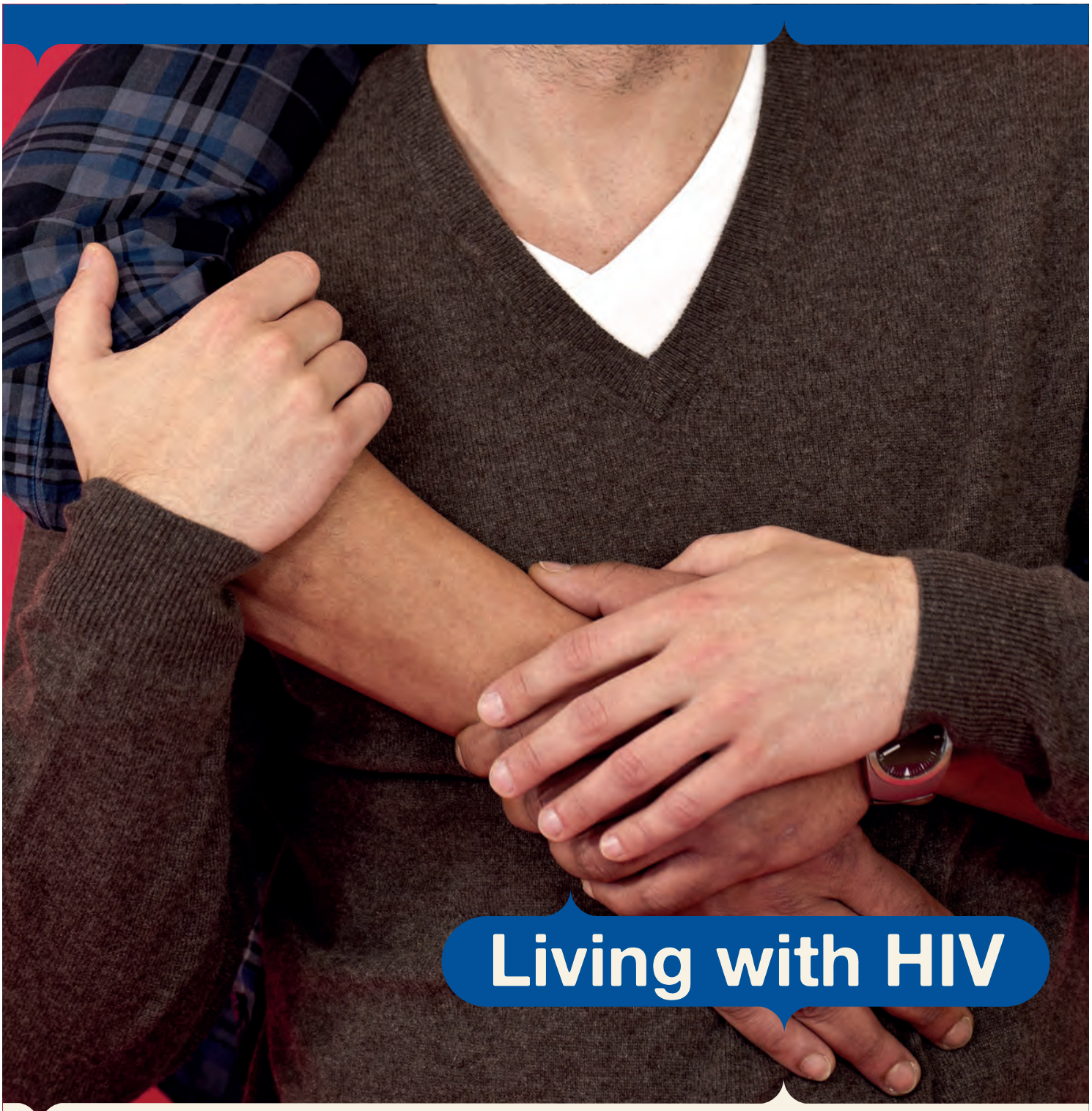

Living with HIV

All-Ireland findings from the 2010 European MSM Internet Survey (EMIS)

Man2Man: Report Two

Daniel McCartney
Mick Quinlan (GMHS HSE)
Susan Donlon (GHN)
Dr Thomas Strong (GHN)
Harry McAnulty (The Rainbow Project)

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GMHS
Féidhmeannacht na Seirbhíse Sláinte
Health Service Executive
GAY HEALTH NETWORK
the rainbow project

Living with HIV

"Living with HIV' is the second of four thematic reports to be published in the 'Man2Man' series. These reports aggregate data generated in the 2010 European MSM Internet Survey (EMIS), and represent the largest ever research sample of men who have sex with men (MSM) across the 32 counties of Ireland. Each report contains information relevant to those working to improve the sexual health and well-being of MSM and presents evidence relevant to policy and programme design for gay and bisexual men in both Northern Ireland (NI) and the Republic of Ireland (RoI).

The EMIS data was significant to the development of the first National HIV Preventions and Sexual Health Programme for MSM in Ireland, a joint initiative by the Gay Health Network and Health Service Executive (HSE).
Launched on 1st. December, 2011, World AIDS Day, this year-long social media campaign is available at www.man2man.ie

Thank you!

All-Ireland findings from the 2010 European MSM Internet Survey (EMIS)

Man2Man Report 2:	Living with HIV	
Published by:	Gay Men's Health Service HSE, Gay Health Network, and the Rainbow Project (June 2012)	
Data Analysis:	Daniel McCartney	
Report Design:	Maurice Farrell	www.Creationpod.ie
Text Editor:	Aengus Carroll	
Funding:	GMHS HSE and GHN	
For Further Information:	www.gmhs.ie www.ghn.ie www.rainbow-project.org	e: gmhsadmin@hse.ie e: info@ghn.ie e: director@rainbow-project.org
EMIS and Other Country Reports:	www.emis-project.eu	

GMHS, GHN and the Rainbow Project would like to acknowledge all of you who completed the questionnaire; the HIV, sexual health and LGBT groups and organisations, social venues and websites who promoted the survey in Ireland and the scientists who organised and conducted EMIS between 2009 and 2011: Axel J. Schmidt (Project co-ordination); Ulrich Marcus (Project initiation and supervision); Peter Weatherburn (Promotion co-ordination); Ford Hickson and David Reid (Technical implementation); Harm J. Hospers (Questionnaire drafting).

The EMIS survey - Introduction:

The European MSM Internet Survey (EMIS) was a joint project of academic, governmental, and non-governmental partners from 33 countries in Europe (EU and neighbouring countries) to simultaneously run an online questionnaire in 25 different languages. This pan-European survey collected information on the knowledge, attitudes, needs and behaviours of men who have sex with men (MSM), including those who identify as gay or bisexual, in relation to HIV, sexual health, and well-being. The EMIS questionnaire was available online between June 4 and August 31, 2010. Following the slogan ***"Be part of something huge!"*** more than 180,000 MSM living in 35 European countries completed the survey, making EMIS the largest international study ever conducted on MSM.

The lead agency, the Gay Men's Health Service (GMHS) - Health Service Executive (HSE) - collaborated with the Gay Health Network (GHN) and the Rainbow Project NI in producing additional analysis and reporting for the all-Ireland dataset. Overall, there were a total of 2,610 valid respondents - 2,194 (RoI) and 416 (NI). Man2Man Reports are available at www.ghn.ie or www.emis-project.eu

Living with HIV in Ireland

This second report focuses on the EMIS survey respondents who indicated that they had tested positive for HIV. In total, 143 men indicated that they were living with HIV in the 2010 survey, representing 5.5% of the total sample. This represents the largest ever all-Ireland sample of gay, bisexual, and other MSM living with HIV. Previous all-Ireland surveys between 2000 and 2008 each yielded an average of 28 respondents living with HIV, thereby not allowing for any meaningful analysis or recommendations. The aim of this second report is to provide insight into five of the key issues faced by gay, bisexual and other MSM living with HIV in Ireland: testing positive; monitoring and treatment; sex lives; relationships and disclosure; and HIV-related stigma.

Demographics

This section further describes the sample of 143 men living with HIV. Of the 143 respondents, approximately 92% were living in the Republic of Ireland and 8% were living in Northern Ireland. The majority of the men reported living in Dublin City and County (51%; n=73). This was more than nine times greater than the second greatest proportion that indicated living in County Cork (5%; n=8). However, a total of 23 respondents (15%) did not report the county where they lived. A total of 34 men indicated that they were born outside of the island of Ireland, representing 24% of the sample. Among those born abroad, over one-quarter (26.5%) were born in England or Scotland.

Country of residence	# of respondents	%
Northern Ireland (NI)	12	8.4
Republic of Ireland (RoI)	131	91.6
Total	143	100.0

The average (mean) age of men living with HIV was 38.1 years, with the median age being 38 years, indicating that half of respondents were aged 38 years or less. The most represented five-year age group was 35-39 (25% of respondents), followed by those aged 40-44 (18%), and those aged 30-34 (17%). Less than one-tenth of respondents were aged 24 years or younger (8%). This represents an older sample compared to the entire sample, where the overall mean age of survey respondents was 33.2 years, with one-quarter of respondents aged 24 years or younger.

Age groups (n=143)	**% Overall**
19 years old or under	1.4
20 – 24 years old	7.0
25 – 29 years old	7.0
30 – 39 years old	42.0
40 – 49 years old	32.9
50 years old or over	9.8

Most respondents (88%) reported being sexually attracted only to men, and 12% were attracted to men and women. A total of 92% identified themselves as gay, with 3% identifying as bisexual. Compared to the entire survey sample, men living with HIV were more likely to identify as gay and be sexually attracted only to men. Men living with HIV were also more open about their sexual orientation to others, with 57% reporting they were 'out' to most people compared to 40% of the entire sample.

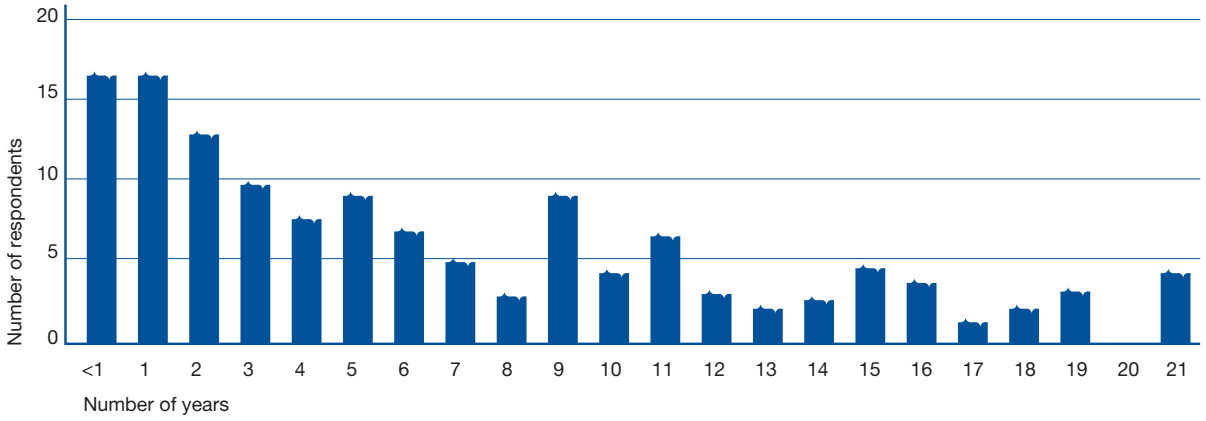
Almost three-quarters of respondents (73%) reported a high level of education (university degree or higher). Over two-thirds (69%) were employed (full or part time), 9% were students, 8% were unemployed, and 13% were classified as 'other' employment status. This included 11% of the HIV+ sample who indicated that they were on long-term sick leave or medically retired; a much higher proportion compared to the entire survey sample where only 1.4% indicated this.

Key issues for HIV-positive MSM:

1. Testing positive

Survey respondents who indicated that they had tested positive were subsequently asked: ***'In which year were you first diagnosed HIV positive?'*** and requested to enter the year. From this information, the number of years diagnosed positive was calculated.

Graph: Number of years diagnosed HIV positive (n=127, missing 16)



At the time of the survey, the average length of time diagnosed HIV positive was 6.3 years, ranging from diagnosed within the previous 12 months to being diagnosed 21 years ago in 1989. Half of the respondents (49.6%) were diagnosed HIV positive for less than 5 years, with one-quarter (25.2%) diagnosed for less than two years.

Those who had been diagnosed within the last ten years at the time of the survey (2001 or later) were asked, ***'When you were first diagnosed with HIV, what was your CD4 count?'*** and could select one of the following: *Less than 200 cells per µl; 200-349 cells per µl; 350-500 cells per µl; More than 500 cells per µl; I don't remember or I don't know.* Of the 95 men who were diagnosed HIV positive within the last ten years, 83.2% (n=79) were able to recall their CD4 count at diagnosis. The following table shows reported CD4 count by number of years since diagnosis.

CD4 count at diagnosis (n=79, missing 16)	**<1 to 4 years**	**5 to 9 years**	**% Overall**
Less than 200 cells per µl	17.3	14.8	16.5
200-349 cells per µl	21.2	18.5	20.3
350-500 cells per µl	26.9	33.3	29.1
More than 500 cells per µl	34.6	33.3	34.2

A patient whose CD4 count at the time of diagnosis is below 350 cells per µl is considered to have a late diagnosis. Late diagnosis is associated with poorer clinical outcomes as well as increased risk of onward transmission. Over one-third (36.8%) of men who remembered their CD4 count fit the criteria for a late diagnosis. The percentage of late diagnoses has increased slightly (though not significantly) to 38.5% among those diagnosed within the last 4 years from 33.3% among those diagnosed 5 to 9 years ago. Men aged 40 years or older were most likely to report a late diagnosis (48.3%), while less than one-quarter (22.7%) of men under the age of 40 years reported a late diagnosis. These data suggest that the rate of late diagnosis has remained constant over the last 10 years, and that older MSM are more at risk for late diagnosis. Moreover, they highlight the continuing need for easy and routine access to HIV testing across all age groups of MSM.

2. Monitoring & Treatment

Participants were asked a series of questions related to monitoring and treatment of their HIV infection. The survey asked: ***'Are you currently taking antiretroviral treatment?'***. Almost three-quarters of respondents (72.7%) indicated that they were currently taking antiretroviral treatment. This substantial percentage is an important positive finding of the survey, and suggests that access to treatment is widely available.

The 39 respondents who indicated that they were not currently on treatment were subsequently asked: ***'Why have you never taken antiretroviral treatment for your HIV infection?'*** and requested to select as many as applied from the eight reasons listed.

Reasons for not taking antiretroviral treatment (n=39)	%
My doctor says I don't need antiretroviral treatment at the moment	79.5
I feel it is not necessary	10.3
To avoid the side-effects	2.6
I'm afraid people will notice	2.6
I don't want to be reminded about HIV every day	2.6
The treatment is not available in the country I live in	2.6
I can't afford the treatment	2.6
Other reason	10.3

The most common reason for not currently being on treatment was having received medical advice that treatment was not required at the time. A much smaller proportion indicated that they personally did not feel it necessary to be on treatment.

For people living with HIV, it is recommended that both CD4 count (a measure of immune system strength) and viral load (a measure of HIV level in the bloodstream) tests be given every three to six months. Respondents were asked: ***'When did you last see a health professional for monitoring your HIV infection?'***. Almost half of all men (44.9%) had been in the past month, while almost all (97.1%) had visited in the past six months. This suggests a high-level of access to HIV-specific medical care in Ireland.

It is also recommended that men living with HIV get tested for other sexually transmitted infections (STIs) regularly (every six months if sexually active), since other infections can increase the risk of HIV transmission and affect viral load. The survey asked all men: ***'When did you last have a test for STIs other than HIV?'***. Overall, over half of men living with HIV (56.6%) reported receiving a test for STIs within the previous six months, while three-quarters (74.8%) received a test within the last year. This is a significantly greater level of testing for STIs among HIV positive men than the entire EMIS survey sample, where just over one-third of men (36.6%) reported testing for other STIs within the previous twelve months.

Viral load is measured by a blood test and helps to inform decisions about treatment. An undetectable viral load normally means that the immune system, together with antiretroviral treatment, is successfully controlling HIV infection. Men were asked: ***'What was the result of your viral load test the last time you had your HIV infection monitored?'***.

Result of previous viral load test (n=136, missing 7)	%
Undetectable	64.0
Detectable	24.3
I was told but I don't remember the result	3.7
It was measured but I was not told the result	1.5
It was not measured	1.5
I don't remember	5.1

Of the 120 men who remembered the result of their last viral load test, 72.5% reported their viral load being undetectable and 27.5% had a detectable viral load. Of the men currently on treatment, 85.6% (n=83) indicated that their previous viral load test was undetectable.

The risk of HIV transmission during unprotected sex is directly related to the level of HIV present in the bloodstream - the lower the viral load, the lower the risk of transmission. To assess knowledge of this fact, men were asked if they knew that the following statement is true: ***'Effective treatment of HIV infection reduces the risk of HIV being transmitted.'***

Among men living with HIV, over three-quarters (76.2%) indicated that they knew this already. While this is greater than the 50% of the entire EMIS sample that knew this, it is important to note that approximately one-quarter of men living with HIV in this sample did not know this. There was a relatively small difference in knowledge of those currently on treatment (77.9%) compared to those who were not on treatment (71.8%). Awareness of the relationship between effective treatment and prevention of onward transmission of HIV provides incentive for testing and treatment, and underscores the importance of adherence to treatment regimens.

3. Sex Lives

The survey asked a series of questions related to the sex lives of respondents. Men were asked: ***'Are you happy with your sex life?'***. A majority of respondents with HIV (52.9%) reported that they were happy with their sex life. A similar proportion (53.4%) of men who had not tested HIV positive responded that they were happy with their sex lives.

The men living with HIV who responded that they were not happy with their sex lives, were asked: ***'Why are you not happy with your sex life?'*** and could select as many that applied from a list of 14 possible reasons.

I am unhappy about my sex life… (n=59, missing 6)	**%**
I worry about passing on HIV or other STIs	29.2
I want a steady relationship with someone	27.7
I am not as sexually confident as I want to be	17.5
I would like more sex with the man/men I have sex with	15.3
My health problems interfere with sex	13.9
I have problems getting or keeping a hard-on (erection)	13.1
My sex drive is too low	8.8
I would like more sexual partners	8.0
I am not having any sex	7.3
I worry about picking up HIV or other STIs	5.8
I have problems in my steady relationship	6.6
I worry about having too many sexual partners	3.6
My partner's health problems interfere with sex	0.7
Other reason	4.4

The most common response was worry about passing on HIV or other STIs. This response was significantly greater among this group than those who were not diagnosed HIV positive (29.2% vs. 2.0%). This highlights that concern about transmitting HIV is prevalent among men living with HIV, and that they see this as contributing to sexual dissatisfaction. Men who had not tested positive for HIV were significantly more concerned about picking up HIV or other STIs compared to men diagnosed HIV positive (14.8% vs. 5.8%).

The second most common reason was that they wanted a steady relationship with someone, however this was not significantly different to those who were not diagnosed HIV positive (27.7% vs. 25.5%). Other reasons with significantly different response rates between the groups included health problems that interfere with sex (13.9% vs. 3.1%) and problems getting or keeping an erection (13.1% vs. 7.0%).

4. Relationships & Disclosure

The survey asked participants a series of questions about 'steady' and 'non-steady' relationships. 'Non-steady' meant men they have had sex with only once, or men they have had sex with more than once but who they don't consider as a 'steady' partner.

Over one-quarter (25.9%) of men diagnosed HIV positive indicated that they were currently in a 'steady' relationship with a male partner. To determine the sero-concordancy of these steady relationships, respondents were asked: ***'Do you and this steady male partner have the same HIV status?'***, and could select one of the following: *Yes, we have the same HIV status; No, one of us is positive and the other is negative; Don't know whether we have the same status or not.*

HIV status of steady male partner (n=37)	%
Yes, we have the same HIV status (sero-concordant relationship)	29.7
No, one of us is positive and the other is negative (sero-discordant relationship)	67.6
Don't know whether we have the same status or not	2.7

Of the 37 men who reported being in steady relationships with a male partner, over two-thirds (67.6%) reported that their partner's HIV status was negative, while almost one-third (29.7%) had a partner who was also HIV positive.

88.1% of men living with HIV in the survey reported having at least one non-steady sexual partner in the previous 12 months. The survey asked a series of questions about the most recent occasion the respondents had sex with a non-steady sexual partner. One of these questions asked: ***'What did you tell him about your HIV status before or during sex?'***.

Disclosure of HIV status with last non-steady sexual partner (n=119)	%
I said nothing about my HIV status	55.5
I told him I was HIV positive	37.8
I told him I didn't know my HIV status	3.4
I told him I was HIV negative	1.7
I don't remember	1.7

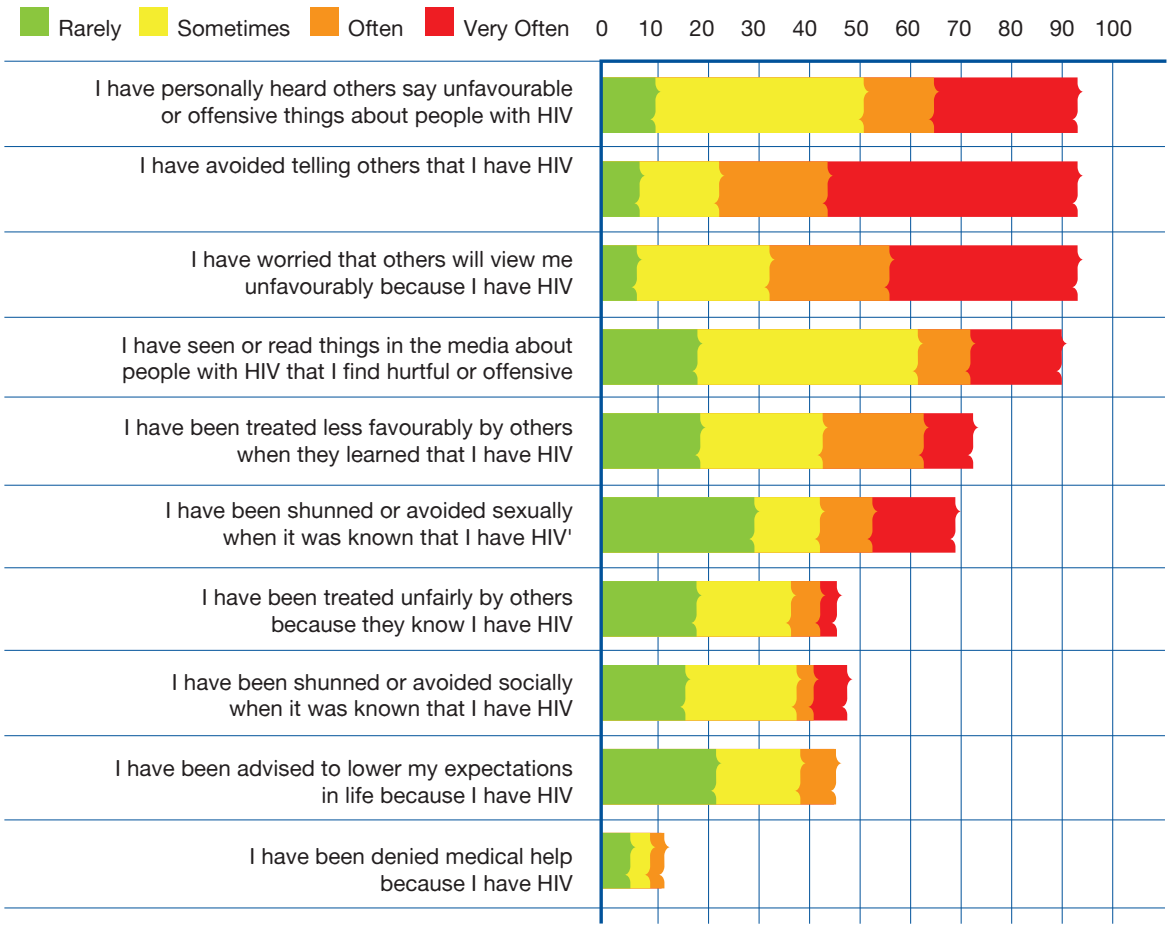
On the most recent occasion, over one-third (37.8%) of men reported that they disclosed their HIV positive status to their non-steady sexual partner before or during sex. The majority (55.5%) of men reported that they did not disclose their HIV positive status. A small percentage (5.1%) indicated that they had not been truthful about their HIV status (either saying they didn't know or that they were negative) to their non-steady sexual partner. Among men who had not tested HIV positive, almost three-quarters (73.3%) reported that they did not disclose their HIV status to their most recent non-steady sexual partner.

The choice of disclosure is an individual one, and can be difficult for many men due to fears of rejection or other negative reactions from potential sexual partners. The rate of non-disclosure and misrepresentation of one's HIV positive status highlights the concerns of many men living with HIV about disclosure, and requires further qualitative research.

5. HIV-related Stigma

Survey respondents living with HIV were asked a series of specific questions related to their experience of stigma and discrimination. To help capture the experience of stigma, respondents were shown a list of statements and were asked: ***'How often have you experienced each of the following?'*** and could select *Never; Rarely; Sometimes; Often; Very often; Does not apply to me.* The following 'barometer' of stigma highlights the proportion of men who have ever experienced HIV-related stigma and discrimination (those who selected rarely, sometimes, often, or very often to each of the statements).

Graph - Stigma 'barometer' (n=143)



The majority of men indicated experiencing disclosure-related concerns, including 93.1% of men indicating that they have avoided telling others that they have HIV (68% indicating they experienced often and very often), and 92.8% indicating that they have worried that others will view them unfavourably because they have HIV (60% indicating they experienced often and very often). A total of 70% of men indicated that they have been shunned or avoided sexually when it was known they were HIV positive (26% indicating they experienced often and very often), while 47% indicated they have been shunned or avoided socially (8% indicating they experience often and very often).

Men also indicated experiencing direct stigma and discrimination. A total of 94% of respondents indicated that they have personally heard others say unfavourable or offensive things about people with HIV, and 91% have seen or read things in the media about people with HIV that is hurtful or offensive. Three-quarters of men indicated that others have treated them less favourably when they have learned that they were living with HIV, and 58% have experienced being treated unfairly by others due to their HIV positive status. A total of 44% of men have been advised to lower their expectations in life because they have HIV, and 11% indicated that they have been denied medical help because they are HIV positive.

Encouragingly, 90% of men have experienced friends that were supportive and understanding upon learning that they were living with HIV, with three-quarters (74.8%) of respondents indicating that this was often or very often the case.

Summary:

The biomedical, social, psychological, and sexual dimensions of the HIV epidemic are changing. The success of antiretroviral treatment in preventing the onset of AIDS in people with HIV, and in suppressing the amount of HIV in their bodies, means that gay, bisexual and men who have sex with men (MSM) with HIV can expect to survive many years with the virus. The clinical outcomes of HIV treatment are promising and continue to improve. Moreover, effective HIV treatment enhances both the health of men with HIV, and enhances prevention efforts, by helping to lower the risk of onward transmission. These changing biomedical aspects of the epidemic are tightly linked to new challenges facing the gay and bisexual community, its advocates, and service providers. These social challenges include, but are not limited to, some of the following aspects of the epidemic that these data snapshot:

- While care for men diagnosed with HIV in Ireland is widely available, as suggested in data pertaining to access to medications and frequency of clinical monitoring, the data presented in this report also suggest that increased efforts need to be focused on earlier diagnosis of HIV in order to improve individual clinical outcomes and collective prevention efforts. Ireland needs to continue to improve awareness of, access to, and administration of HIV testing among MSM.

- Because HIV positive MSM are surviving with the virus, there is an increase in HIV positive MSM population overall. Yet a significant defining experience of being HIV positive continues to be isolation, as indicated in data showing that a majority of these men frequently worry about the stigmatising ramifications of HIV disclosure, both in social and sexual contexts. HIV positive MSM report substantial experience of stigma and discrimination, though they also acknowledge that friends can be a source of support. Together these data indicate that LGBT communities throughout Ireland need to evolve effective ways to enhance the sense of belonging and inclusion felt by HIV positive men, so that the burdens of isolation are lessened.

- There is intricate complexity within the sexual world that HIV creates. HIV positive MSM undertake a complicated series of decisions in relation to their sexual and romantic partnerships and practices - when to disclose, under what circumstances, who to seek as a sexual partner - and they must consider all of these in light of a range of possible repercussions, including outright rejection and sexual dissatisfaction. Within the context of HIV in Ireland, research needs to be undertaken into how MSM, including those who identify as gay and bisexual, are negotiating and navigating their sexual practices.

This Man2Man Report 2: Living With HIV is dedicated to the memory of Noel Walsh who led the way in advancing the cause of people living with HIV in Ireland. As a long term member of the Gay Health Network (GHN), Noel ensured that the vision of GHN was inclusive of challenging and combating HIV-related stigma. This report indicates how vital this challenge continues to be.

EMIS Partners:

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Living with HIV
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