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## About HIV Ireland

Established in 1987 (Dublin AIDS Alliance).

NGO / registered Charity.

Guiding Principles: non-judgemental; human rights-based approach; harm reduction ethos; inclusive; informed choices; equality and dignity and respect.

- Free HIV and STI testing, free condoms and outreach services.
- Community Supports for PLWHIV, including free counselling, advocacy and mediation.
- Education and Training Programmes and Educational Resources Service.
- Campaigns and awareness raising initiatives.
- Policy, Advocacy and Research.



## **HIV in Ireland 2017**

**Findings from the:**

- (1) National HIV Knowledge and Attitudes Survey 2017**
- (2) People Living with HIV Stigma Survey 2017**



**2006-2007**



### **Irish Political Leadership in 2006:**

Ireland's then Taoiseach (Prime Minister), Bertie Ahern addressed the UN General Assembly High Level Meeting on HIV and AIDS in June 2006, and called on political leaders to work to make our societies more open, caring, inclusive and non-judgemental.

*“As a first step we will have a National Campaign to combat stigma and discrimination against people infected with HIV in Ireland coinciding with World AIDS Day on 1<sup>st</sup> December this year.”*

## Multi-Stakeholder Forum established

- Domestic and International NGOs.
- Statutory Agencies.
- People living with HIV.
- Funded by Department of Foreign Affairs (Irish Aid) and the Department of Health.

## Overview of the Campaign:

- Website: [stampoutstigma.ie](http://stampoutstigma.ie)
- Television Advertising.
- Newspaper Advertising.
- Media Seminar.
- Personally Speaking book – stories and experiences from PLWHIV.
- Postcards.
- **3 x Studies**
- Pre and post-campaign evaluation.

## Study 1: Telephone Survey '**Attitudes to HIV in Ireland**'

- Involved a national telephone survey among a random sample of 1,022 adults aged 18+.
- Covering the following topics:
  - People with HIV Viewed Negatively by Society
  - Attitudes Towards People with HIV

## Study 2: Telephone Survey **'People in the Workplace with HIV & AIDS'**

- Involved a telephone survey with four specific workplace groups:
  - 62 secondary schools
  - 23 unions
  - 51 doctors & dentists
  - 81 small businesses
  - Resulting in a total of 217 workplace interviews
- Covering the following topics:
  - Presence of HIV in the Workplace
  - Procedures for Dealing with HIV Issues in the Workplace
  - Concerns about HIV in the Workplace
  - Information & Guidelines
  - Illegality of Discrimination

## Study 3: Self-Completion Survey **'People living with HIV'**

- Involved a self-completion study among 73 people living with HIV
- Covering the following topics:
  - Demographic Profile of Sample Living with HIV
  - People with HIV Viewed Negatively by Society
  - Perceptions of Discrimination by Society
  - Illegality of Discrimination
  - Receipt of Information on HIV Stigma and Discrimination



## Summary Findings: Stigma and Discrimination

- This was the first national report on HIV-related stigma in Ireland  
**HIV Related Stigma and Discrimination in Ireland Today**  
**(report published 2008)**
- The report revealed that ignorance and stigma surrounding HIV and AIDS remains strong in Ireland.

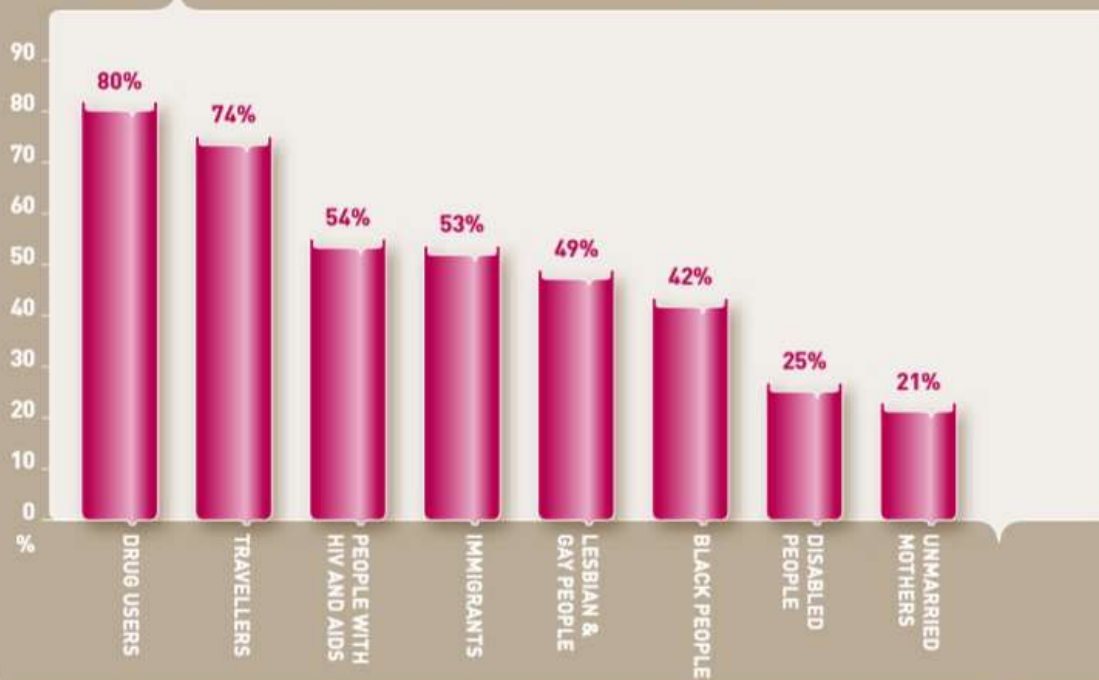
## Summary Findings: Stigma and Discrimination

- The perception that people with HIV are viewed negatively by society is higher among people living with HIV than among the general public:

84% of those who are living with HIV agree that people with HIV are viewed negatively by society here in Ireland (N = 63)

54% of the general public agree with it; they rank it third to drug users and travellers (N = 1,022)

Chart 2.1. Groups of People Viewed Negatively by Society, % / N = 1,022

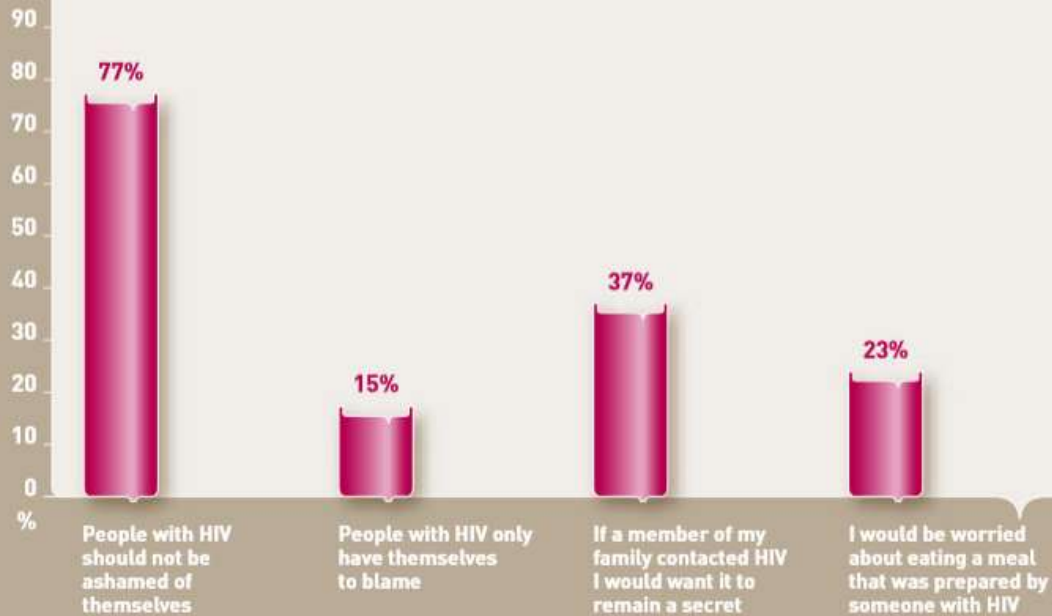


## Summary Findings: Stigma and Discrimination

- There is a notable level of sympathy and understanding among the general public towards those with HIV and AIDS:
  - 77% agree that people with HIV **should not be** ashamed of themselves and just 15% agree that people with HIV only have themselves to blame.
- However, 23% would be worried about eating a meal that was prepared by someone with HIV and 37% agree that if a family member were to contract the virus they would keep the HIV status of him/her a secret.

(Thus, the more personal the experience of HIV, the greater the perceived stigma and discrimination).

Chart 2.2. Agreement with Statements in Relation to HIV and AIDS, % / N = 1,022



## Summary Findings: People Living with HIV

Ever experienced discrimination in Ireland by:

- Friends – 49%
- Local Community – 43%
- A doctor - 37%
- A dentist – 34%
- Family – 28%
- Social Welfare – 25%
- Workplace – 21%
- School or College – 18%
- HIV treatment clinic - 15%

## Summary Findings: Illegality of Discrimination

- Just over half (56%) of those living with HIV are aware that it is illegal to discriminate against a person with HIV.
- All 4 workplace groups claim a high level of awareness. Many commented that it is to be expected.

100% of unions are aware.

Over 90% of schools and small businesses are aware.

Lowest for doctors and dentists: 88% aware.

There was little uncertainty expressed: 3% overall.

## Qualitative Research – people living with HIV

- 8 semi-structured interviews.
- 7 Focus Group discussions.
- 41 participants (54% male; 46% female).
- Age range: 20 to 55 years.



## Summary Findings: Qualitative Research – people living with HIV

- **Disclosure is an issue:** 75% of focus group participants had none or very limited disclosure.
- **Stigma leads to discrimination in healthcare:** refusal of services and/or treatment; disrespect; segregation.
- **Self Stigma is significant:** the majority of participants offered at least one example of self-stigmatising behaviour.
- **Discrimination occurs in the workplace**
- **Using medication can disclose HIV status:** 50% of respondents indicated that they had direct experiences of this.
- **Criminalisation of sexual activity is a concern.**
- **Developing new relationships is a challenge.**

## Summary Findings: Qualitative Research – people living with HIV

- **There is stigma on the ‘gay scene’.**
- **Men who have sex with men feel blamed for HIV** (by society).
- **Travel restrictions affect quality of life:** particular references made to the US travel ban.
- **Positive perspective from an African experience:** would prefer to be living in Ireland than in Africa. *“I am glad I live here away from my family. I don’t care as much about being rejected by people I don’t know, but if it was your father or your mother, brother or sister, it would be a very different story. That is the kind of thing that would kill you fast.”*
- **HIV positive drug users face double stigma.**

## Conclusions and Recommendations

This study in 2007 established a benchmark against which future developments and progress can be compared. It identifies the value of research in this area and proposes that stigma and discrimination needs to be continually monitored and assessed in order to strategically manage its causes and effects over time.

### Recommendations:

- Further research to understand the impact of HIV-related stigma.
- A national information strategy on the rights of PLWHIV.
- Develop a national standard to measure HIV-related stigma and monitor discrimination.
- Resource a national intervention strategy to continue highlighting HIV-related stigma and discrimination.

# 2007

+10 years

# 2017

*2007 to 2017: decreasing levels of funding and resources (and commitments)*



**2008: 4-year HIV & AIDS Education and Prevention Plan**

**2015: 5-year National Sexual Health Strategy**

Stigma acknowledged as a barrier in the provision of sexual health education, information and services; and non-disclosure of HIV status.





# HIV in Ireland 2017

**(1) National HIV Knowledge and Attitudes Survey 2017**

**(2) People Living with HIV Stigma Survey 2017**



# HIV in Ireland 2017

## National HIV Knowledge and Attitudes Survey 2017

- Ethical Approval through Mater Misericordiae University Hospital.
- Distribution of an online omnibus survey (Empathy Research).
- 1,013 randomly sampled participants, over 18 years old, and living in the Republic of Ireland.
- Stratified by gender, age and region of the country with a margin of error of +/- 3.2%.
- 51% female; 49% male; 58% aged 25 to 53 years; 10% aged 18 to 24 years.

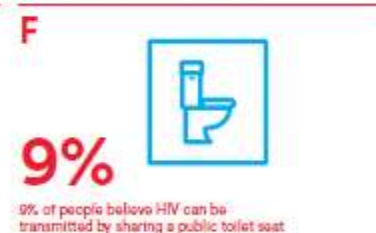
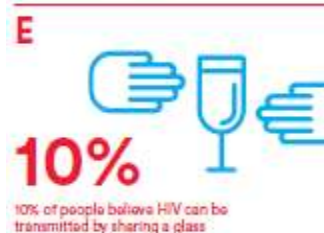
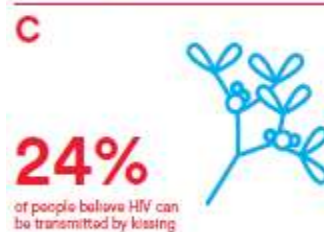
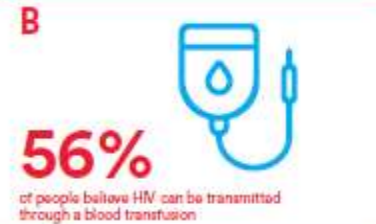
# HIV in Ireland 2017

## National HIV Knowledge and Attitudes Survey 2017

### Knowledge of HIV Transmission

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

% believed that HIV can be transmitted by:  
Sharing needles and syringes – 98%  
Sex without a condom (man and woman) – 96%  
Sex without a condom (MSM) – 96%



# HIV in Ireland 2017

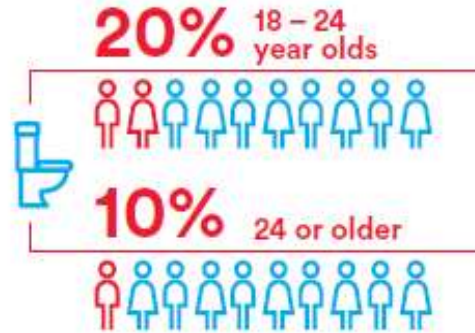
## National HIV Knowledge and Attitudes Survey 2017

### Knowledge of HIV Transmission

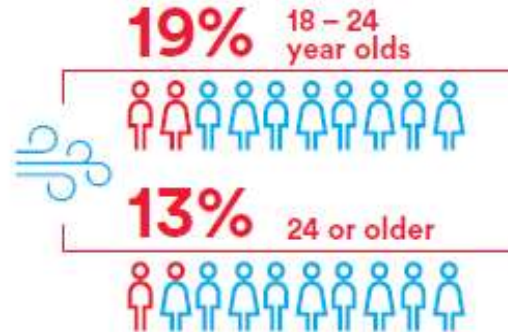
Younger people had higher levels of misinformation than older age groups.



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



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





# HIV in Ireland 2017

## National HIV Knowledge and Attitudes Survey 2017

### Attitudes to PLWHIV

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

# HIV in Ireland 2017

## National HIV Knowledge and Attitudes Survey 2017

### Beliefs regarding HIV

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

Agree	Ireland
I don't have much sympathy for people with HIV if they were infected through unprotected sex	17%
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	93%



# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

- **Ethical Approval through Mater Misericordiae University Hospital.**
- **Distribution of a survey (online and hard copies).**



# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Participant Profile

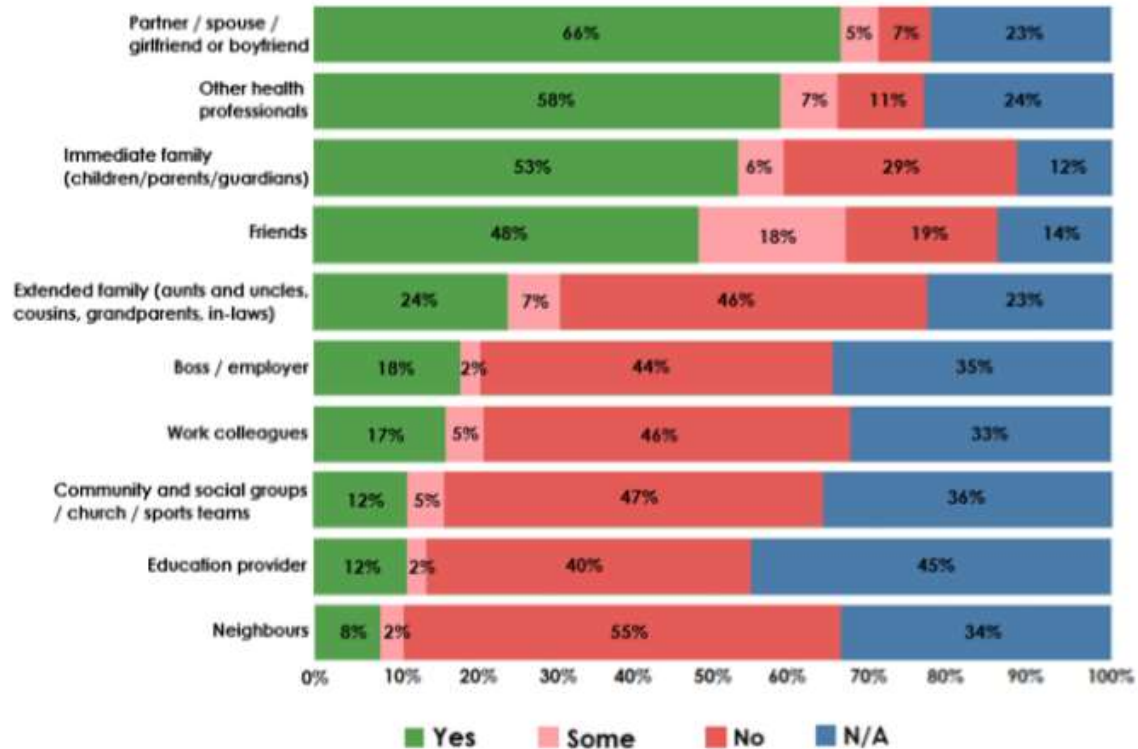
- 168 participants, over 18 years old, living in the Republic of Ireland and who identified as being HIV positive.
- 82% male; 17% female. One respondent reported their gender as other.
- 81% aged 25 to 54; 61% under 44 years old; median age of 40 years.
- 58% working; 21% unemployed.
- Education - degree or higher 76%.
- Born in Ireland 64%, EU 14%, Africa 9%
- Diagnosed in Ireland 75%, EU 10%, Africa 6%
- 52% living in Dublin.
- Single 54%; 32% married or in relationship.
- 17% diagnosed with HIV under 2 years ago; 49% diagnosed between 2 and 10 years ago; 33% diagnosed 11 years ago or more.

# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Disclosure

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

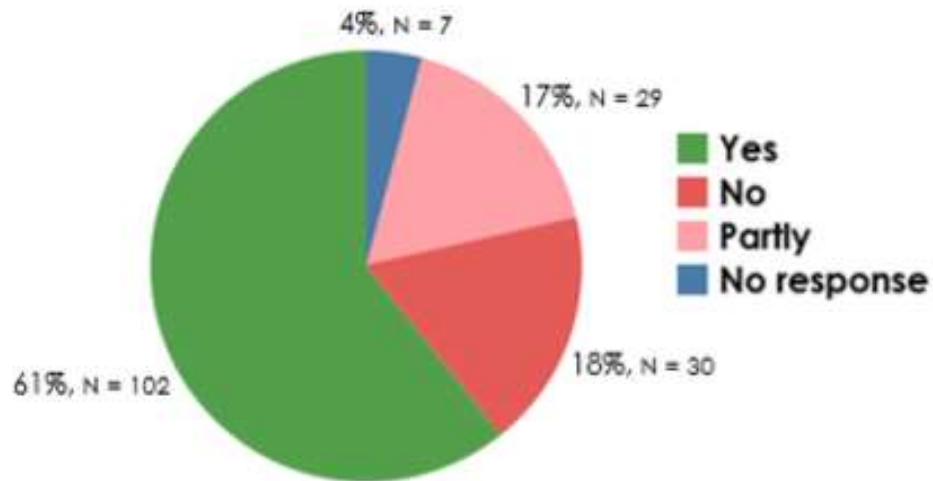


# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Disclosure

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

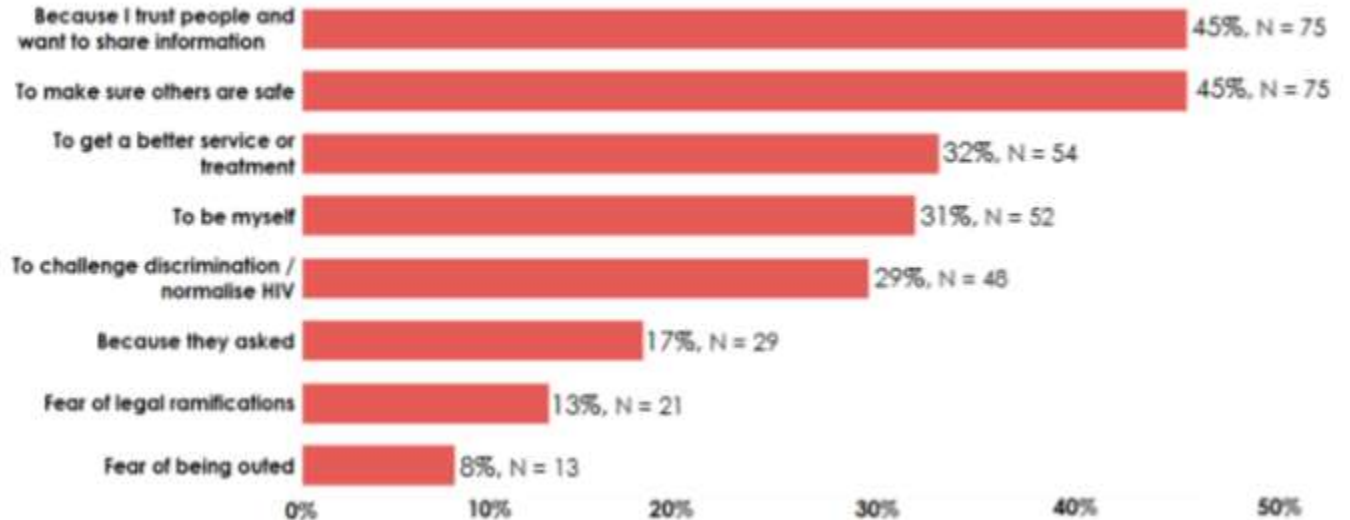


# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Disclosure

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

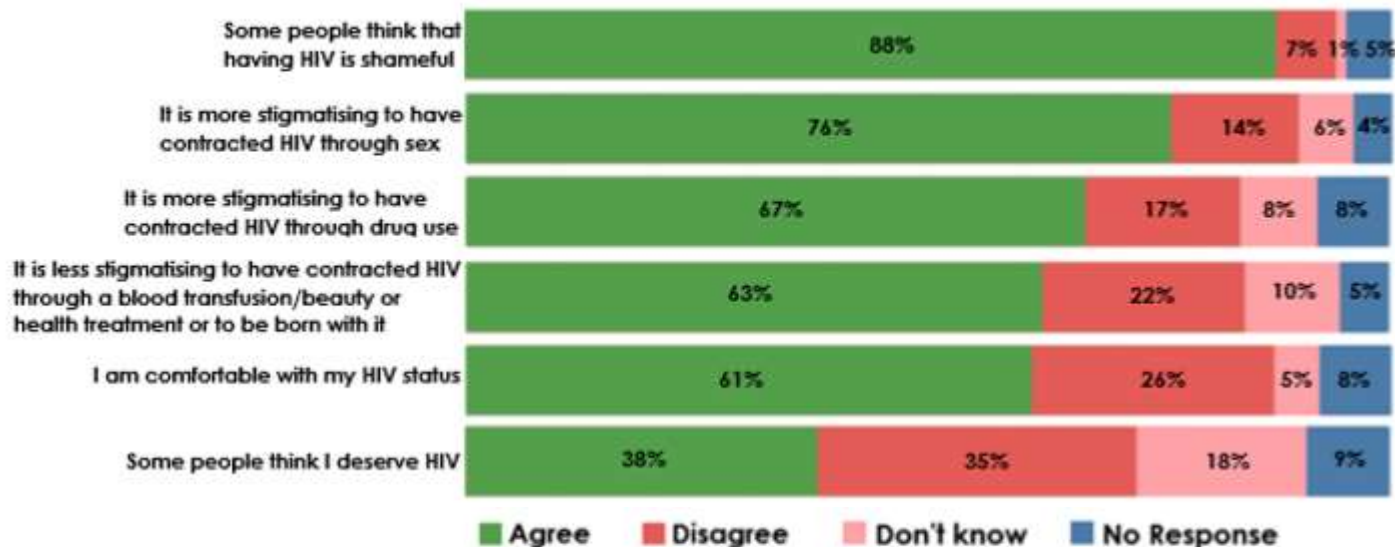


# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Statements regarding people's attitudes to those living with HIV

Figure 38: Did Respondents Agree or Disagree With The Statements



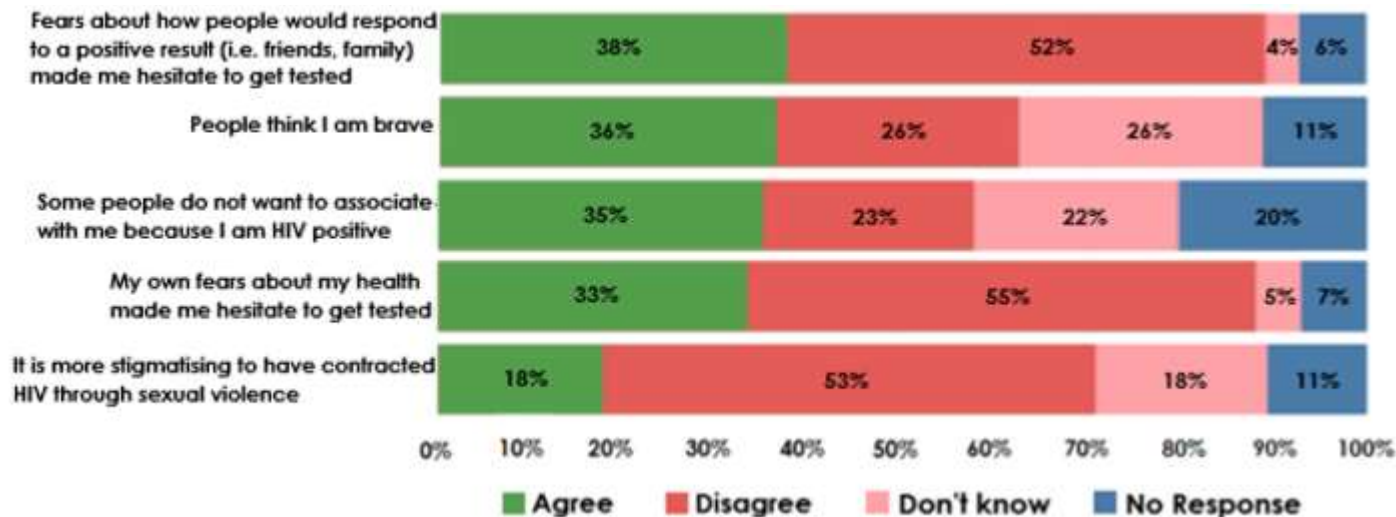


# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Statements regarding people's attitudes to those living with HIV

Figure 38: Did Respondents Agree or Disagree With The Statements



# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Perceived Stigma: fear of the following happening in the last year

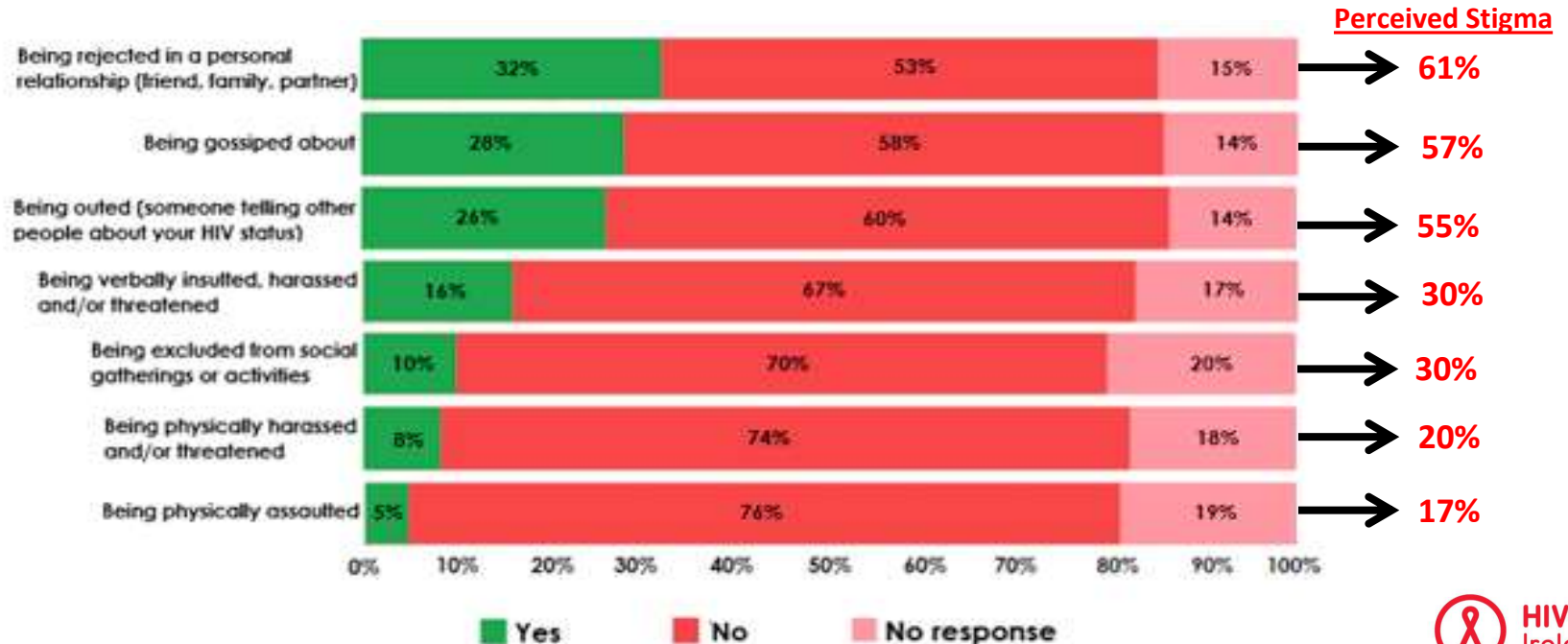


Only one in five people had no fears about being stigmatised

# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Enacted Stigma: experience of these things happening in the last year

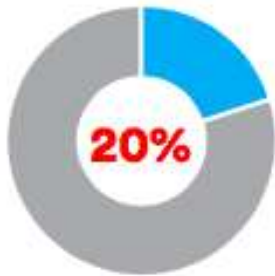


# HIV in Ireland 2017

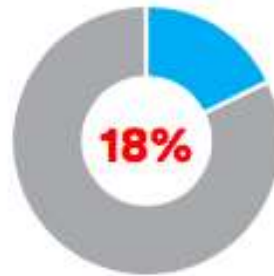
## People Living with HIV Stigma Survey 2017

### Who stigmatises?

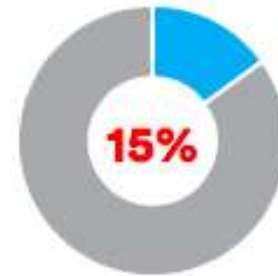
Respondents felt most stigmatised by groups they most often disclose their HIV status to.



Immediate family



Health professionals



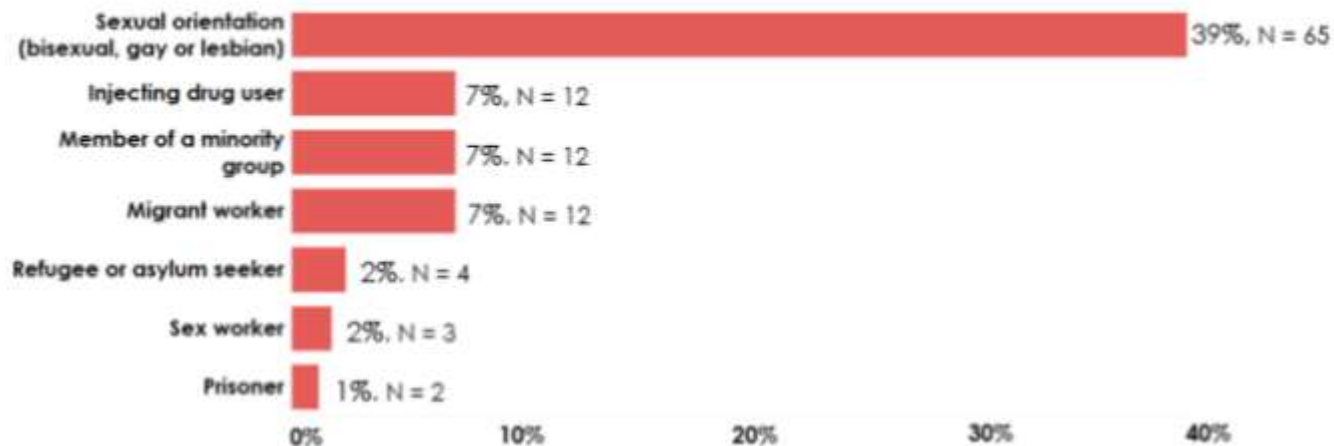
Friends

# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Double Stigma

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



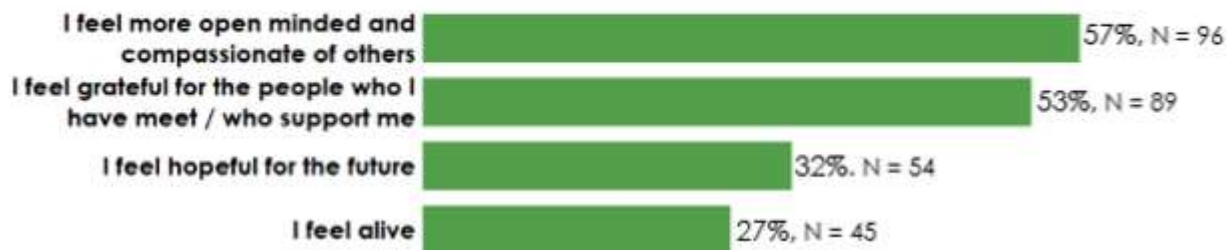
# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Feelings towards own HIV status

■ Positive feelings

Figure 43: Respondents Feelings Toward Their own HIV Status

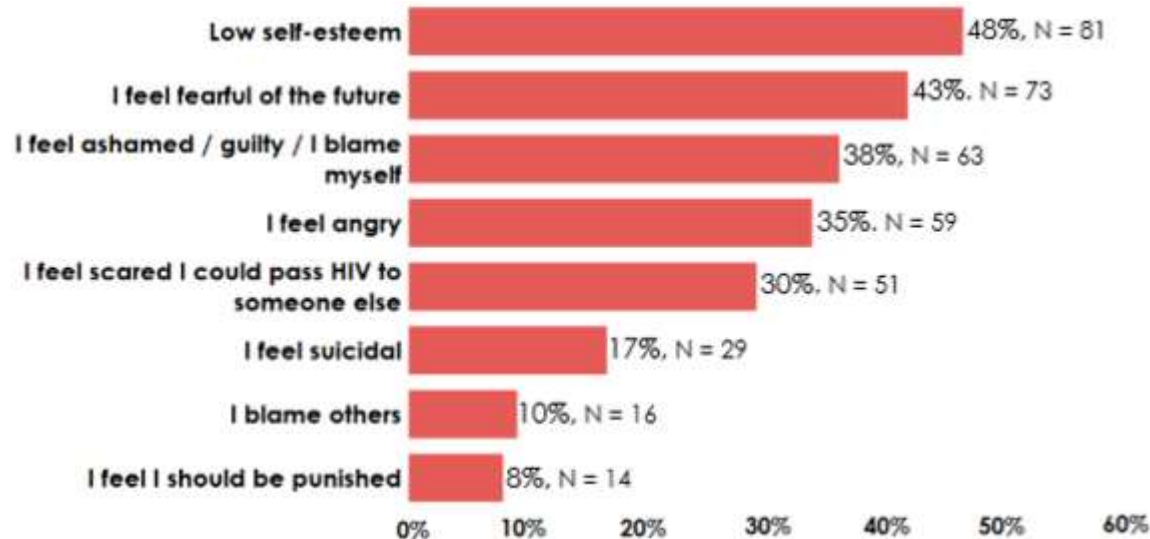


# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Impact of Stigma: Feelings towards own HIV status

■ Negative feelings

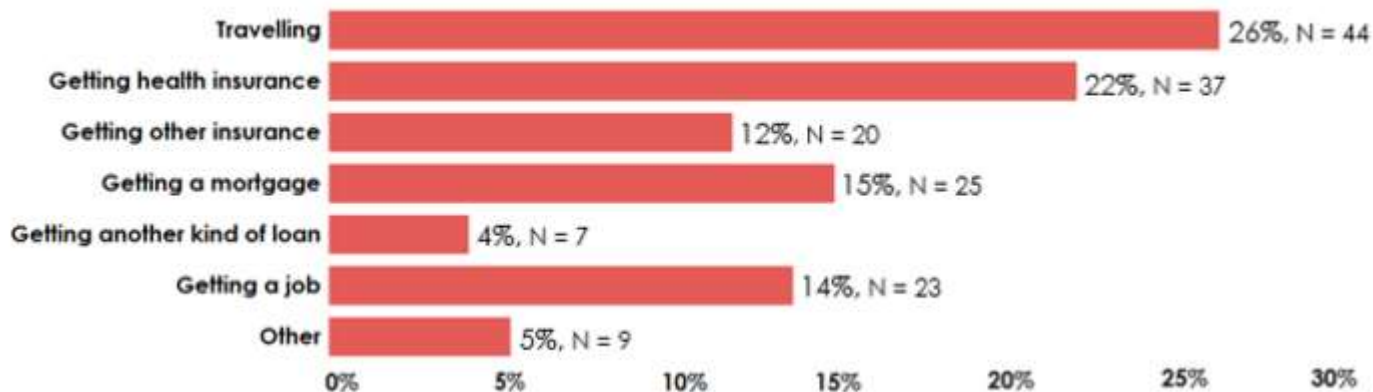


# HIV in Ireland 2017

## People Living with HIV Stigma Survey 2017

### Impact of Stigma: Has being HIV Positive prevented you from doing things?

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





# HIV in Ireland 2017

National HIV Knowledge and Attitudes Survey 2017

People Living with HIV Stigma Survey 2017

## Summary Findings

- HIV stigma is still a reality, and there is a significant burden caused by HIV stigma in Ireland.
- Stigmatisation of people living with HIV in health services.
- Stigmatising attitudes to HIV remain in the general population.
- Knowledge in the general population is good but there is room for improvement. Myths around HIV transmission still exist.
- Young people are more likely to have knowledge gaps about HIV transmission than older people.

# HIV in Ireland

## Priorities for Ireland? Similarities with 2007 findings...

### Disclosure remains an issue.

- 2007 qualitative research – 75% of participants had none or limited disclosure.
- 2017 – while a majority had disclosed to partners, immediate family, friends and health professionals, a majority also had limited or no disclosure to extended family, employers, work colleagues, community and social groups, education providers and neighbours.

# HIV in Ireland

## Priorities for Ireland? Similarities with 2007 findings...

### **Stigma and discrimination remains an issue in healthcare services.**

- 2007 study of PLWHIV – 37% of participants reported ever experiencing discrimination by a doctor, and 34% by a dentist.
- 2017 – 18% of participants reported ever feeling stigmatised within health services (excluding GPs), 14% felt stigmatised by GPs, and 16% by other health professionals.

# HIV in Ireland

## Priorities for Ireland? Similarities with 2007 findings...

### **Self stigma remains significant.**

- 2007 study of PLWHIV – 84% of PLWHIV agree that people with HIV are viewed negatively society; 54% of the general public agreed with this.
- 2007 attitudes to PLWHIV study – 77% of the general public agreed that PLWHIV should NOT be ashamed of themselves, and just 15% agreed that PLWHIV only have themselves to blame.
- 2017 – 88% of PLWHIV believe that some people think that having HIV is shameful. 38% of PLWHIV believe that some people think they deserve HIV. 83% of general public agree that PLWHIV deserve the same level of support and respect as people with cancer.
- 2017 - 76% of PLWHIV believe that it is more stigmatising to have contracted HIV through sex. Just 17% of the general public agree that they don't have much sympathy for PLWHIV if they were infected through unprotected sex.

# HIV in Ireland

## Priorities for Ireland?

### **Education to increase knowledge and improve/change attitudes.**

- There are still myths about HIV transmission, and there was a low level of knowledge (19%) about effective HIV treatment reducing the risk of transmission (to zero) in the 2017 research.
- In the 2017 research, while a majority of the general public indicated supportive attitudes, a significant minority indicated that if a family member, neighbour or work colleague disclosed to them, it would change their relationship with them.

# HIV in Ireland

## Priorities for Ireland?

### **Mental Health and HIV.**

There is still a significant burden caused by an HIV diagnosis and by HIV-related stigma for people living with HIV in Ireland.

Examples from 2017 survey: 43% feel fearful of the future; 38% feel ashamed/guilty/blame themselves; 17% feel suicidal; 8% feel they should be punished.

# HIV in Ireland

*“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.”*



# HIV in Ireland

## Political Leadership and commitment for Ireland?

### Irish Political Leadership in 2006:

Ireland's then Taoiseach (Prime Minister), Bertie Ahern addressed the UN General Assembly High Level Meeting on HIV and AIDS in June 2006, and called on political leaders to work to make our societies more open, caring, inclusive and non-judgemental.

*“As a first step we will have a National Campaign to combat stigma and discrimination against people infected with HIV in Ireland coinciding with World AIDS Day on 1<sup>st</sup> December this year.”*





## Acknowledgements:

Survey participants.

Partner organisations and individuals for promoting and facilitating the survey.

Members of the Steering Group (Dr Patrick Murphy, Lysander Preston, Alan Macken, Susan Donlon, and Dr Erin Nugent).

Quality Matters and Empathy Research, and Claire Connaughton.

National AIDS Trust UK: 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 Attitudes1 survey.

Dr Patrick Mallon, Mater UCD, and Positive Now for facilitating two focus groups to support the design aspect of the questionnaires.

Janssen Ireland and Dublin Frontrunners Athletics Club (funding).



# HIV in Ireland 2017

Full Report:

[www.hivireland.ie](http://www.hivireland.ie)