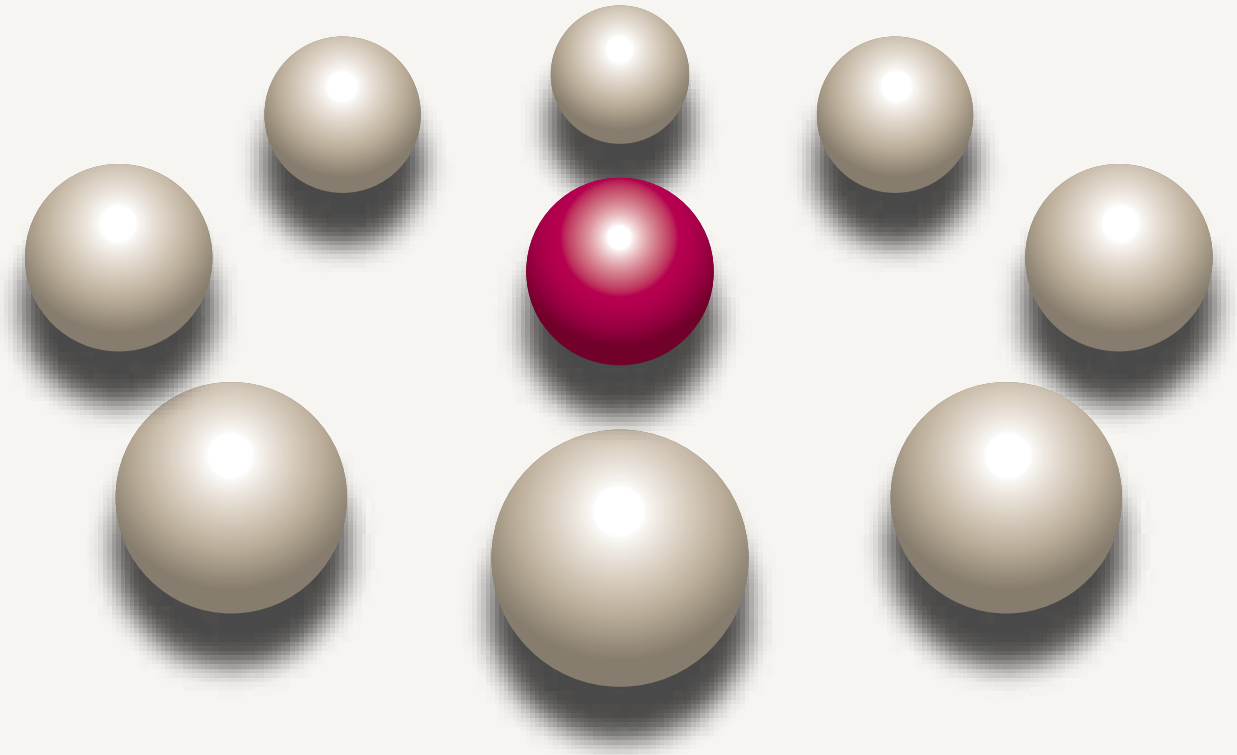
STAMP OUT STIGMA

Challenging HIV and AIDS discrimination

# HIV RELATED STIGMA AND DISCRIMINATION IN IRELAND TODAY



## LIST OF ACRONYMS

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ASTI | Association of Secondary Teachers Ireland |
| DOHC | Department of Health and Children |
| HIV | Human Immunodeficiency Virus |
| HSE | Health Service Executive |
| IBEC | Irish Business and Employers Confederation |
| ICGP | Irish College of General Practitioners |
| ICTU | Irish Congress of Trade Unions |
| IDA | Irish Dental Association |
| ISME | Irish Small and Medium Enterprises |
| PLHIV | People living with HIV |
| SOSC | Stamp Out Stigma Campaign |
| TUI | Teacher's Union of Ireland |
| VEC | Vocational Education Committees |

## ACKNOWLEGMENTS

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We would also like to express our deepest gratitude to Public Communications Centre for their skill, expertise and commitment in compiling this report.

public communications centre

The National Stamp out Stigma campaign is a partnership made up of representatives working in the area of HIV & AIDS both in Ireland and abroad, including development civil society organizations, statutory agencies and HIV positive people themselves. People living with HIV in Ireland are central to this Multi-Stakeholder Forum (MSF) which was responsible for developing and overseeing the national campaign. The National Stamp out Stigma Campaign is co- funded by the Department of Foreign Affairs (Irish Aid) and the Department of Health and Children.

For more information visit **www.stampoutstigma.ie**

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## INTRODUCTION FROM THE CHAIRPERSON

The National Stamp Out Stigma campaign is the result of a unique partnership of HIV positive people, domestic and international development agencies working in the field of HIV and AIDS and statutory agencies. This partnership is called the Multi-Stakeholder Forum (MSF).

People living with HIV (PLHIV) played a central role in developing the concept of this national campaign which is co- funded by the Department of Foreign Affairs (Irish Aid) and the Department of Health and Children.

Although it is almost twenty five years since AIDS became recognised, its impact on the world continues to be serious this, however, differs depending on the society and country in question: developed countries have medical treatments and the resources and infrastructure to make them universally available and can now regard living with HIV or AIDS as a long-term manageable condition. In these countries the life expectancy for PLHIV is approaching the population norm.

Access to medical care and treatment is generally available and indeed many PLHIV continue to be economically active because their health allows it. It is sometimes assumed that living with HIV in Ireland today is similar to other chronic medical conditions.

In developing countries HIV and AIDS continue to have a devastating effect, having the potential to slow if not reverse gains made in standards of living in recent years. Although anti-retrovirals are available in some settings these still only reach a fraction of those who need them and there are considerable cultural, economic and social barriers to achieving universal access to prevention, care and treatment for all.

There is one highly significant parallel in both settings, that of stigma and discrimination. In both settings the stigma associated with HIV seriously compromises the quality of life of PLHIV. Very little research has been carried out in Ireland in the area of stigma and discrimination. The findings of this significant research will act as a benchmark for all further research into the experiences of HIV-related stigma and discrimination in Ireland.

**Noel Walsh**

Chair





## 1. ABOUT THIS REPORT

This report combines the findings from three studies on stigma and discrimination towards, and experienced by, people with HIV in Ireland in 2007. These studies were the first of their kind and will act as a benchmarking for HIV-related stigma in Ireland. The three studies are as follows:

| | | |
|---|---|---|
| **Study 1:** | Telephone Survey: | **'Attitudes to HIV in Ireland',** May 2007, by Red C |
| **Study 2:** | Telephone Survey: | **'People in the Workplace with HIV & AIDS',** June 2007, by the Public Communications Centre |
| **Study 3:** | Self-Completion Survey: | **'People Living with HIV',** July / August 2007, by the Public Communications Centre |

In addition, this report refers to relevant national data on people with HIV detailed in 'Newly diagnosed HIV infections in Ireland: Quarter 3&4 2006 & 2006 Annual Summary', May 2007, a report by the Health Protection Surveillance Centre, HSE.

This report is available on the website: www.ndsc.ie.

## 2. OBJECTIVE OF THIS REPORT

The objective of this report is to present a comprehensive account of the findings from the above mentioned three studies 1, 2 and 3 on stigma and discrimination towards people with HIV in Ireland today.

The rationale behind the three studies was to assess HIV-related stigma and discrimination in Ireland as a benchmark of the experiences of people with HIV in Ireland in 2007 and to identify areas for further study.

### EACH STUDY HAD SPECIFIC TARGET GROUPS:

| | |
|---|---|
| **Study 1:** | Targeted the general public. |
| **Study 2:** | Targeted four workplace groupings: schools, unions, doctors and dentists, small businesses. |
| **Study 3:** | Targeted people living with HIV. |

By combining all three sets of findings, this document compares the experiences of people living with HIV with the perceptions and behaviour of other groups that have influence on them. It does so in different contexts: for example, it establishes the attitudes and actions of the employer as well as the experiences of the worker with HIV; it ascertains the concerns of doctors and dentists as well as the experiences of patients with HIV.

This document draws on the wealth of topics that are covered in the three reports – some of which are common to all three and others which are pertinent to one or two. In doing so, this report brings the findings together under the following headings:

1. **People Living with HIV:** demographic profile of people living with HIV
2. **Society in General:** attitudes of the general pubic towards people with HIV
3. **Family and Friends:** perceived discrimination of family and friends towards people with HIV
4. **Local Community:** perceived discrimination of the local community towards people with HIV
5. **Workplace:** perceived discrimination of the workplace towards people with HIV; management of HIV issues in the workplace, procedures in place for dealing with HIV issues, concerns about people with HIV in the workplace
6. **Students:** perceived discrimination of schools and college towards students with HIV; management of HIV issues in school, procedures in place for dealing with HIV issues, concerns about students with HIV in school
7. **Patients:** perceived discrimination of the medical profession towards patients with HIV; management of HIV issues in the doctors' and dentists' practices, procedures in place for dealing with HIV issues, concerns about patients with HIV in doctors' and dentists' practices
8. **Social Welfare:** perceived discrimination of social welfare towards people with HIV

9. **Information & Guidelines:** receipt of information and guidelines on managing HIV issues, interest in receiving such and preferred sources of advice
10. **Illegality of Discrimination:** awareness among people living with HIV and other groups that it is illegal to discriminate against a person with HIV

## 3. METHODOLOGIES EMPLOYED

The three studies employed different methodological approaches and covered some issues in common as well as particular issues.

### REPORT 1:

Telephone Survey: **Attitudes to HIV in Ireland**, May 2007 by Red C:

- 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
  - Recall of advertising or promotional activity about HIV or AIDS stigma or discrimination in the past 6 months
- The fieldwork period was 7th to 9th May 2007

### REPORT 2:

Telephone Survey: **People in the Workplace with HIV & AIDS,** June 2007 by PCC:

- 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
  - The fieldwork period was 24th May to 11th June 2007

### REPORT 3:

Self-Completion Survey: **People Living with HIV,** July/August 2007 by PCC:

- 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
- The fieldwork period was July to August 2007





## 4. CONSTRAINTS OF THE RESEARCH

It must be noted that HIV is a sensitive issue for research purposes. It affected the response rate in Report 2 whereby the progress of achieving the desired workplace sample was hindered by the following:

- Refusal to participate in the survey
- Termination of interviews while in progress
- Non-fulfilment of pre-arranged appointments

This sensitivity of the topic impacted upon the methodology employed. The telephone interview technique generated a better response that the self-completion method. Where respondents requested a fax or an e-mail of the questionnaire, the returns were less successful:

- The response rate was poorer
- The completion rate was remarkably lower: questions were left unanswered
- The level of information provided was more limited than that elicited from the telephone interviews

## 5. READING THE FIGURES

The results are presented in percentages in this document. This is for comparative purposes whereby it allows for comparisons to be made across the different sample groups. In making these comparisons, it must be borne in mind that the sizes of the various samples vary greatly: from the smallest group of 23 unions to the largest group of 1,022 adults in the national population.

Furthermore, the percentages are calculated using only relevant answers. For example, where a question was not answered by all respondents, only those answers that were given are included in the calculation of percentages: i.e. the missing answers and non-relevant answers are excluded. This ensures a more accurate picture of the issue under investigation. The inclusion of these answers in the analysis would affect the true representation of each possible answer in the overall picture. For instance, of the 73 people living with HIV, only 52 defined their experience of discrimination by the workplace. The missing 21 answers may have occurred for a variety of reasons: non-relevance, refusal to answer, misunderstanding of the question or failing to notice the question. Of the 52 responses, 11 claimed discrimination by the workplace. This figure is calculated as 21% of those living with HIV who have experience of the workplace, claim discrimination by it. If this figure were to be calculated as a percentage of 73, the finding would read: 15% of those living with HIV regardless of whether they have experience of the workplace, claim discrimination by it.

Thus, in reading the percentages in this report, it is important to bear in mind that they represent all relevant responses rather than the full sample for each case. The actual relevant sample size is supplied in brackets for clarification: i.e. it is depicted as 'N'.

# SUMMARY

## 1. STIGMA & DISCRIMINATION

- The research identifies the presence of stigma and discrimination towards people living with HIV in Ireland today. This stigma and discrimination occurs at different levels and to varying degrees across various sections of society from home life to work life, from school life to dealing with the medical profession, from community life to dealing with social welfare.
- 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)
- 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 (N = 1,022). Thus, the more personal the experience of HIV, the greater the perceived stigma and discrimination.

## 2. LIVING WITH HIV

- For people living with HIV, the highest level of discrimination is experienced by social others: 49% claim discrimination by friends (N =66) and 43% by the local community (N = 60).
- This is followed by the medical profession where there is a considerable level of discrimination: 37% claim discrimination by a doctor (N = 70) and 34% by a dentist (N = 62).
- In turn, people living with HIV claim discrimination by the following: 28% by the family (N = 64), 25% by social welfare (N =65), 21% by the workplace (N =52) and 18% by school or college (N = 44).
- The lowest level of discrimination is by the most relevant other: HIV treatment clinic (15%) (N =67).
- It is probable that some of the lower levels of claimed discrimination may be explained by non-disclosure of one's HIV status.

## 4. WORKPLACE STIGMA

- There is low occurrence of staff with HIV in the workplace. This perception is accompanied by uncertainty: around 20% are unsure of having staff with such (N = 73). This reverts to the possibility of non-disclosure.
- Of the four workplace groups studied, unions were the only one to claim the presence of staff who are HIV positive – albeit at a low level of 4% (N =23).
- On the other hand, all claim some incidence of students/members/patients with HIV:
  - This is significantly highest for doctors & dentists: 78% (N = 51)
  - Lower for unions at 13% and schools at 5% (N = 23)
  - Again, there is uncertainty: 31% overall being unable to give a definite answer (N = 136).
- With regard to schools, there is low occurrence (7%) of having received an application for a school place from a student who is HIV positive. There is high certainty about this: only 3% are unsure (N =62).

## 4.1 PROCEDURES IN THE WORKPLACE FOR DEALING WITH HIV ISSUES

- The occurrence of procedures for dealing with HIV issues does not necessarily match the apparent need.
- There is a low incidence of procedures for staff: 8% (N =216) while there is a greater occurrence of procedures for students/patients: 31% (N = 136).
- The procedures for staff focus on the issue of health and safety in the workplace. The procedures for students primarily involve the adaptation of other policies & procedures while the procedures for patients focus on hygiene and infection controls.





## 4.2 CONCERNS ABOUT HIV IN THE WORKPLACE

- There are concerns about employing people with HIV. It is highest for doctors and dentists where 65% of them claim to have concerns (N = 51). This is followed by schools at 32% (N = 62) and small businesses at 30% (N =81). Only 9% of unions claimed such (N = 23).
- The concerns focus on the impact on the workplace and others within it rather than on the individual with HIV. Schools appear to be more sensitive to the individual with HIV than any other workplace group.

## 5. INFORMATION AND GUIDELINES

- Those living with HIV are more likely to have received information on HIV stigma and discrimination than the four workplace groups. Half of those living with HIV have received such information: 51% (N = 70).
- By comparison, there was limited receipt of information and guidelines on managing HIV issues in the workplace to date. It is the highest for doctors & dentists at 31% (N = 51), followed by schools at 16% (N = 62). It is minimal for small businesses at 4% (N = 81) and not at all by unions (N = 23).
- There is a recognised need for such information and guidelines by all four workplace groups: especially by unions where 83% say 'very useful' (N = 23). This is followed by schools at 68% (N =62) and small businesses at 54% (N = 81). Doctors & dentists fall lowest at 49% as many claim previous knowledge (N = 51).
- The main sources of advice on managing HIV issues in the workplace are similar for all four workplaces. They rely on health specific statutory bodies as well as relevant professional bodies. There is some uncertainty about where to source advice.

## 6. ILLEGALITY OF DISCRIMINATION

- There is awareness of the illegality of discriminating against a person with HIV. Those living with HIV demonstrate less awareness than the four workplace groups.
- Just over half of those with HIV are aware that it is illegal to discriminate against a person with HIV: 56% (N = 70).
- All 4 workplace groups claim a high level of awareness. Many commented that it is to be expected.
  - 100% of unions are aware (N = 22)
  - Over 90% of schools (N = 62) and small businesses (N = 81)
  - It is the lowest for doctors & dentists: 88% (N = 50)
- There was little uncertainty expressed: 3% overall (N = 215).

# MAIN FINDINGS

## 1. PEOPLE LIVING WITH HIV

Taken from Studies 3 and 4

- As a backdrop to this report, the following illustrates the profile of people living with HIV in Ireland today.
- It is drawn from two data sets: the 73 people living with HIV who participated in this study and the most recent data on the 337 newly diagnosed cases with HIV in 2006.
- There is no national data on HIV prevalence. It is known that the cumulative total number of HIV infections reported from 1990 to the end of 2006 is 4,419 but there are no corresponding mortality figures which would allow one to draw a current national picture.
- To summarise; the typical profile of the HIV target groups is:
  - Slightly more male than female
  - Spread across all age groups but predominantly falling into the 30 to 40 year age group: with males being typically older than females
  - Predominantly heterosexual with a significant percentage of men who have sex with men.
  - Notably non-injecting drug users
  - Living in all parts of Ireland – with a concentration in Dublin, Kildare and Wicklow; it should be noted however that many respondents did not disclose their place of residence. (29% are Unknown)
  - Irish nationals as well as people from other parts of the world, it should also be noted, however, that Geographic Origin is Unknown for 36% of respondents
- The chart depicting this information is presented overleaf.

Chart 1.1. People Living with HIV

| DEMOGRAPHICS | REPORT 3<br><br>2007 survey<br>73 people living with HIV | REPORT 4<br><br>2006 national data<br>337 newly diagnosed with HIV |
|---|---|---|
| GENDER | 56% male, 44% female<br>(N = 73) | 63% male, 37% female<br>(N = 337) |
| AGE | 3% = 20 years and under<br>18% = 21 to 30 years<br>44% = 31 to 40 years<br>34% = 41 to 50 years<br>1% = 51 years and over<br><br>Males: older<br>Females: younger<br>(N = 73) | 1% = 19 years and under<br>31% = 20 to 29 years<br>45% = 30 to 39 years<br>16% = 40 to 49 years<br>6% = 50 years and over<br><br>Males: older<br>Females: younger<br>(N = 337) |
| SEXUAL ORIENTATION | 65% heterosexual<br>26% gay man<br>(N = 69) | 50% heterosexual<br>25% gay man<br>(N = 337) |
| INJECTING DRUG USE | 25%<br>(N = 72) | 17%<br>(N = 337) |
| AREA OF RESIDENCE | 52% Dublin, Kildare, Wicklow<br>19% rest of country<br>29% unknown *<br>(N = 73) | 53% Dublin, Kildare, Wicklow<br>29% rest of country<br>18% unknown*<br>(N = 337) |
| GEOGRAPHIC ORIGIN | 53% Ireland<br>8% Africa<br>3% other<br>36% unknown*<br>(N = 73) | 37% Ireland<br>32% Africa<br>25% other<br>6% unknown*<br>(N = 337) |

* The high incidence of 'unknown' could be interpreted as a reluctance to be identified.





## 2. SOCIETY IN GENERAL

Taken from Studiets 1 and 3

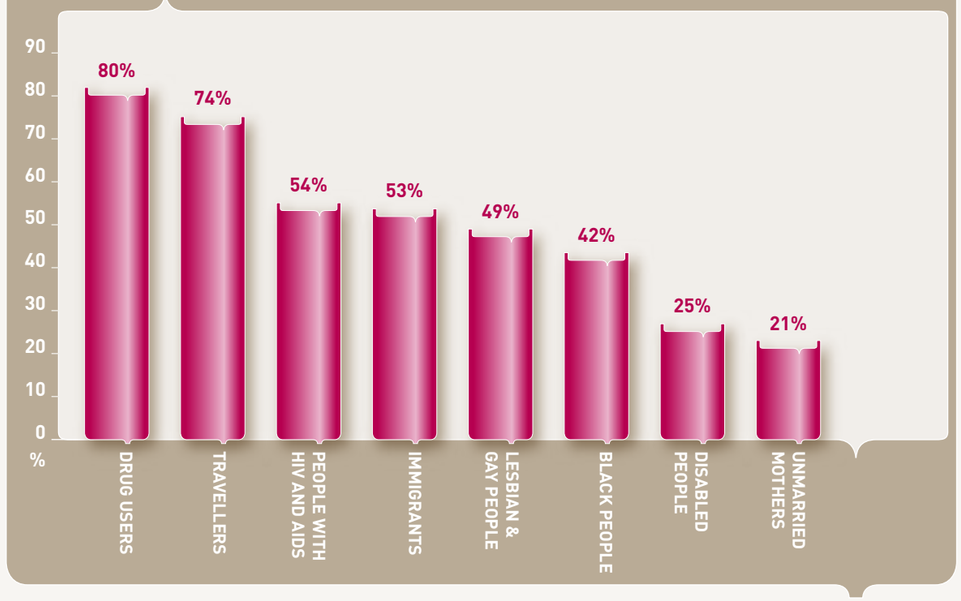
What people living with HIV say:

- 84% of people living with HIV identify societal stigma and discrimination claiming that people with HIV are viewed negatively by society in Ireland today (N = 63).

What the general public says:

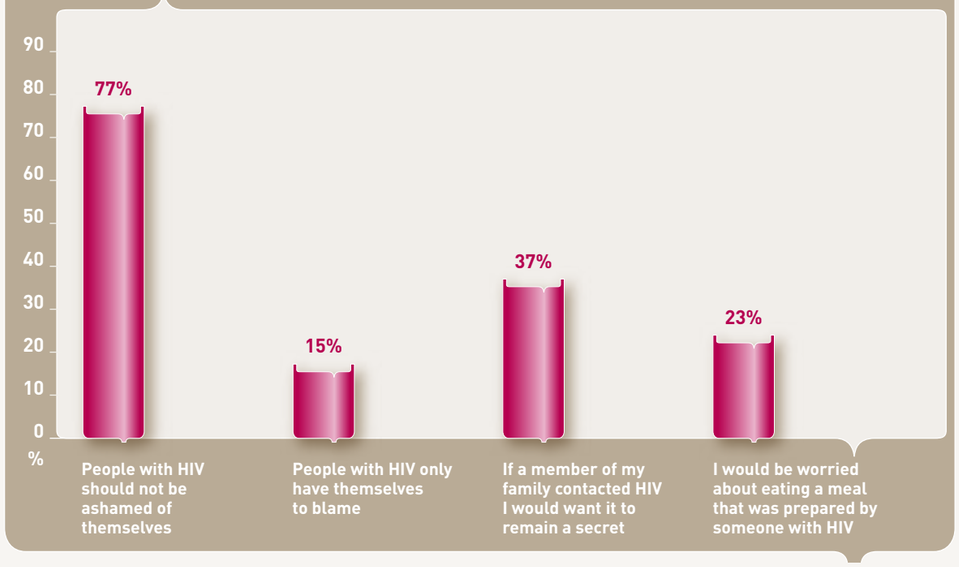
- One in two people claim that people with HIV and AIDS are viewed negatively by society.
- As a minority group in society today, they are the third most likely to suffer from such societal discrimination.
- Drug users and members of the Travelling Community are presumed to suffer higher rates of discrimination.
- There is no demographic variance in the profile of person who says people with HIV and AIDS suffer discrimination.

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




- This negative attitude towards people with HIV is manifested in the response to four attitudinal statements as shown in chart 2.2 below.
- Over one-third of the national population are of the opinion that they would keep the HIV status of a family member secret.
- Almost one quarter would be worried about eating a meal that was prepared by someone with HIV.
- On the other hand, there is sympathy and understanding that people with HIV should not be ashamed of themselves.
- A minority of people think that people with HIV only have themselves to blame.

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



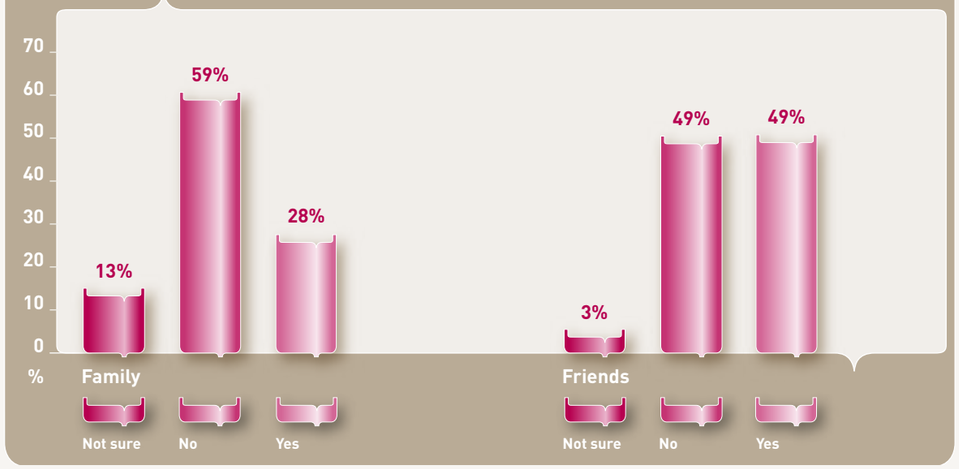

## 3. FAMILY & FRIENDS

Taken from Studies 1 and 3

What people living with HIV say:

- People living with HIV claim that they have experienced greater discrimination by friends than family.
- Almost one half claim discrimination by friends while just over a quarter claim discrimination by family.
- There is greater certainty about discrimination by friends. Over one tenth are uncertain of discrimination by family: claiming that they are 'not sure' that they have experienced such discrimination.

**Chart 3.1.** Ever Experienced Discrimination in Ireland by Family and Friends, % / Family N = 64, Friends N = 66




What the general public says:

- As mentioned in chart 2.2 above, the general public is reluctant to share the HIV status of family members with others – i.e. over one-third of the national population are of the opinion that they would keep the HIV status of a family member secret.





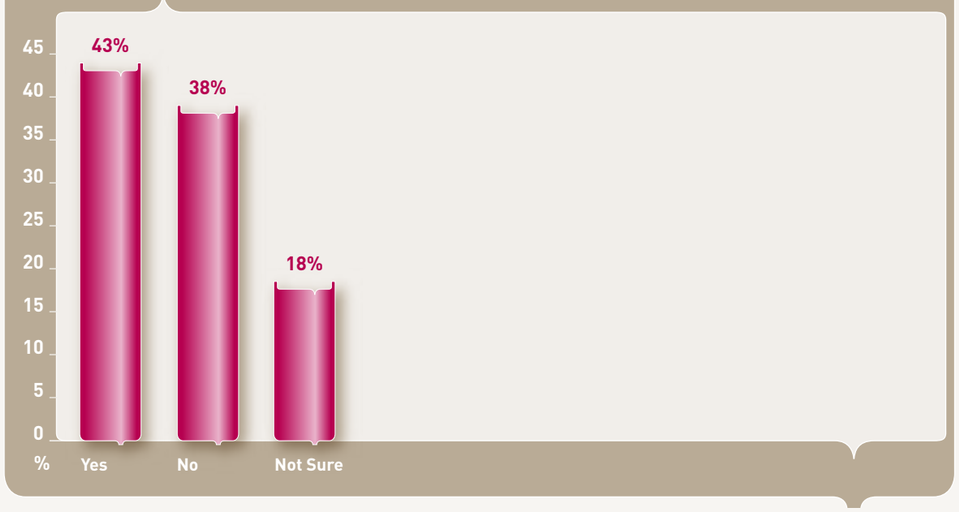
## 4. LOCAL COMMUNITY

Taken from Study 3

What people living with HIV say:

- Two out of every five people living with HIV perceive discrimination by their local community.
- This is higher than discrimination by family but lower than that by friends as illustrated in chart 3.1.
- Almost one in five are not sure – which is higher than either family or friends.

**Chart 4.1.** Ever Experienced Discrimination in Ireland by Local Community, % / N = 60



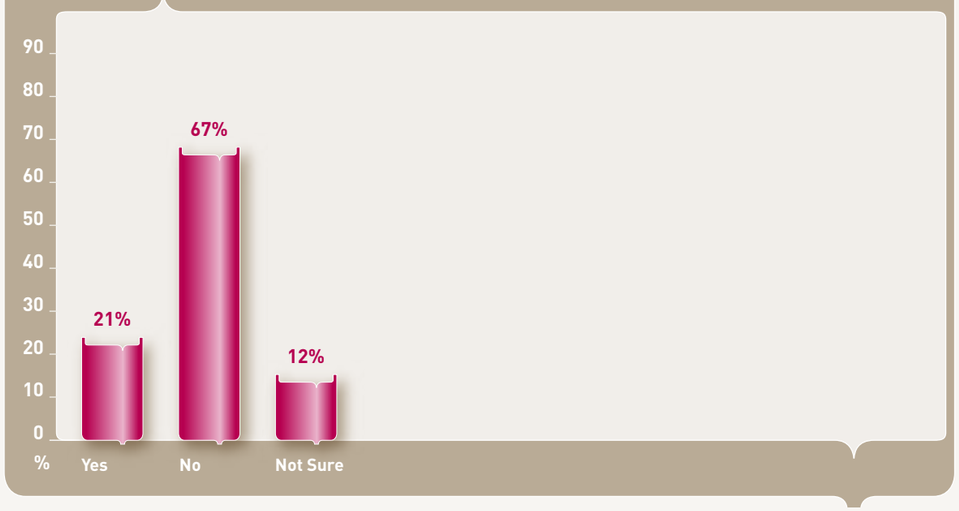

## 5. WORKPLACE

Taken from Studies 2 and 3

What people living with HIV say:

- One fifth of people living with HIV claim to have experienced discrimination in the workplace.
- One tenth are unsure.

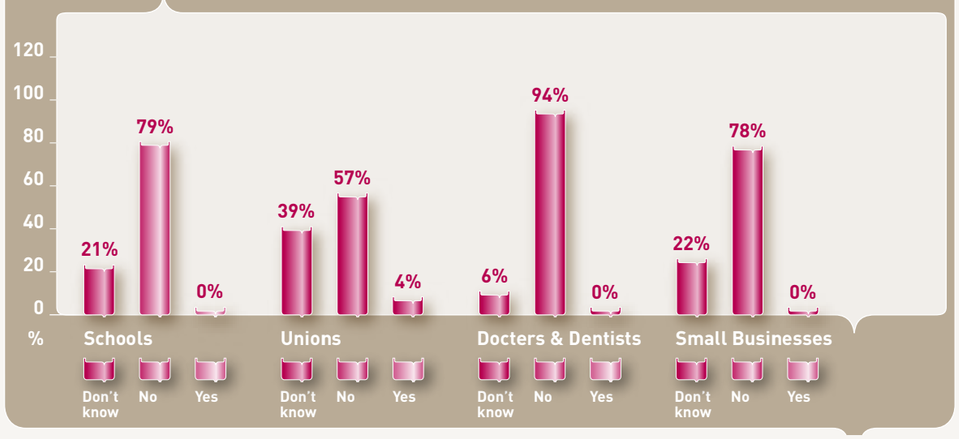
**Chart 5.1.** Ever Experienced Discrimination in Ireland in the Workplace, % / N = 52



**What the workplace says about staff:**

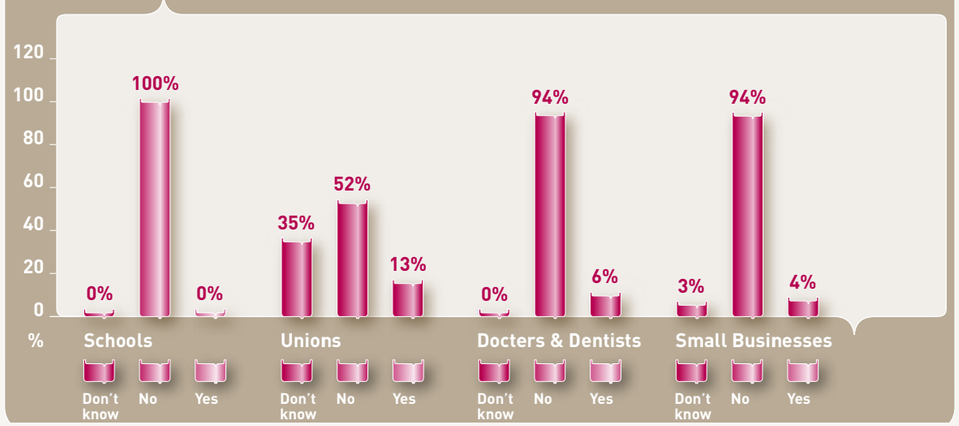
- The research identifies a minimal known presence of people with HIV in the workplace.
- Only one of the four workplaces claimed to have staff who are HIV positive, albeit a low figure: 4% of trade unions.
- There is a noticeable level of uncertainty around the issue. Almost 40% of unions and over 20% of both school and small businesses are unsure of the incidence of HIV among staff. This may be reflecting advances in treatment and increasing ability of PLHIV to remain in work without disclosing their HIV status. Equally it could be a reflection of stigma associated with disclosure.
- The greatest kevel of certainty is among doctors and dentists: only 6% are unsure

**Chart 5.2.** Presence of Staff Members who are HIV Positive,
% Schools / N = 62, Unions N = 23, Doctors & Dentists N = 51, Small Businesses N = 81




- The four workplaces have had minimal experience of dealing with HIV and AIDS issues in relation to staff.
- The highest incidence is among unions: 13%.
- This is followed by doctors and dentists at 4% and small businesses at 4%.
- Schools have had no incidence at all.
- Again, there is limited uncertainty around this – with the most notable level being among unions: 35%.

**Chart 5.3.** Ever Dealt with an HIV and AIDS issue in Relation to Staff,
% / Schools N = 62, Unions N = 23, Doctors & Dentists N = 50, Small Businesses N = 81

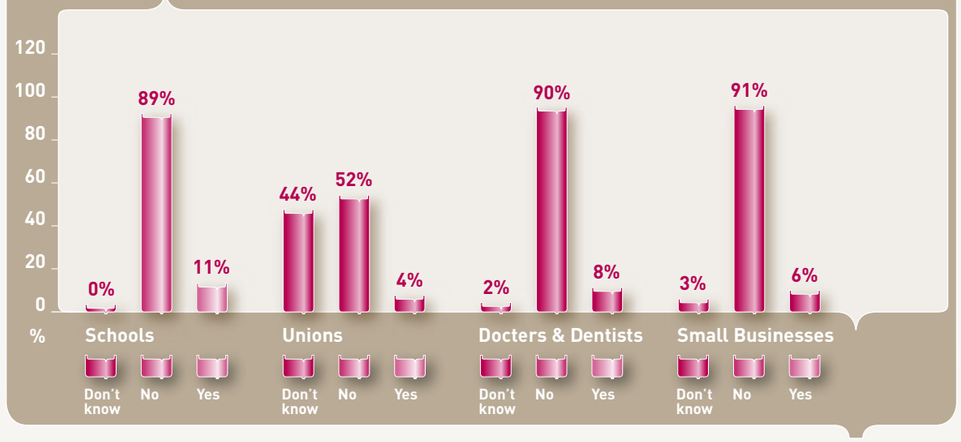






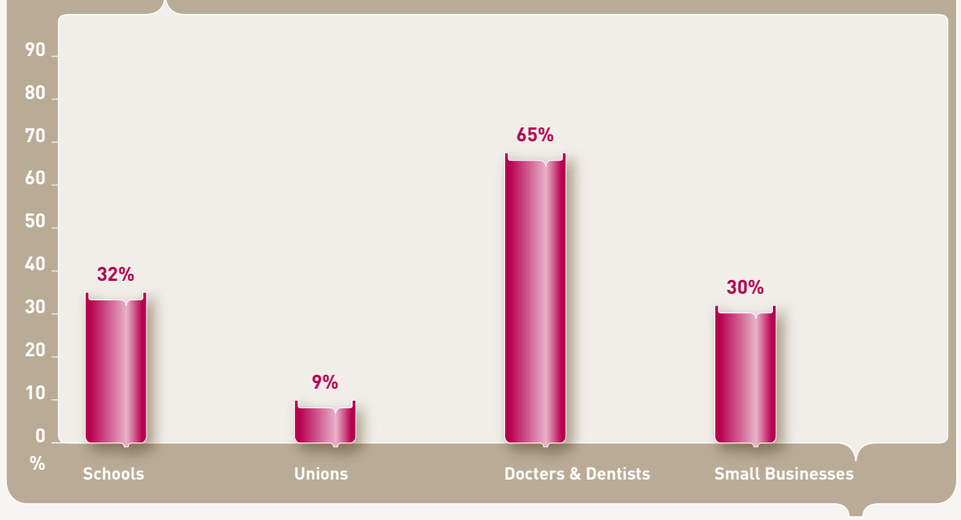

- There is a low occurrence of procedures for dealing with issues relating to staff who are HIV positive.
- This is in keeping with the low incidence of staff with HIV; thus, indicating a minimal need for procedures.
- It is the highest for schools; followed by doctors & dentists and small businesses, albeit minimal.
- It is the lowest for unions and they demonstrate the greatest uncertainty too.

**Chart 5.4.** Any procedures in place for dealing with HIV issues in relation to staff,
% / Schools N = 62, Unions N = 23, Doctors & Dentists N = 50, Small Businesses N = 81




- There appears to be no universal or formal procedure in place.
- The procedures draw on the issue of health and safety in the workplace.
- There is a focus on hygiene precautions and the issue of preventing transmission.
- There is a recognised need for expertise and guidance in dealing with HIV issues among staff.
- There was reference to the management of discrimination of staff with HIV in the workplace.
- There are concerns about employing people with HIV.
- This concern is greatest among doctors and dentists at 65% - which is twice as high as schools and small businesses.
- The lowest level of concern is among unions at 9%.

**Chart 5.5.** Any Concerns about Employing People with HIV,
% / Schools N = 62, Unions N = 23, Doctors & Dentists N = 51, Small Businesses N = 81



- The concerns are many and varied – and differ according to the workplace.
- The schools expressed:
  - Concerns for the health of the person with HIV and his/her work performance as well as the transmission of HIV to others.
  - They are concerned about the reactions of others and the stigmatization of the person with HIV.
  - They are also concerned about the school's information and knowledge regarding HIV.
  - Likewise, the two unions mentioned concern for the health of the person with HIV.
  - Doctors and dentists and small businesses focus their concern on the impact on the workplace more than on the individual with HIV:
  - The main concern is for the transmission of HIV.
  - There is concern for the performance of the HIV+ person in terms of their capability and productivity.
  - There is mention of the risk to the workplace reputation and the reaction of others.
  - There is a concern for the management by the workplace of the HIV issue.
  - There is minimal reference to the health of HIV+ person, especially among doctors and dentists.
  - Non-disclosure is an issue for doctors and dentists in particular.

**What the unions say about members:**

- There is low awareness among the 23 unions interviewed of members who are HIV positive. 13% answered 'yes' but a large majority of 74% answered 'don't know.
- There is also a high level of uncertainty of having ever dealt with an issue in relation to a union member who is HIV positive: 61% 'don't know' while 17% claim 'yes'.
- No union has procedures in place for dealing with HIV issues in relation to members: 48% said 'no' while 52% said 'don't know.

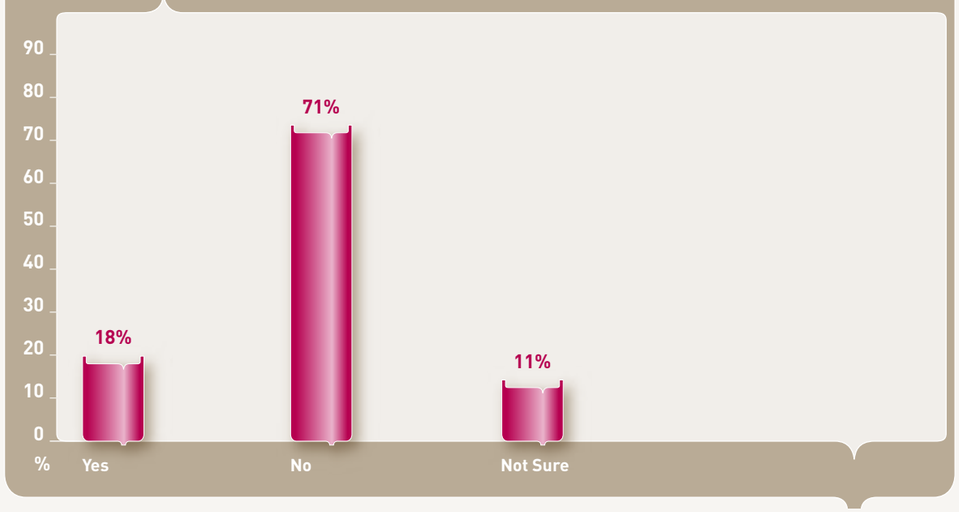
## 6. STUDENTS

Taken from Studies 2 and 3

**What people living with HIV say:**

- One in five people living with HIV claim to have experienced discrimination in school or college.
- One in ten are unsure.

**Chart 6.1.** Ever Experienced Discrimination in Ireland in School or College, % / N = 44








**What schools say:**

- There is minimal experience of students with HIV in the 62 secondary schools interviewed.
- Only 5% claim to have students who are HIV positive. There is a high level of uncertainty about this: 39% are unsure.
- A few, 7%, have received an application for a school place from a student who is HIV positive; 3% are unsure.
- Only 8% have had to deal with an issue that related to HIV and AIDS in relation to a student.
- Despite this, one quarter, 24%, claim to have procedures in place for dealing with issues relating to students who are HIV positive. They primarily involve the adaptation of other policies & procedures in the school rather than a dedicated policy; and focus on the care of the individual with HIV.
- One third, 32%, have concerns about taking students who are HIV positive. These concerns focus on the health of the person with HIV, transmission and general 'health concerns'. There are concerns for the reaction of others as well as stigmatization of the HIV+ person. There are also concerns for the school's management of HIV issues in terms of precautions and knowledge.

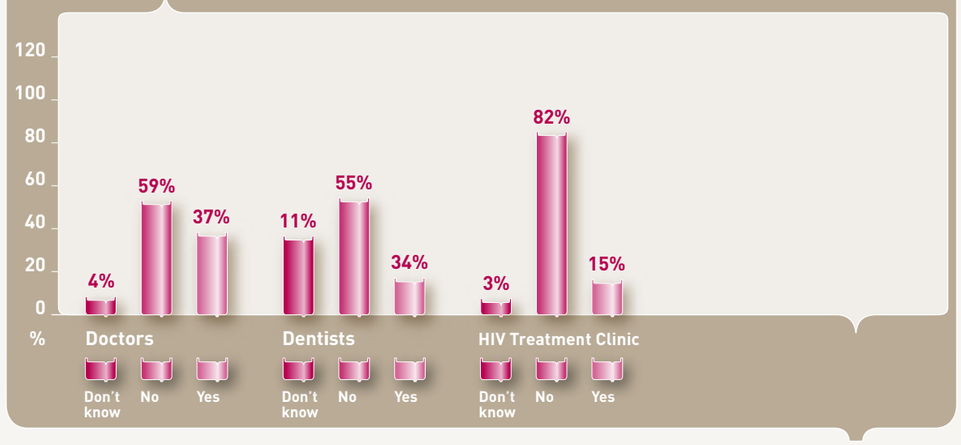
## 7. PATIENTS

Taken from Studies 2 and 3

**What people living with HIV say:**

- There is an apparent high incidence of discrimination by doctors and dentists towards people living with HIV.
- Over one third of people living with HIV made this claim: 37% for doctors and 34% for dentists.
- On the other hand, the experience of discrimination in a HIV Treatment Clinic is notably low: 15%.
- There is some level of uncertainty around these experiences, being greatest for dentists: 11%.

**Chart 7.1.** Ever Experienced Discrimination in Ireland by a Doctor, a Dentist and a HIV Treatment Clinic, % / Doctors N = 70, Dentists N = 62, HIV Treatment Clinic N = 67




**What doctors and dentists say:**

- There is a high incidence of treating patients with HIV by the 51 doctors and dentists interviewed: 78% claim such. There is a high level of certainty about this: only 2% answered 'don't know'.
- Just over a half (52%) of the doctors and dentists have ever dealt with an issue that related to HIV and AIDS in relation to a patient; only 2% are unsure (N =50).
- One half of doctors and dentists, 53%, claim to have procedures in place for dealing with issues relating to patients who are HIV positive (N =50). This is lower than the apparent need: 78% have patients who are HIV positive. This could be explained by having universal precautions in place where all patients are seen as a potential risk for HIV rather than having special procedures pertaining to HIV and AIDS specifically.
- The 53% who claim to have procedures describe the focus being on hygiene and infection controls.

In addition, there are dedicated appointments and time allocations. There is also some reliance on referral to others.

- Almost one half, 47%, expressed concern about taking patients who are HIV positive. The concerns focus on the impact on the practice in terms of necessary precautions and management issues. The greatest single concern is fear for transmission of HIV. There is some concern for the stigmatization of the individual.

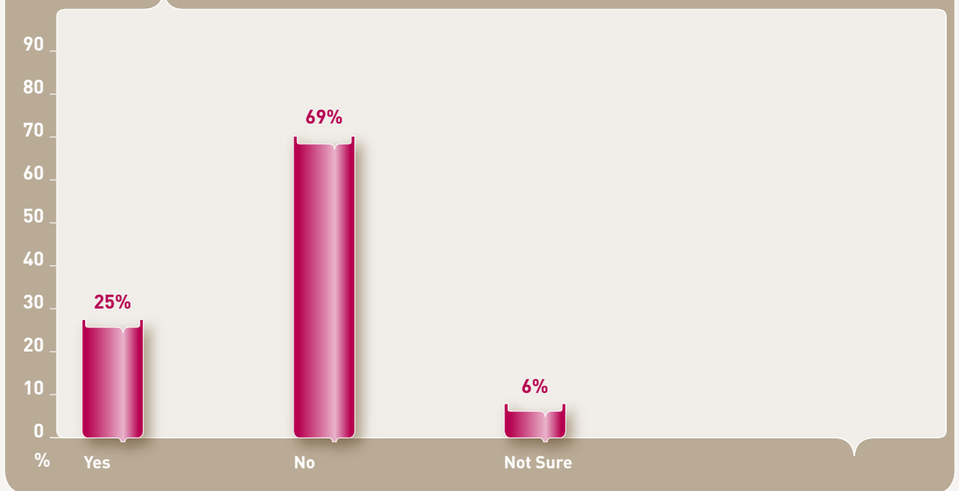
## 8. SOCIAL WELFARE

**Taken from Study 3**

**What people living with HIV say:**

- One in four people living with HIV claim to have experienced discrimination by social welfare.
- There is a high level of certainty about this: only 6% are not sure.

**Chart 8.1.** Ever Experienced Discrimination in Ireland by Social Welfare, % / N =65




## 9. INFORMATION & GUIDELINES

**Taken from Studies 2 and 3**

**What people living with HIV say:**

- Half of the people living with HIV have received information on HIV stigma and discrimination: 51% (N = 70).

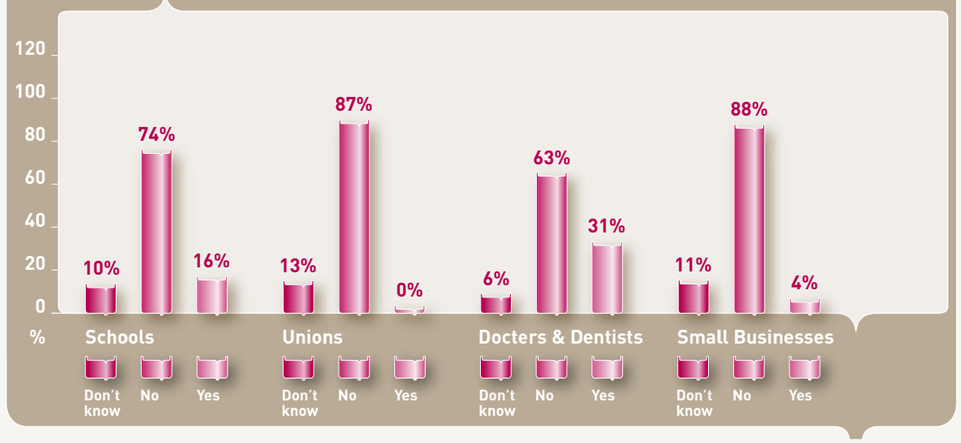
**What the workplace says:**

- There has been limited receipt of any information or guidelines on managing HIV issues in the workplace.
- The highest incidence is among doctors and dentists: one in three has received such.
- This is followed by schools: 16%.
- A very small proportion of small business received: only 4%.
- No unions claim to have received any information or guidelines.
- There is some uncertainty around this – averaging at around 10% overall.



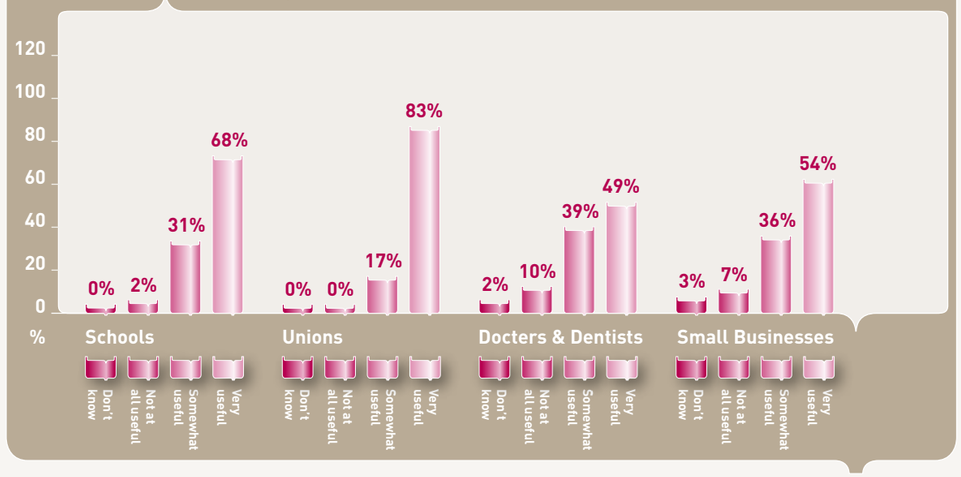


**Chart 9.1.** Receipt of Information or Guideline on Managing HIV Issues in the Workplace
% Schools N = 62, Unions N = 23, Doctors & Dentists N = 51, Small Businesses N = 81




- There is a high appreciation by all four workplace groups for the usefulness of receiving information or guidelines on managing HIV issues in the workplace.
- The highest level of appreciation is by unions: 83%.
- The lowest is by doctors & dentists: 49%. This may be attributed to the fact that many claim previous knowledge already
- Over two thirds of schools and over one half of small businesses claim a high level of usefulness also.
- There is very little uncertainty on this matter.

**Chart 9.2.** Usefulness of Receiving Information or Guidelines on Managing HIV Issues in the Workplace, % Schools N = 62, Unions N = 23, Doctors & Dentists N = 51, Small Businesses N = 81




- The main sources of advice on managing HIV issues in the workplace are similar for all four workplaces.
- Respondents identified health specific statutory bodies and relevant professional bodies such as:
  - HSE, Department of Health and Children, Equality Authority and other government bodies or agencies.
  - ASTI, TUI, VEC, ICTU, Irish Dental Association, ICGP, IBEC, ISME and others.
- There are variances by workplace group:
  - Schools mainly use the HSE but they also source others.

- Unions almost equally seek advice from 4 sources: HSE, ICTU, Equality Authority and Department of Health & Children
- Doctors & dentists rely on their own professional groups and organizations as well as state bodies and hospitals
- Small businesses rely on Department of Health & Children, IBEC and HSE as well as a range of other sources
- There is some uncertainty about where to source advice.

## 10. ILLEGALITY OF DISCRIMINATION

**Taken from Studies 2 and 3**

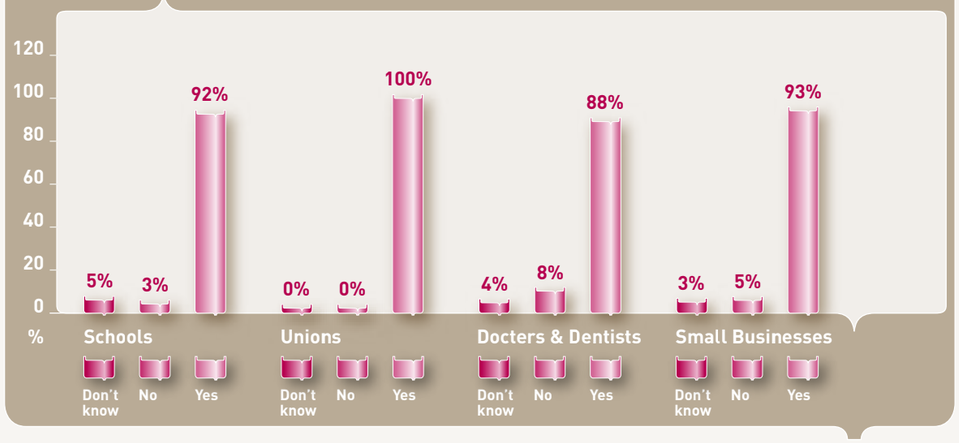
**What people living with HIV say:**

- Just over half (56%) of people living with HIV are aware that it is illegal to discriminate against a person with HIV (N = 70).

**What the workplace says:**

- There is a high awareness among the four workplace groups that it is illegal to discriminate against a person with HIV.
- The unions are the most aware: all 23 claim they know this.
- Approximately 90% of other 3 niches are aware: 93% of small businesses, 92% of schools and 88% of doctors and dentists.
- A small proportion of uncertainty is expressed.

**Chart 10.1.** Did you know it is illegal to discriminate against a person with HIV in the workplace/school?, % Schools N = 62, Unions N = 22, Doctors & Dentists N = 50, Small Businesses N = 81








## CONCLUSIONS

- HIV-related Stigma and discrimination exists in Irish society today.
- Stigma is experienced by those living with HIV in all walks of their lives: especially by friends & local community as well as by the medical/dental professions; this also includes family, social welfare services, the educational system and employment.
- Stigma manifests itself in the negative attitudes of the general public: People with HIV are the third highest group to be viewed negatively by society.
- There is significant ignorance and fear in terms of the transmission and management of HIV issues in the four workplace groups: this is expressed in the procedures used, the concerns evoked and the notable need for information.
- GPs and Dentists demonstrate comparatively high levels of concern regarding the provision of treatments to PLHIV: as reported by people with HIV and as expressed by doctors & dentists themselves.
- There is a critical need for information and guidance: to alleviate concerns and misconceptions about interacting with people with HIV.
- There is need for information on stigma and discrimination for people with HIV: only fifty percent of PLHIV claim that they have received such.
- There is apparent non-disclosure by people with HIV of their status: reinforcing negative expectations around stigma and discrimination and the need for information.
- The illegality of discrimination is accepted: it is possibly expected rather than clearly understood. There is comparatively low awareness of the illegality of discrimination among PLHIV.
- There is a critical role for communication to alleviate stigma & discrimination: on both sides:
  1. People living with HIV
  2. The general public as well as specific target groups such as work, schools, medical profession, social welfare, etc.
- This study establishes a benchmark against which future developments and progress can be compared: it identifies the value of research 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

## RECOMMENDATION 1:

Further research is needed to understand the impact of HIV-related stigma and discrimination on the population of PLHIV.

Rationale: While this bench marking exercise is a positive first step, this report highlights the need for further research into stigma and discrimination in Ireland and which should reflect international best practice.

- Further research should be carried out with larger numbers of the sub-groups surveyed to give a representative and clear view of HIV related stigma in Ireland today.
- There is a need to separate out and examine experiences of stigma and discrimination by PLHIV to give a clearer picture of stigma and discrimination in Ireland.
- Research should focus on the different sub-populations of PLHIV and examine whether experiences of stigma and discrimination are influenced by membership of particular sub-groups.
- Further research is needed to examine the phenomenon of lower stigma levels being associated with distance from the issue. i.e. the finding that there are greater feelings of stigma associated with HIV when it becomes a personal issue.

## RECOMMENDATION 2:

A national information strategy on the rights of PLHIV will be developed targeting HIV positive people as well as employers and service providers.

Rationale: A need for information and guidelines on the rights of PLHIV was expressed by all participants in the study.

- PLHIV will have greater awareness of their rights with regard to employment and the take-up of services, including health, social services, education and housing.
- Employers, unions, schools and other educational institutions, primary health care providers, housing bodies will have greater awareness that to discriminate on the basis of HIV status is illegal under the Employment Equality Act 1998 and the Equal Status Acts 2000 and 2004.

## RECOMMENDATION 3:

A national standard to measure stigma and monitor discrimination towards PLHIV will be developed.

Rationale: In order to assess levels and types of stigma and discrimination and develop effective programmes it is crucial to understand the phenomenon of stigma in Ireland. It is also vital to document the evidence. A set of validated indicators will be developed for agencies' monitoring and evaluation systems to track and report on stigma and discrimination.

## RECOMMENDATION 4:

A national intervention strategy will be resourced to continue highlighting HIV-related stigma and discrimination.

## RATIONALE:

The Stamp out Stigma campaign 2007 has been a very successful first step in challenging HIV-related stigma in Ireland. It is recognised, however, that challenging HIV-related stigma requires a sustained and comprehensive intervention involving PLHIV and service providers. As indicated in the findings, PLHIV experience stigma and discrimination in the community and in a number of service delivery settings.

## INTERVENTIONS WILL INCLUDE :

- liaison with professional bodies, training institutions and other representative bodies.
- capacity building to encourage the greater involvement of PLHIV in highlighting stigma and discrimination.

## Stigma:

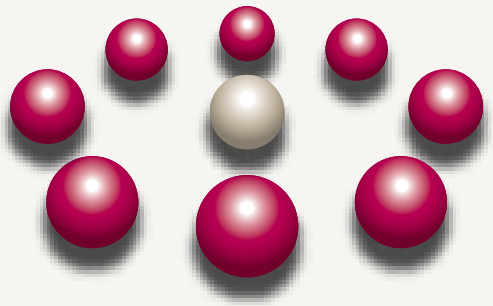
Stigmatization is a social practice that brands an individual or group as disgraceful and devalues them because of some actual or perceived characteristic. It is a powerful force that negatively influences not only the way an individual or group is viewed, but also often the individual or group's self-perception and self-image.

*(Source USAID, January 2006, Can We Measure HIV&AIDS Related Stigma and Discrimination)*

## Discrimination:

When stigma is acted upon, the result is discrimination. Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatised.

*(Source UNAIDS, 2005, HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programme)*



STAMP OUT STIGMA

Challenging HIV and AIDS discrimination

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