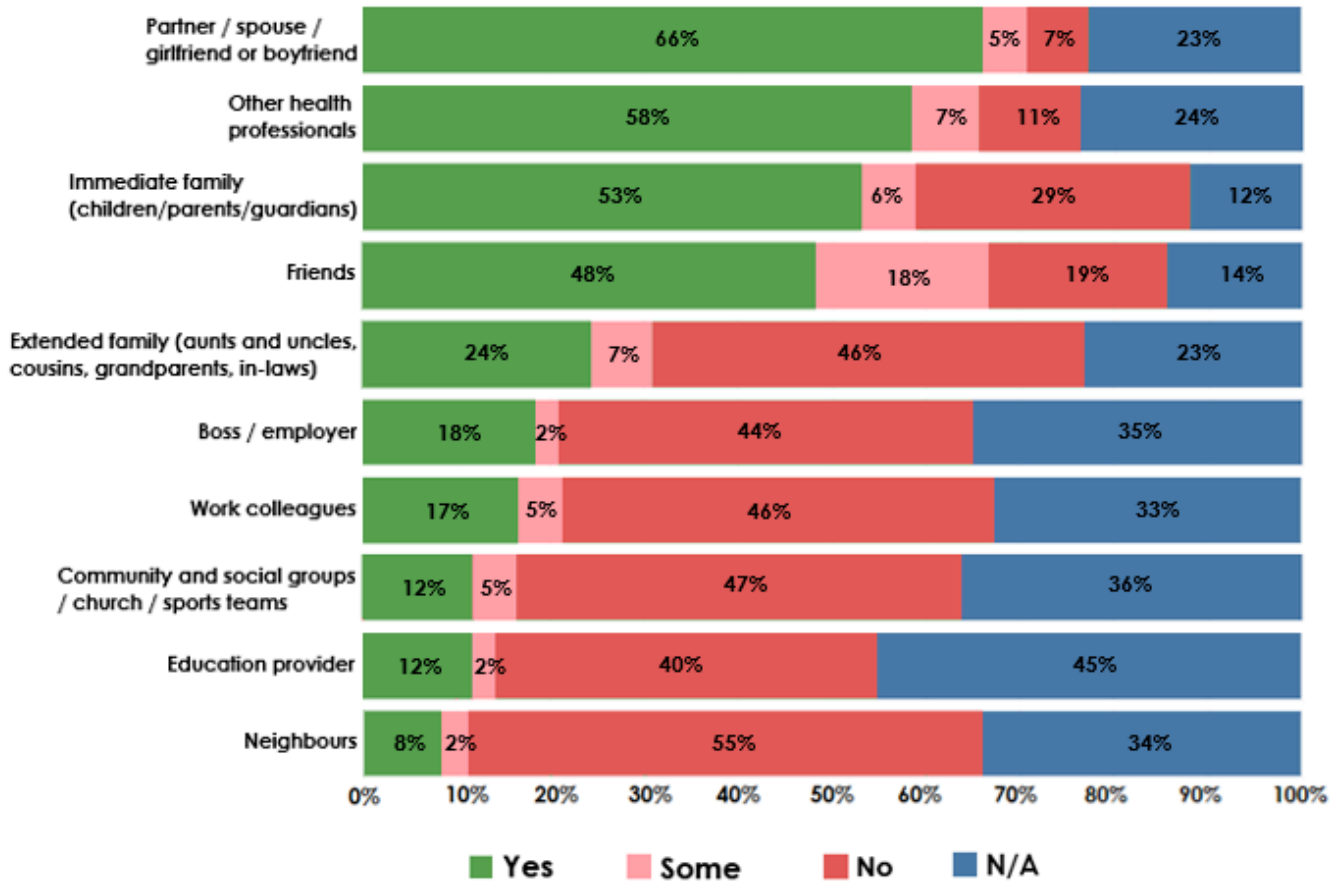
A clear majority of respondents (83%, n = 91) to whom the question was applicable reported that they had not disclosed their HIV status to their neighbours. 76% (n = 68) to whom the question was applicable had not disclosed their HIV status to work colleagues, 74% (n = 78) had not disclosed their status to community and social groups/church/sports teams, 74% (n = 67) had not disclosed their status to educational providers, 68% (n = 73) had not disclosed their status to their boss/employer and 59% (n = 75) had not disclosed their status to their extended families (aunt and uncles, cousins, grandparents, in-laws).

Respondents are more likely to disclose their HIV status to their partner, close family members, health professionals and friends, at least 68% of respondents to whom the question was applicable had disclosed their HIV status to all or some of these groups. Respondents were most likely not to disclose their HIV status to their neighbours, work colleagues, community/social groups, education providers, their boss/employer and their extended family at least 59% of respondents to whom the question was applicable had not disclosed their HIV status to these groups.

<sup>42</sup> Some respondents stated the question was not applicable to them, this is likely to be as they did not have a relationship with the person or service in question.

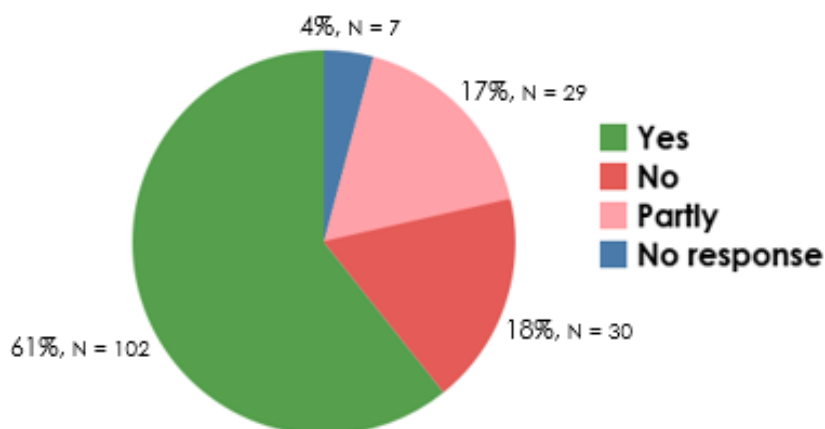


Figure 35: Did Respondents Disclose their HIV Status to The Following Groups



Respondents were also asked that if they did not tell some people was this because they were afraid that they would be judged or treated differently. The majority of respondents reported that they did not disclose their HIV status to some people as they were afraid or partly afraid that they would be judged or treated differently (79%, n = 132). 17% (n = 29) responded that a fear of being judged or treated differently did not impact their disclosure decisions.

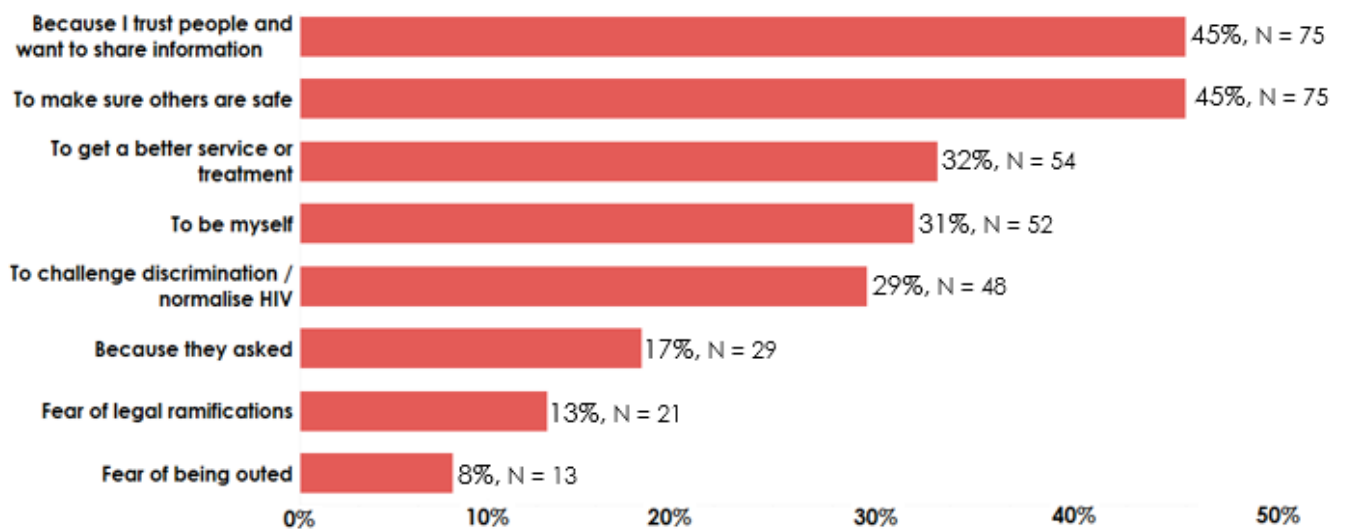
Figure 36: If Respondents had not Disclosed their HIV Status was this Because they were Afraid they would be Judged or Treated Differently



## Why Disclose HIV Status

Respondents were asked what were the most common reasons for disclosing their status. Almost half of respondents reported that they disclosed their HIV status because they trust people and want to share information about themselves (45%, n = 75) or because they wanted to make sure that others are safe (45%, n = 75). 32% (n = 54) disclosed as they are looking to get a better service or treatment, (31%, n = 52) to be themselves and (29%, n = 48) to normalise HIV. 17% (n = 29) reported they disclosed their status as someone asked them to, 13% (n = 21) for fear of legal ramifications and 8% (n = 13) for fear of being outed.

Figure 37: Why Disclose HIV Status (Respondent Choose As Many As Apply)



## Stigma and HIV

### Attitudes to People with HIV

Respondents were asked if they agreed or disagreed with a number of statements regarding people's attitude toward people with HIV.

A large majority of respondents (88%, n = 147) agreed that some people think that having HIV is shameful. Most people also 76% (n = 128) agreed that it is more stigmatising to have contracted HIV through sex or through drug use 67% (n = 113). Well over half of respondents also agreed that it is less stigmatising to have contracted HIV through a blood transfusion/beauty or health treatment or to be born with it (63%, n = 105).

Although the majority of respondents agreed that they are comfortable with their HIV status (61%, n = 103) a large minority reported that they were not comfortable with their status (26%, n = 44). The cohort most likely to disagree that they were comfortable with their HIV status are those diagnosed in the past 2 years (52%, n = 14). In contrast, only 12% (n = 2) of respondents who were diagnosed over 20 years reported not being comfortable with their status.

The majority of respondents disagreed that their own fears about their health made them hesitate to get tested (55%, n = 92), fears about how people would respond to a positive result made them hesitate to get tested (52%, n = 87).

It was also considered more stigmatising to have contracted HIV through sexual violence (53%, n = 89).

A similar proportion of respondents agreed and disagreed with the statements that: some people think I deserve HIV (agree 38%, n = 64, disagree 35% n = 58), some people think that I am brave (agree 36% n = 61, disagree 26%, n = 44) and that some people do not want to associate with them because they are HIV positive (agree 35%, n = 59, disagree 23%, n = 38).

A large minority of respondents did not know whether: some people think that I am brave (26%, n = 44) and that some people do not want to associate with them because they are HIV positive (22%, n = 37), some people think I deserve HIV (18%, n = 31) or if it is more stigmatising to have contracted HIV through sexual violence (18%, n = 31).

Figure 38: Did Respondents Agree or Disagree With The Statements

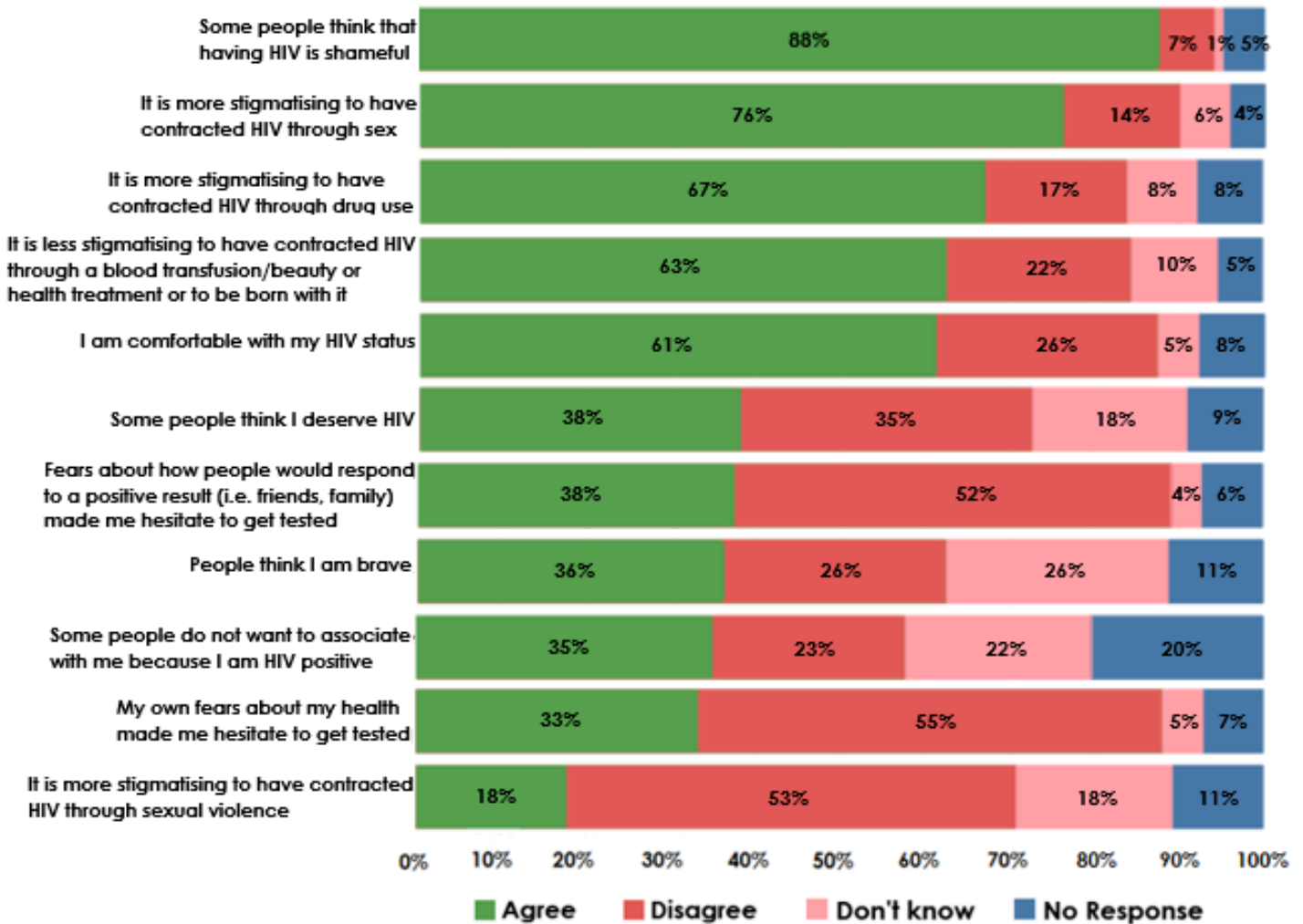


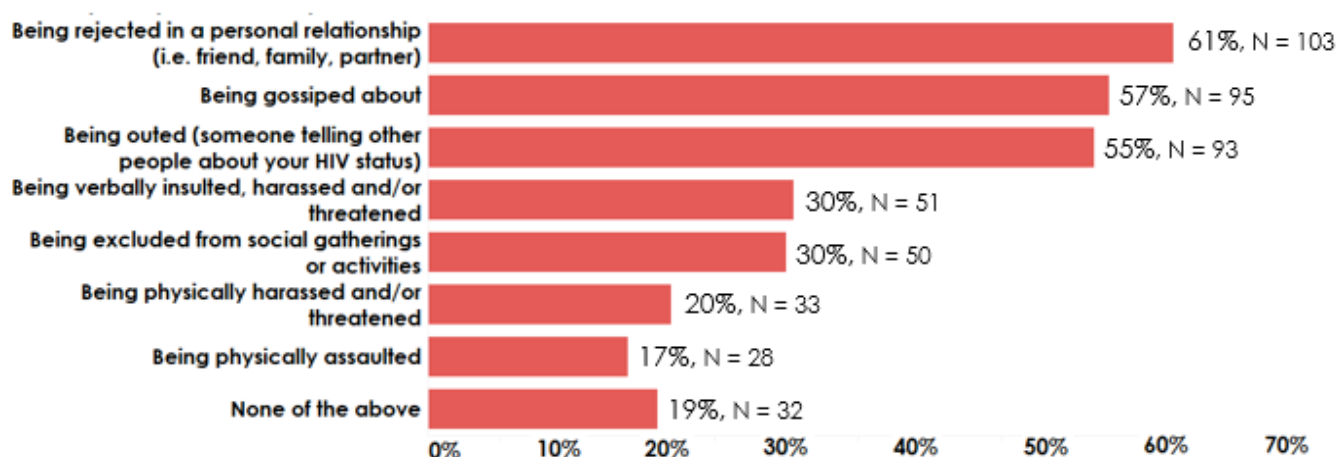
Figure 38 indicates that the majority of respondents agreed that there is stigma associated with being HIV positive, even more so if it was contracted through sex or drug use. The survey indicates that a sizeable minority are not comfortable with their HIV positive status and there is a belief among respondents that persists that some people think they deserve to have HIV.

## Fear of Negative Experiences as a Result of Being HIV Positive

Respondents were asked if they had experienced fears about a number of negative experiences happening to them because of their HIV status, over the past year. The majority of respondents reported that they had been afraid, in the last year, of being rejected in a personal relationship (61%, n = 103), being gossiped about (57%, n = 95) or being outed as HIV positive by someone else (55%, n = 93).

30% of respondents feared being verbally assaulted, harassed or threatened (n = 51) or being excluded from a social gathering (n = 50) due to their HIV status. 20% (n = 33) reported that they feared being physically threatened or harassed, 17% (n = 28) reported fear of being physically assaulted in the last year and 19% (n = 32) reported they did not fear any of these negative events happening to them.

Figure 39: In the Last Year Have Respondents Been Fearful of any of the Following Things Happening Because of their HIV Status: (Yes)



## Experiences Resulting from Being HIV Positive

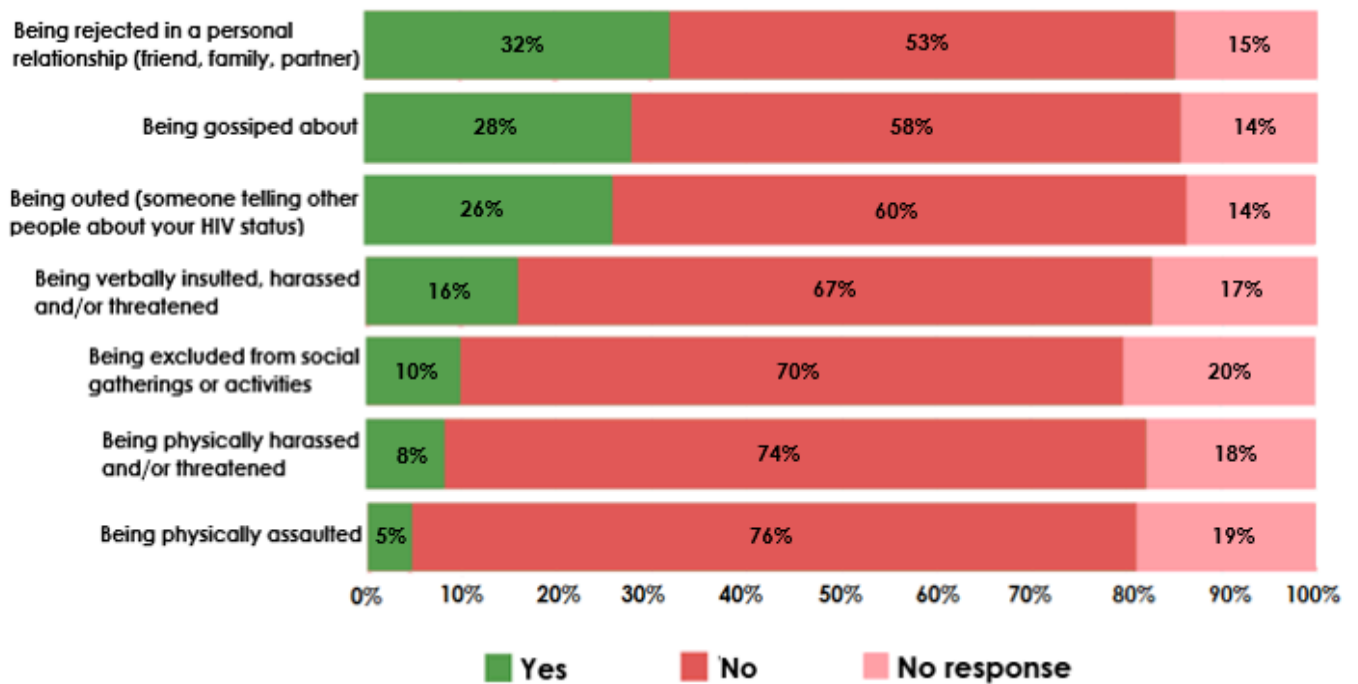
Respondents were asked if any of the experiences below happened to them because of their HIV status in the past year.

In the last year because of their HIV positive status a large minority of respondents reported that they had been rejected in a personal relationship (32%, n = 54) or that they had been gossiped about (28%, n = 47). 26% (n = 44) had their HIV status outed by someone and proportionally African respondents reported being outed more than other nationalities with 47% (n = 7) reporting that they had experienced this.

16% (n = 27) reported being verbally insulted, harassed and/or threatened, 10% (n = 17) were excluded from social activities, 8% (n = 14) were physically harassed and/or threatened and 5% (n = 8) were physically assaulted.

Respondents in the last year are most likely to have been rejected in a personal relationship, gossiped about or outed as being HIV positive by somebody else. Respondents were least likely to be physically harassed, threatened or physically assaulted.

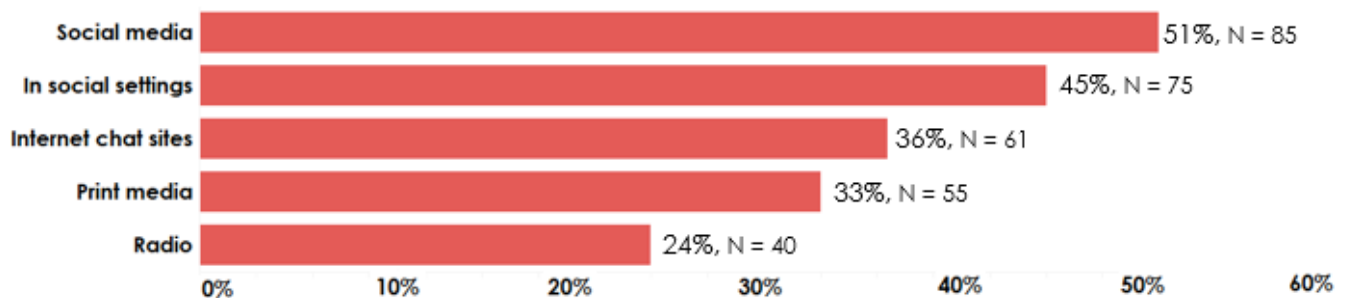
Figure 40: In the Past Year Have any of the Following Happened



### Offensive Language

Respondents were asked had they felt offended by language used in the media. The majority of respondents reported that they felt offended by language used on social media (51%, n = 85), and 45% (n = 75) reported they felt offended by language used by people in social settings. 36% (n = 61) reported that they felt offended by language on internet chat sites and in print media (33%, n = 55), while 24% (n = 40) felt offended by language used on radio.

Figure 41: Have Respondents Felt Offended by the Language Used in any of the Following:



### What Type of Language Offends People Living with HIV

114 respondents provided examples of the type of language that offended them. Of these respondents, 35 identified the use of judgmental, defamatory and stereotyped language as being offensive. Three respondents specifically highlighted joking about HIV as being offensive. The following quotes highlight people's reactions to this question:

*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*  
(Respondent 56)

*It is especially offensive when someone gets infected by someone who has HIV. Bad language is used, they say people with HIV infect those who do not have it so that they spread the disease*  
(Respondent 117)

*Africans, they spread AIDS* (Respondent 42)

21 respondents identified the use of the words 'clean/unclean/dirty' in relation to an individual's HIV status as being offensive. Three respondents highlighted the use of the terms on dating apps as being offensive:

*The use of the term "clean" on dating apps* (Respondent 56)

*It shocks me when people ask are you dirty or clean, instead of positive or negative* (Respondent 152)

*"Clean/dirty" language used to describe sero-status* (Respondent 105)

21 respondents identified the most offensive language as relating to inaccurate information. Four respondents highlighted the implication that if a person was HIV positive they must have been promiscuous as being particularly offensive:

*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* (Respondent 65)

*Ignorant and uninformed language that makes you feel you are (being HIV positive) less as a person* (Respondent 123)

*Statements that insinuate HIV is only passed by gay men*  
(Respondent 149)

Seven respondents stated that it is offensive when people mix up or involuntarily using the terms 'HIV' and 'AIDS' interchangeably:

*Calling it (HIV)AIDS when it's not as was done on Prime Time<sup>43</sup> a few weeks ago* (Respondent 69)

*People's lack of understanding of HIV, and putting HIV and AIDS in the same category* (Respondent 137)

*I get offended when people confuse HIV with AIDS* (Respondent 162)

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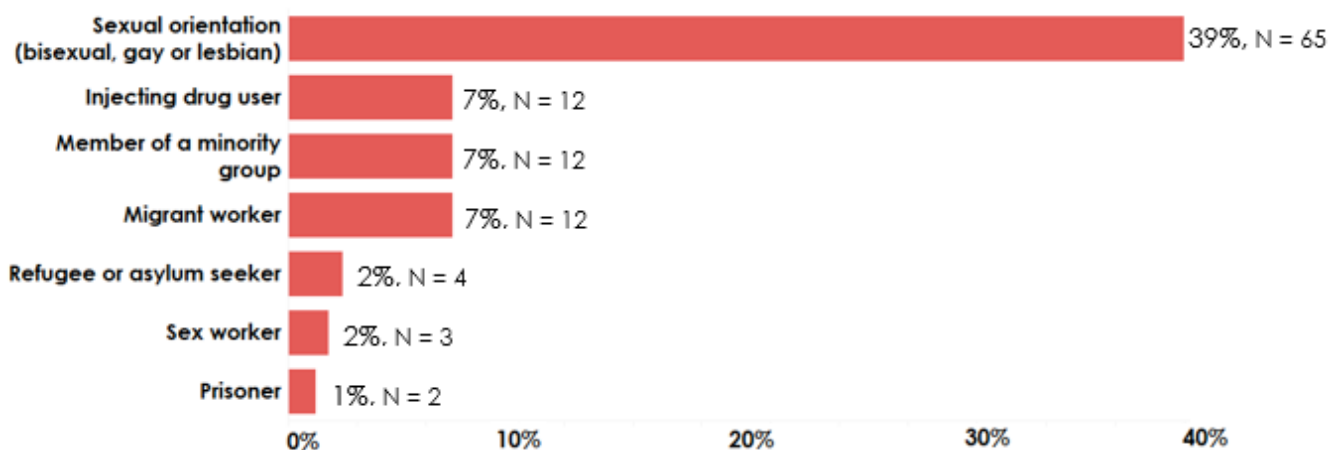
<sup>43</sup> Prime Time - A national Irish current affairs television programme

## Double Stigma

Respondents were asked if they experienced stigma and/or discrimination for reasons other than their HIV status.

The majority of respondents (65%, n = 110) reported that they had experienced stigma for reasons other than their HIV status. The most frequently reported reason for experiencing stigma other than HIV was sexual orientation with 39% (n = 65) respondents reporting having experienced this form of stigma. Seven percent had experienced stigma for being either a member of a minority group (n = 12), a migrant worker (n = 12) or an injecting drug user (n = 12) and a small minority had experienced stigma as a result of being a refugee or asylum seeker (2%, n = 4), a sex worker (2%, n = 3) or a prisoner (1%, n = 2).

Figure 42: Have Respondents Experienced Stigma for Reasons other than their HIV Status (Choose One)



## Respondents Experiences of Being HIV Positive

### Respondents Feelings about their HIV Status

Respondents were asked in the past year, what were their most common feelings in relation to their HIV status. This question highlighted that an HIV diagnosis brings with it both positive and negative feelings and experiences. The majority of respondents reported that they felt more open minded and compassionate of others (57%, n = 96) and that they are grateful for the people who have supported them in dealing with being HIV positive (53%, n = 89). 32% (n = 54) felt hopeful for the future and 27% (n = 45) felt alive.

Almost half of respondents in the last year have felt low self-esteem (48%, n = 81) and 45% (n = 73) have felt fearful of the future due to their HIV positive status. 38% (n = 63) felt ashamed/guilty as a consequence of being HIV positive, 35% (n = 59) felt angry and 30% (n = 51) felt scared that they could pass on HIV to someone else.

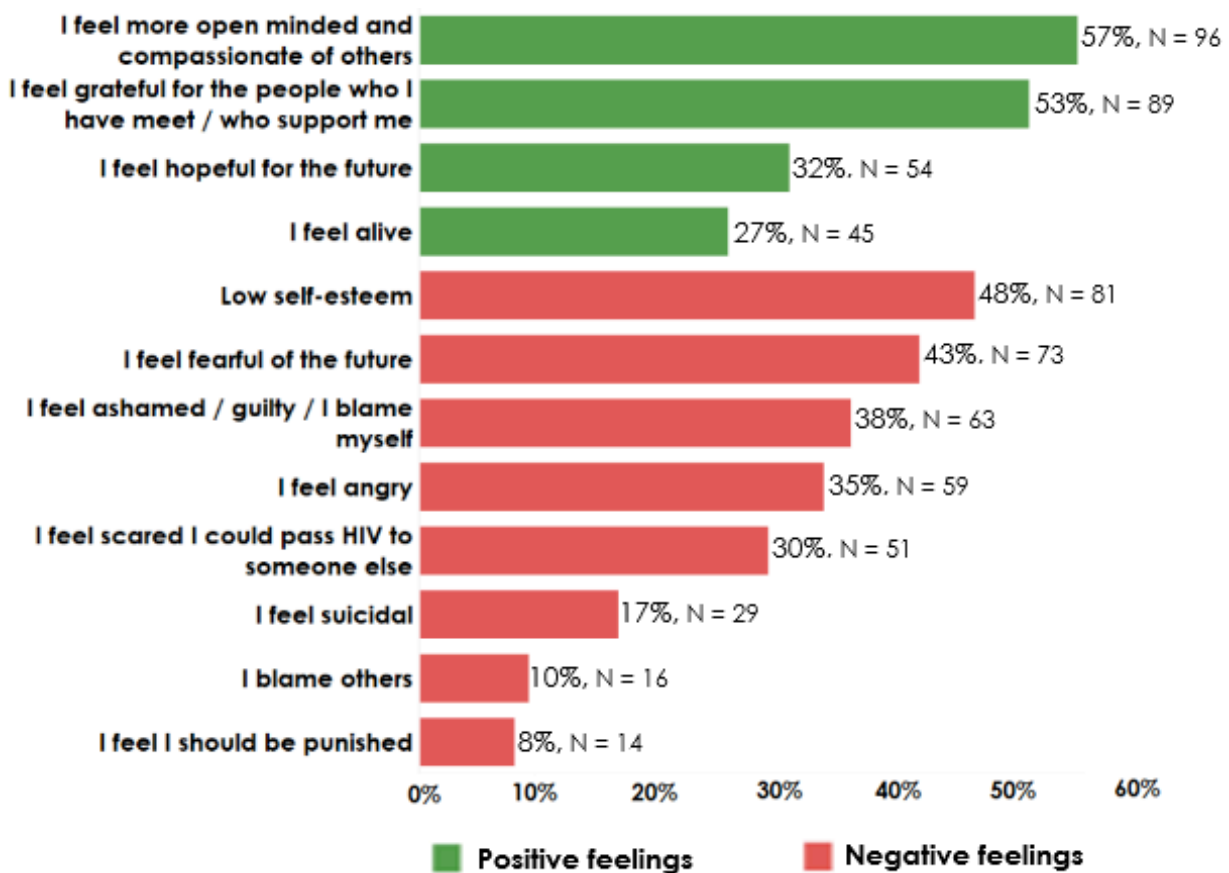
17 % (n = 29) of respondents felt suicidal in the last year, this compares with a range of 3.7% - 4% in the general population who have felt suicidal according to research from other jurisdictions<sup>44,45</sup>. 10% (n = 16) have felt like they blame others regarding their HIV

<sup>44</sup> <https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6013a1.htm>

<sup>45</sup> <https://www.samhsa.gov/data/sites/default/files/NSDUH-DR-FFR3-2015/NSDUH-DR-FFR3-2015.htm>

status and 8% (n = 14) reported they felt that they should be punished in regard to their HIV status.

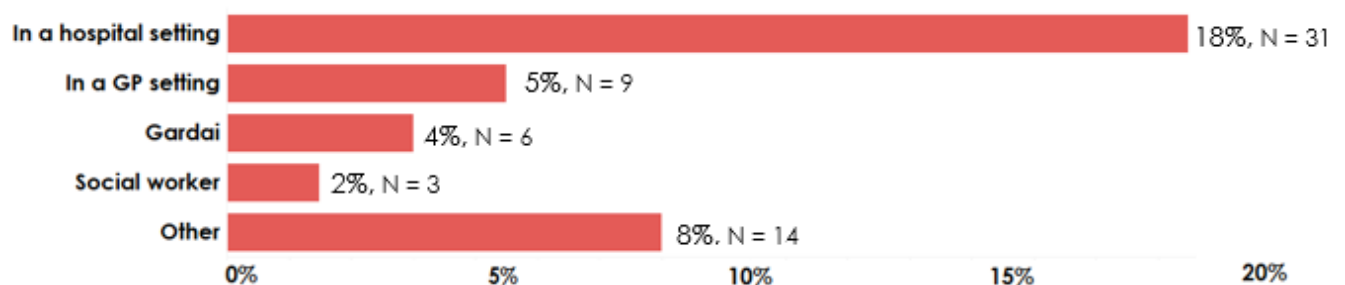
Figure 43: Respondents Feelings Toward Their own HIV Status



### Accidental Disclosure of HIV Status

18% (n = 31) of respondents had their HIV status accidentally disclosed in a hospital setting, 5% (n = 9) in a GP setting, 4% (n = 6) by the Gardaí and 2% (n = 3) by a social worker. Other settings where respondents had their status accidentally disclosed included, the dentist (n = 3), the workplace (n = 2), the pharmacy (n = 2) and the prison system (n = 1).

Figure 44: Has Respondents HIV Status Been Disclosed Accidentally in the Following Settings



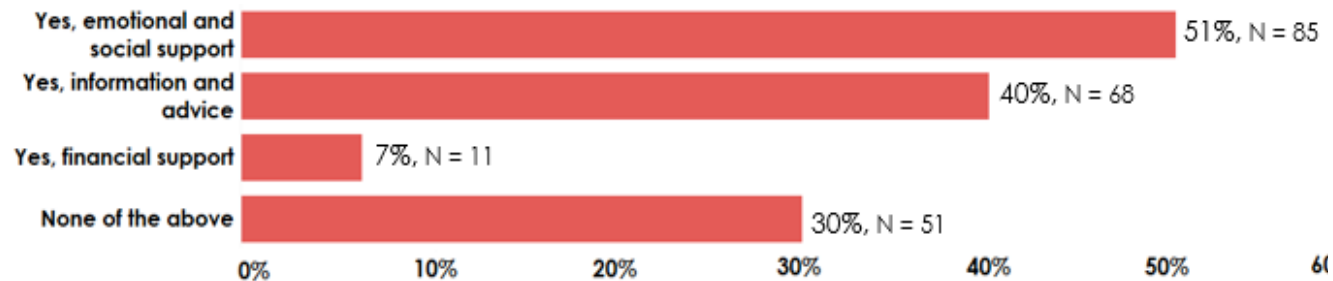
### Supporting Others Living with HIV

A majority of respondents reported that they provided emotional and social support (51%, n = 85) to another person living with HIV in the past year. 40% (n = 68) provided



information and advice while 7% (n = 11) provided financial support to another person with HIV. 30% (n = 51) of respondents did not provide another person who was living with HIV with any of these supports.

Figure 45: Had Respondents Supported Other People With HIV In The Past Year



### Stigmatisation by Groups

Respondents were asked had they ever felt that they had been stigmatised by any of the following groups, because they were HIV positive.

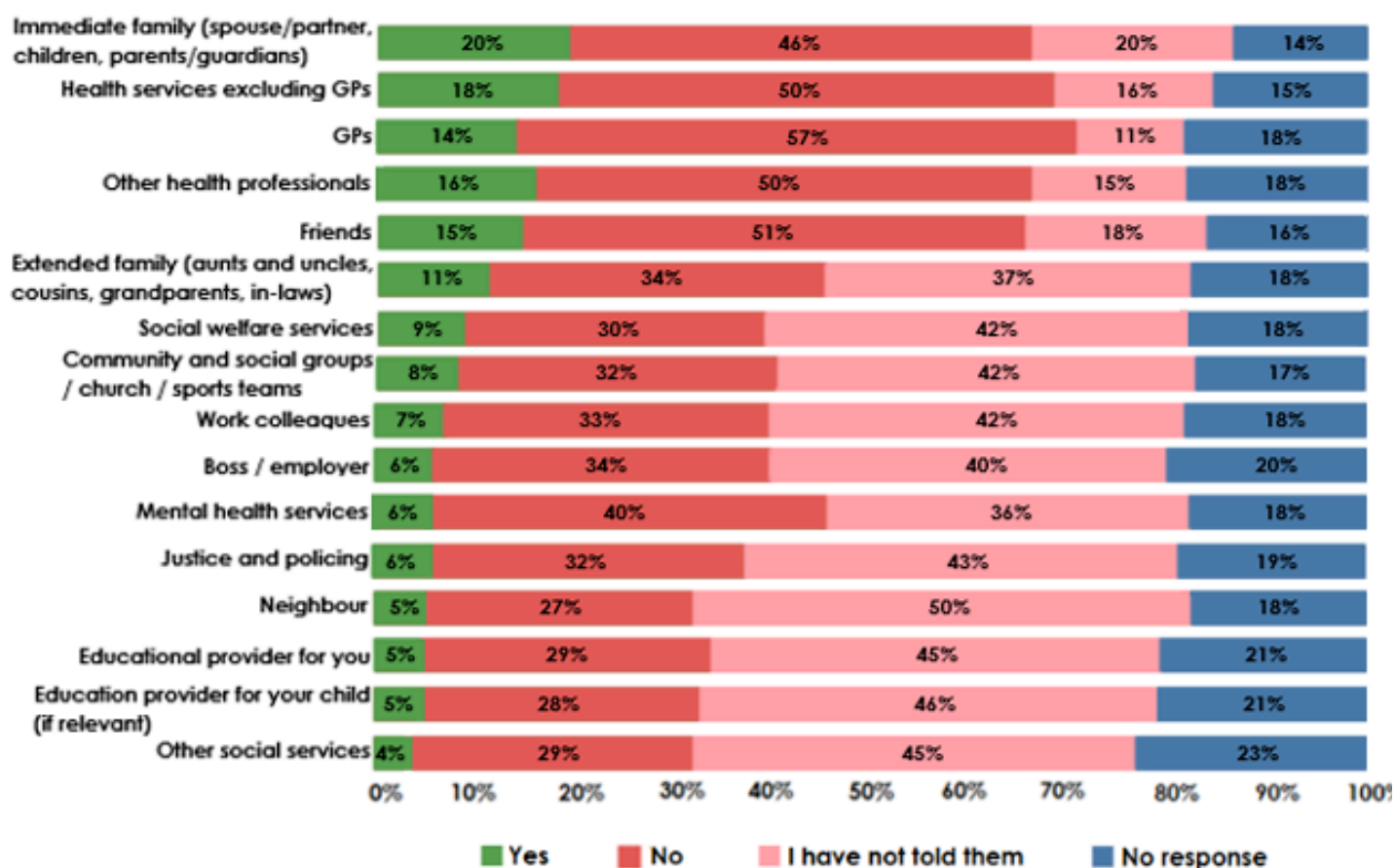
More than a quarter of respondents to whom the question was applicable<sup>46</sup> reported that they had felt stigmatised by their immediate family (30%, n = 33) or by health professionals excluding GP's (27%, n = 31).

A smaller proportion of respondents to whom the question was applicable reported that they felt stigmatised by their extended family (25%, n = 19), other health professionals (24%, n = 27), friends (23%, n = 25), social workers (23%, n = 15), community and social groups (21%, n = 14) and GP's (20%, n = 24).

Stigmatisation among other groups occurred less frequently. Respondents are less likely to have felt they were stigmatised by groups (work colleagues (18%, n = 12), neighbours (17%, n = 9), justice and policing services (16%, n = 10), boss/employers, educational providers (15%, n = 8), mental health services (13%, n = 10) and other social services (11%, n = 6)) that they did not disclose their HIV positive status to. Only 4% - 7% of total respondents reported having felt stigmatised by these groups. This suggests that knowledge of a person's HIV status is a prerequisite of being stigmatised.

<sup>46</sup> Question is applicable to any respondent who had disclosed their HIV positive status, i.e. respondents that selected 'Yes' or 'No'

Figure 46: Had Respondents Ever Felt Stigmatised by any of the Following Groups, Due to their HIV Status:



Respondents were further asked if they had ever felt that they had been stigmatised by any other groups because they are HIV positive.

Table 15: Other Groups Respondents Felt Stigmatised by

Group	Number
LGBT Community	4
Dentists	3
Justice Services	2
Immigration services	2
HIV support groups	1
Financial services	1

Four of the 13 responses identified the LGBT community as stigmatising people with HIV. This is illustrated in the following quote:

*I have to say that most stigma comes from the gay community. Guys are afraid to date me when I disclose my HIV status. People need to be educated that 'undetectable' means zero transmission!!!!!! (Respondent 83)*

Three of the 13 responses identified dentists as a group that stigmatises people with HIV. This is illustrated below:

*Even though I am UVL<sup>47</sup>, I will not tell my dentist, as I feel he would be prejudicial, and I don't want him to know (Respondent 146)*

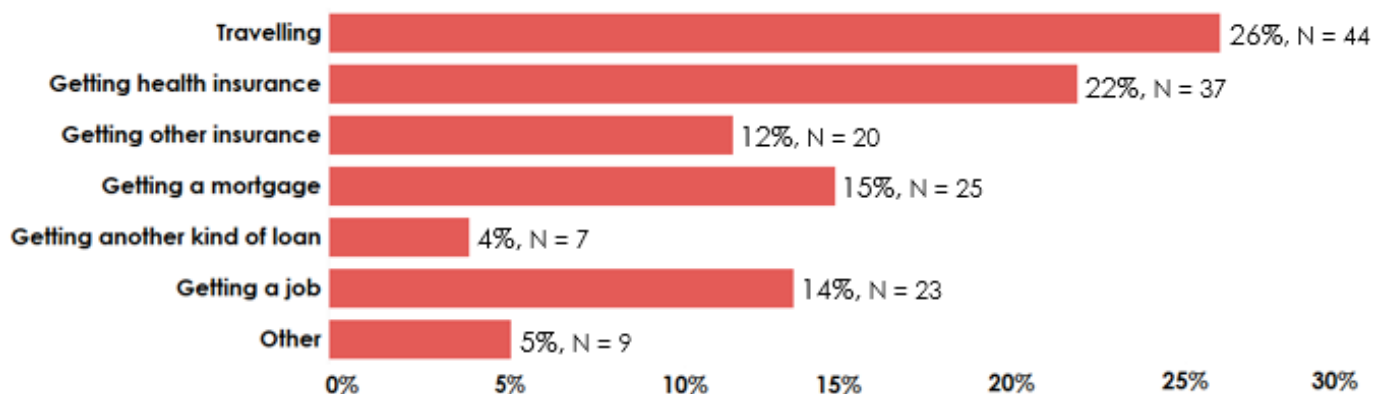
Respondents also mentioned that they had felt stigmatised by the justice system, immigration services, financial services and by HIV support groups:

*HIV support groups are focused on gay men instead of just people living with HIV, as a woman I am excluded (Respondent 108)*

### HIV Status Preventing People from Doing Things

Respondents were asked has being HIV positive prevented them from doing a number of activities outlined below. More than a quarter of respondents have been prevented from going travelling (26%, n = 44) due their HIV status, 22% (n = 37) have been prevented from getting health insurance and 12% (n = 20) have been prevented from getting other forms of insurance. 15% (n = 25) of respondents have been prevented from getting a mortgage while 4% (n = 7) have been prevented from getting another kind of loan and 14% (n = 23) reported they have been stopped from getting a job as a result of their status. Other activities that respondents reported they had not engaged in as a result of being HIV positive included; boxing, getting a tattoo, getting a visa, getting a pension, moving job and finding a meaningful relationship.

Figure 47: Has HIV Prevented Respondents from Doing any of the Following



### Other Stigmas Related to Being HIV Positive

Eighty respondents provided information about other ways in which HIV stigma affected them. Of those, 22 described that HIV stigma affects their relationships with other people. Within this group, six respondents highlighted that they feared the negative judgement of new romantic partners if they were to disclose their HIV status.:

*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*

<sup>47</sup> UVL - Undetectable Viral Load

*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, your right (and desire) to express yourself sexually against the possible repercussions down the line of not immediately disclosing*  
(Respondent 28)

*It affects my attitude towards relationships, difficulties with disclosure upfront, it's a barrier to engaging in a relationship*  
(Respondent 29)

*Meeting casual sex partners is difficult once you are honest with them and tell them you are undetectable* (Respondent 113)

Nine respondents described how HIV stigma makes them feel isolated and alone:

*As a straight, young Irish woman with HIV also it can feel a little like you are somewhat of an anomaly as the focus is overwhelmingly on gay and bisexual men, and that can increase the sense of isolation*  
(Respondent 28)

*I am newly diagnosed and very afraid and alone about it all*  
(Respondent 68)

*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* (Respondent 95)

Eight respondents described that HIV stigma puts pressure on them to keep their HIV status secret:

*Only my mother knows, my father would disown me if he knew my status* (Respondent 58)

*You suffer endless fear of attending the clinic and meeting someone you know and the consequences of this* (Respondent 88)

*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* (Respondent 152)

Eight respondents described that HIV stigma affects their mood and makes them feel depressed, anxious, angry, or suffer from low self-esteem:

*I feel unable to climb Maslow's hierarchy of needs; depressive episodes; hearing HIV negative guys have rampant unprotected sex and think they are okay while I'm undetectable and cannot pass the virus on be stigmatised by their actions that are leading to the increase in infection. #notafuckingsecondclasscitizen*  
(Respondent 46)

*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. (Respondent 136)*

*I am always wary of my status being found out but the stigma I believe is worse, within my very self and being, as I think I am hardest upon myself, as I am most angry at myself at this late stage in life (being diagnosed at 56 years of age, 6 months ago), and I hate myself for it. I have attempted OD, spending a week in hospital, soon after diagnosis. Life has lost its 'buzz', fun, meaning and zest for living post diagnosis sadly (Respondent 146)*

Four respondents described that HIV stigma limits their ability to travel to other countries for work and recreation:

*I can't really work in other countries which doesn't allowed HIV positive people work. e.g. Australia, Canada and Singapore (Respondent 73)*

*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. In 2011 my employer (European oil company) became aware of my HIV status before I did. The diagnosis was facilitated via a compulsory bi-annual medical test; a pre-requisite requirement for the issue of a local work visa. On my initial HIV diagnosis in-country, my employer terminated my consultancy contract within 24 hrs, quoting it as force majeure incident. Fortunately, I had departed the country the day before on regular travel back to Ireland, therefore being saved an official deportation as a persona no grata (Respondent 149)*

Four respondents described that HIV stigma affects their experience of the health system:

*It affects my health care! Clinics and dispensing of medication are not to a satisfactory level. You also cannot remain anonymous attending a HIV clinic (Respondent 7)*

*Having to disclose HIV status in hospital is difficult as I have felt staff gossiped about me and wrote it across my file when I was going for an operation (Respondent 154)*

## Summary

There is a strong perception among the HIV positive community that there is significant stigma attached to being HIV positive. A strong majority of respondents were of the view that some people within the general population believe that having HIV is shameful and that contracting HIV through sex or drug injection are more stigmatising than other forms of contraction. This implies that there is a hierarchy of stigma for how HIV is transmitted. For instance, the majority of those surveyed agree

that it is less stigmatising to have contracted HIV through a blood transfusion or beauty/health treatment or to be born with it.

The survey indicates that a sizeable minority are not comfortable with their HIV positive status, this discomfort is strongest among people who have been diagnosed with HIV in the past two years. There also persists a belief among more than a third of the survey respondents that some people believe that they deserve to be HIV positive.

Respondents were most likely to disclose their HIV status to their partner, immediate family, health professionals and friends, however, people living with HIV were also more likely to have felt stigmatised by the same groups. When respondents disclosed their HIV status they were most likely to do so because they trust people and want to share information about themselves and to keep others safe.

Respondents were most likely to fear being rejected in a personal relationship if they disclosed their HIV status. They were also fearful of having their HIV status outed by a third party. This may feed into the fact that the majority of respondents have not disclosed their HIV status at some point as they are afraid that they will be judged negatively or treated differently. A large minority of respondents reported that they had been outed as HIV positive by somebody else and proportionally this affected African respondents more than other groups. The setting where respondents were most likely to be outed by accident was a hospital.

A large minority of respondents feared being verbally assaulted, harassed or threatened due to their HIV positive status. However, approximately half of the proportion of respondents who feared being verbally assaulted reported that they had been verbally assaulted, harassed or threatened due to their HIV status. Proportionally the group most likely to experience this form of harassment was African born. The majority of total respondents reported that they experienced stigma for a reason other than being HIV positive in the past year, most commonly due to their sexuality (being gay/lesbian/bisexual). Other reasons for stigmatisation included being a member of a minority group, being a migrant worker and being an injecting drug user.

A significant challenge that many people feared and experienced was social exclusion or loneliness. Some respondents reported that they were rejected in a personal relationship in the past year due to their HIV status and the majority reported that they were fearful of being rejected from a personal relationship because of their HIV status.

Language used by the media, especially social media and the general population causes offense, through the use of stereotypical and defamatory language in relation to HIV. Specifically, the use of the terms 'clean'/'dirty' to describe a person's HIV status were considered very offensive by many. The use of inaccurate terminology such as using 'AIDS' to describe 'HIV' was also highlighted as a cause of offense.

Respondents reported that their HIV status had impacted on their day to day life with a large minority having been prevented from travelling, getting health insurance, or getting a mortgage due to their status.

Respondents were asked in the past year, what were their most common feelings in relation to their HIV status. This question highlighted that an HIV diagnosis brings with it both positive and negative feelings and experiences. Almost half of respondents reported having low self-esteem and a large minority reported feeling suicidal in the past year due to their status. Conversely just over half of respondents reported that they felt more open minded and compassionate of others in the past year and that they are grateful for the people who have supported them in dealing with living with HIV.

This survey, completed by 168 people living with HIV, provides significant insight into the frequency, nature and impact of stigma in relation to HIV. On behalf of HIV Ireland we would like to thank all those people who used this process to tell their story and provide insight into this overlooked aspect of living with HIV in Ireland today.

## 6 Conclusion

The surveys undertaken in this research aim to contribute to a better understanding of HIV related stigma and its impact in Ireland today. From this wealth of data presented in the report the research team has identified six key themes which hold significance for policy and practice. These are outlined below:

### Theme 1 - 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 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 raising in Ireland. However a number of myths in relation to HIV contraction remain, 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.

Other false perceptions also persist in the general population, the majority of respondents reporting 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.

### Theme 2 - 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 34-year olds were three times more likely to think HIV can be transmitted by sitting on a toilet seat than older people and almost twice as likely to think HIV can be transmitted by sharing a glass. Young people 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.

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 across all age groups that 'young people should be taught about HIV transmission during secondary school'.

### Theme 3 - Four Decades on from the AIDS Crisis, HIV Stigma is Still a Reality

The majority of people provided answers which indicated they did not hold stigmatising views. For instance, over 80% of people thought that people living with HIV deserve the same level of support and respect as people with cancer. There is,



however, a minority of the population who report discriminatory or stigmatising views, for instance 7% of people did not agree with the statement above.

At least one in ten people stated that if they found out that their neighbour was living with HIV it would change their relationship with them or that they wouldn't feel comfortable working with a colleague who was HIV positive. These minority views do not go unnoticed. The surveys highlighted that there is a strong perception among people living with HIV that stigma is still attached to being HIV positive, with almost nine in ten of the view that some people believe that having HIV is shameful.

There was also a belief amongst those living with HIV that contracting HIV through sex or drug injection is more stigmatising than other forms of contraction, implying a hierarchy of stigma for how HIV is transmitted. Double stigma is also an issue. On top of feeling stigmatised for being HIV positive some people living with HIV felt doubly stigmatised for a variety of other reasons including their sexuality, being an injecting drug user, being a member of a minority group and/or being migrant worker.

A quarter of people living with HIV are not comfortable with their own HIV positive status. This discomfort is strongest among people who have been diagnosed with HIV in the past two years. There also persists a belief among some people living with HIV that others believe that they deserve to be HIV positive.

Language used in both traditional and social media was commonly described as being offensive to people living with HIV. The use of 'clean/dirty' to describe a person's HIV status and the interchangeability of 'HIV' and 'AIDS' were identified as being particularly stigmatising.

[In response to being asked what kind language is offensive] "Are you clean?" To which I respond, while thinking I've showered today... Yes, I am mister!"

#### Theme 4 - There is a Significant Burden Caused by HIV Stigma in Ireland

Stigma and the fear of stigma affects 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 experienced being 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, being outed as HIV positive by other people and to a lesser extent, violence. The majority of people had not disclosed their HIV status at some point as they are afraid they would be judged or treated differently if they did. Approximately double the proportion of people living with HIV feared the negative effects of stigma, as listed above, as

actually experienced them in the last year. This suggests that stigma produces a ripple effect in the community of people living with HIV with any negative experiences amplifying the fears of suffering other negative consequences. International research reflects the pattern highlighted in this data. Perceived stigma is more frequent than experienced stigma, and in its self can have a very significant negative impact on a individuals sense of safety and wellbeing.

Past research also tells us that people living with HIV are more likely to have more negative self-perceptions, lower self-compassion and self-esteem than the general population. The stress that stigma can cause may explain why in the past year almost two in ten people living with HIV have felt suicidal. More than a third also report as having suffered from low self-esteem, anger, felt guilty/ashamed or 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 health insurance or to get a job.

*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.*

## Theme 5 – Stigmatisation of People Living with HIV in Health Services

Though many people living with HIV describe positive experiences in 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, health services, GP's) as the groups that 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 and wrote it across my file when I was going for an operation.*

People living with HIV were fearful of being outed in a hospital setting. An example was provided of staff discussing well known HIV specific medication with the person living with HIV while visitors were present. For some this fear was realized – a hospital setting was the most common setting where HIV people were accidentally outed as HIV positive.

## Theme 6 - HIV Brings Challenges and Opportunities

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

The majority 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 a majority of people living with HIV have provided emotional and social supports to someone else living with HIV while almost half 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.*

## Summary

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 exists 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 high level of low self-esteem and suicidal thoughts 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 the health services. Health service groups were some of the most likely groups to make them feel stigmatised because of their HIV status and a hospital setting was the most common setting where they had been outed accidentally as 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 but 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 stigma target itself, society at large is not immune from the negative effects resulting from HIV-related stigma. It is hoped that this research will shine a light on this issue and provide data to support informed and effective policy making.

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## 8 Appendix 1: Cross Comparison of HIV/AIDS Strategies

To evaluate the strategy that governs the area of HIV/AIDS in Ireland, a cross comparison was undertaken between Ireland's current strategy (the National Sexual Health Strategy) and three others: the previous national strategy (HIV and AIDS Prevention Plan 2008 - 2012<sup>48</sup>) and two current international HIV strategies (from the United States<sup>49</sup> and Australia<sup>50</sup>). All four strategies were measured against the UN's 'three ones' guiding principles for national authorities and their partners, and the 12 essential policy actions outlined in the UNAIDS 'Intensifying HIV Prevention' strategy(1). Overall, the current national strategy scored well in meeting the 15 items (the 'three ones and the 12 essential policy actions), meeting 12 of the 15 criteria. All of the other strategies met 13 of the fifteen criteria. Where Ireland's current strategy falls down relates primarily to the overall approach, rather than the content of the strategy itself.

In addition to this, explanatory notes will reference the UN General Assembly's *2016 Political Declaration On HIV And AIDS: On The Fast-Track To Accelerate The Fight Against HIV And To End The AIDS Epidemic By 2030 (6)*, where additional detail highlights particular successes or gaps in relation to the current strategy and structures.

Standard or Essential Policy Action	2008 Strategy	2015 Strategy	National AIDS Strategy (U.S)	7 <sup>th</sup> National HIV Strategy 2014-2017 (Australia )
1. One agreed HIV/AIDS Action Framework <sup>51</sup>	Yes	No	Yes	Yes
2. One National AIDS Coordinating Authority	Yes	No	Yes	No
3. One agreed country level monitoring and evaluation system	No –	Yes <sup>52</sup>	Yes	Yes
4. Measures are taken to eliminate discrimination and combat stigma	Yes	Yes <sup>53</sup>	Yes <sup>54</sup>	Yes <sup>55</sup>
5. Leadership from all sections of society	Yes	Yes <sup>56</sup>	Yes <sup>57</sup>	No

<sup>48</sup> [http://health.gov.ie/wp-content/uploads/2014/03/HIVAIDS\\_educationand-pp\\_review-.pdf](http://health.gov.ie/wp-content/uploads/2014/03/HIVAIDS_educationand-pp_review-.pdf)

<sup>49</sup> <https://www.hiv.gov/federal-response/national-hiv-aids-strategy/overview>

<sup>50</sup> <http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hiv>

<sup>51</sup> In addition to this, the 2011 Commitment notes that signatories: "Commit to update and implement, by 2012, through inclusive, country-led and transparent processes, multi-sectoral national HIV and AIDS strategies and plans, including financing plans, which include time-bound goals to be reached in a targeted, equitable and sustained manner, to accelerate efforts to achieve universal access to HIV prevention, treatment, care and support by 2015"

<sup>52</sup> See Strategy 2015 – Recommendation 6.3 , 6.4, 5.5 & 5.6

<sup>53</sup> See Strategy 2015 – Recommendation 3.1

<sup>54</sup> See indicator 13 - *Decrease stigma among persons with diagnosed HIV infection by at least 25 percent.*

<sup>55</sup> Yes, but unlike all other objectives there is a lack of a nationally agreed indicator for measuring progress in reducing the health impact of stigma, discrimination and legal and human rights in the Strategy

<sup>56</sup> See Strategy 2015 – Recommendation 6.1

<sup>57</sup> See action 1.C.5, 3.C.3 & 3.C.4



6. Involve people living with HIV in the design, implementation and evaluation of prevention strategies	Yes	No	No	Yes <sup>58</sup>
7. Address cultural norms and beliefs	No <sup>59</sup>	Yes <sup>60</sup>	Yes <sup>61</sup>	Yes <sup>62</sup>
8. Promote gender equality and address gender norms	Yes <sup>63</sup>	Yes <sup>64</sup>	No	Yes
9. Promote widespread knowledge and awareness of transmission / prevention	Yes	Yes <sup>65</sup>	Yes <sup>66</sup>	Yes
10. Promote links between HIV prevention and sexual and reproductive health	Yes	Yes <sup>67</sup>	Yes	Yes
11. Support mobilisation of community-based responses throughout continuum of prevention, care and treatment	Yes	Yes <sup>68</sup>	Yes <sup>69</sup>	Yes <sup>70</sup>
12. Promote programmes targeted at HIV prevention needs of key affected groups and populations	Yes	Yes	Yes	Yes
13. Mobilise and strengthen financial and human and institutional capacity across all sectors, particularly in health and education	Yes	Yes	Yes <sup>71</sup>	Yes <sup>72</sup>
14. Review and reform legal frameworks to remove barriers to effective, evidence-based HIV prevention, combat stigma and discrimination, and protect the rights of people living with HIV or vulnerable or at risk to HIV	Yes <sup>73</sup>	Yes	Yes	Yes <sup>74</sup>
15. Ensure that sufficient investments are made in	Yes <sup>75</sup>	Yes	Yes <sup>76</sup>	Yes <sup>77</sup>

<sup>58</sup> See section 6.1 in Seventh National HIV Strategy 2014-2017

<sup>59</sup> See 2008 Strategy- Action Area 3 – Preventing new Infections: Population Group 1 pg 42 where culturally appropriate programs are addressed rather than explicitly tackling underlying beliefs/norms

<sup>60</sup> See Strategy 2015 – Recommendation 3.1

<sup>61</sup> See Goal 2 and Action 1.C.3 'Achieving A More Coordinated National Response To The Hiv Epidemic

<sup>62</sup> See recommendation 7.1 in 7th National HIV Strategy 2014-2017 (Australia)

<sup>63</sup> Mentions 'gender equality' but no explicit reference to 'gender norms. See 2008 Strategy - Action Area 3 – Preventing new Infections: Population Group 1 Young People pg 45

<sup>64</sup> See Strategy 2015 – Recommendation 3.5- however gender equality or norms not explicitly mentioned

<sup>65</sup> See Strategy 2015 – Recommendation 3.14- 3.19

<sup>66</sup> See Goal 2: Increasing Access To Care And Improving Health Outcomes For People Living With Hiv

<sup>67</sup> See Strategy 2015 – Recommendation 5.1.- 5.4

<sup>68</sup> See Strategy 2015 – Recommendation 4.14 ' Develop and implement a 'hub and spoke' model of care for sexual health services' within ideally local setting or primary care setting

<sup>69</sup> See 1.C.4 Expand public outreach, education, and prevention efforts on HIV and intersecting issues,

<sup>70</sup> See recommendation 7.1 in 7th National HIV Strategy 2014-2017 (Australia)

<sup>71</sup> See Goal 4 See indicator 13 - Achieving A More Coordinated National Response To The Hiv Epidemic

<sup>72</sup> See recommendation 7.4 in 7th National HIV Strategy 2014-2017 (Australia)

<sup>73</sup> See Strategy 2008 - Yes on 3 counts a plan to review of the current legislation governing prostitution to ensure that access to health and social services is not impeded (see Action Area 3 – pg 50) , a plan to implement 'An assessment of needle exchange provision in Ireland' in full (Action Area 3- pg 47) and clarification on age of consent (Action Area 3 – pg 44)

<sup>74</sup> See recommendation 7.5 in 7th National HIV Strategy 2014-2017 (Australia)

<sup>75</sup> See 2008 Strategy - Action Area 3 – Preventing new Infections: Population Group 2 MSM pg 45

<sup>76</sup> See Action 1.C.2

<sup>77</sup> See recommendation 7.4 in 7th National HIV Strategy 2014-2017 (Australia)

the research and development of, and advocacy for, new prevention technologies				
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