

Speaker Name	Statement
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Date: 30 June 2016	

The *People Living with HIV* Stigma Index

STIGMASurveyUK - 2015

Alastair Hudson

FPA

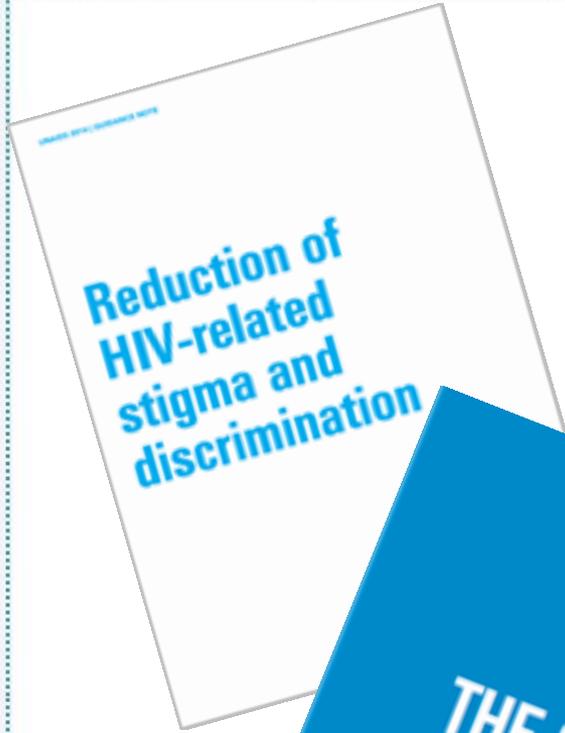
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Public Health
England



#zerodiscrimination: UNAIDS



GETTING TO ZERO

ZERO NEW HIV INFECTIONS

ZERO DISCRIMINATION

ZERO AIDS RELATED DEATHS

Methodology

THE STIGMA INDEX UK 2015: a new methodology for measuring the experiences of stigma among people living with HIV

UK STIGMA INDEX 2015 SURVEY



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Introduction

HIV-related stigma underpins the imbalance of power that many people living with HIV (PLHIV) experience. Building on The People living with HIV Stigma Index 2009, a new online survey was created by the StigmaIndexUK working group. Here we discuss the unique features of the StigmaIndex UK2015 survey design and assess the success of the recruitment method and its representativeness.

Objective

We aimed to refine a survey instrument relevant to the UK, that responds to the dynamic nature of stigma and examine HIV-related stigma experienced among people living with HIV in a range of settings and scenarios (e.g. healthcare, employment, family and friends). We also aimed to explore a number of recruitment strategies and administer the survey in accessible ways.

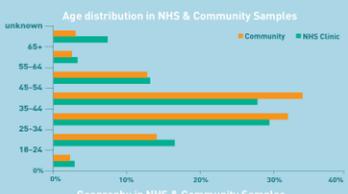
Method

- An advisory board led by people living with HIV was set up. Members also included academics, clinicians, epidemiologists and civil society representatives
- The survey questions were developed to focus on felt, anticipated and enacted stigma within different settings. Further questions were asked around resilience and participants' knowledge and experience of HIV in regards to their rights and the law
- Snap survey software allowed for the survey to be completed online, as well as through a tablet-based application
- The opportunity to win one of 20 iPads was offered to participants as an incentive for completing the survey
- The survey was promoted through community groups and HIV clinics following ethics approval from the National Health Service ethical board
- A 24/7 peer-led support hotline was operational during the 4 month recruitment period

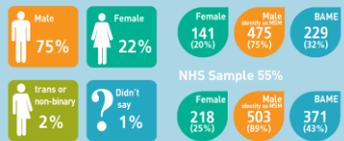


Results

- 1576 people from all regions of the UK completed the survey, corresponding to approximately 2% of all adults living with diagnosed HIV in the UK
- The 1576 respondents represent an 82% increase on the number of responses and broader geographical reach compared with the 2009 survey
- 45% of respondents were recruited through community outreach with the remainder recruited through HIV clinics
- 1182 (75%) were men and 359 (23%) women, 2% identified as trans or non-binary and 1% preferred not to say
- Compared to national demographics, men who have sex with men (MSM) were overrepresented whereas women and persons of black ethnicity were underrepresented



Gender



Conclusions

- The 2015 methodology used a dual arm recruitment (community and clinic based) method and a secure online questionnaire. Although peer support was available, all respondents completed the survey independently and no adverse events were reported
- The change in recruitment method resulted in a higher number of respondents who were more broadly representative of all adults living with HIV in the UK
- The high response rate will enable sub-group analyses in order to compare the way stigma is experienced by different groups of

people living with HIV in the UK. A description of HIV-related stigma in different settings will also highlight best practice and areas for improvement.

- The 2015 methodology represents a successful and acceptable way to recruit and assess stigma in a developed country setting that could be trialled in other countries, depending on local cultural acceptability
- The process of refining the survey was successful and demonstrated the importance of tailoring research tools to respond to the changing nature of HIV in the UK and associated stigma.

www.stigmaindex.org.uk

2009 Survey

- 867 participants
- Recruited by UK community & policy organisations
- Peer-led interviews

2015 Stigma Index UK (Jan – April 2015)

- 1,576 individuals
- Recruited by over 120 cross sector community organisations and 46 NHS clinics
- Self-completed survey online (SNAP)
- Ethical approval (NHS)
- Prize draw to win an iPad as incentive
- 24/7 hotline - No adverse events

Self completed online survey

Experiences of stigma in different settings:

- Sexual relationships
- Family & Friends
- Work place
- Health and social care services
- Educational settings
- Religious activities
- Social services
- Police, prison & detention services

Survey tools:

- Resilience score
- PHQ2 depression screening tool

Different experiences of stigma:

- Internalised (fear, worry)
- Enacted (avoiding situations)
- Discrimination (treated differently)*
- Disclosure control & support
- Pressure to disclose

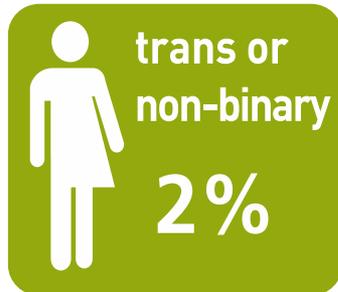
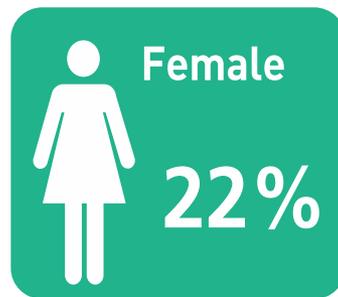
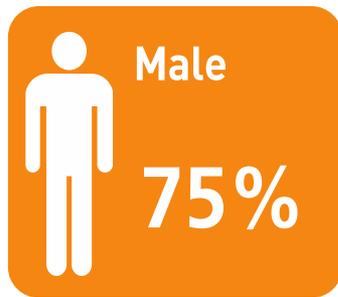
Participant information:

- Age
- Gender
- Ethnicity
- Sexuality
- Sex work
- Use of drugs
- Prisoner status
- Migrant status
- Disability

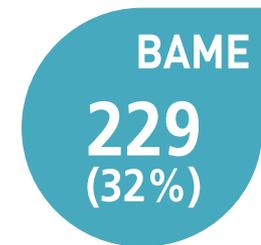
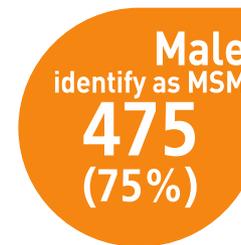
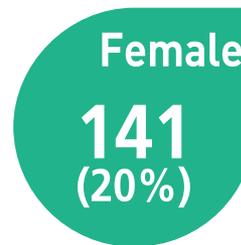
Who took part

Total: **1,576** participants

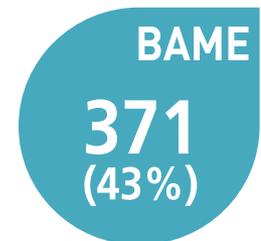
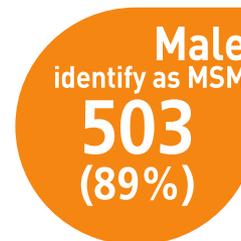
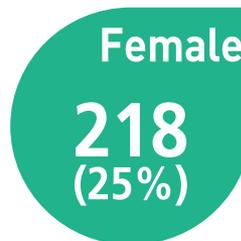
Gender



Community Sample 45%

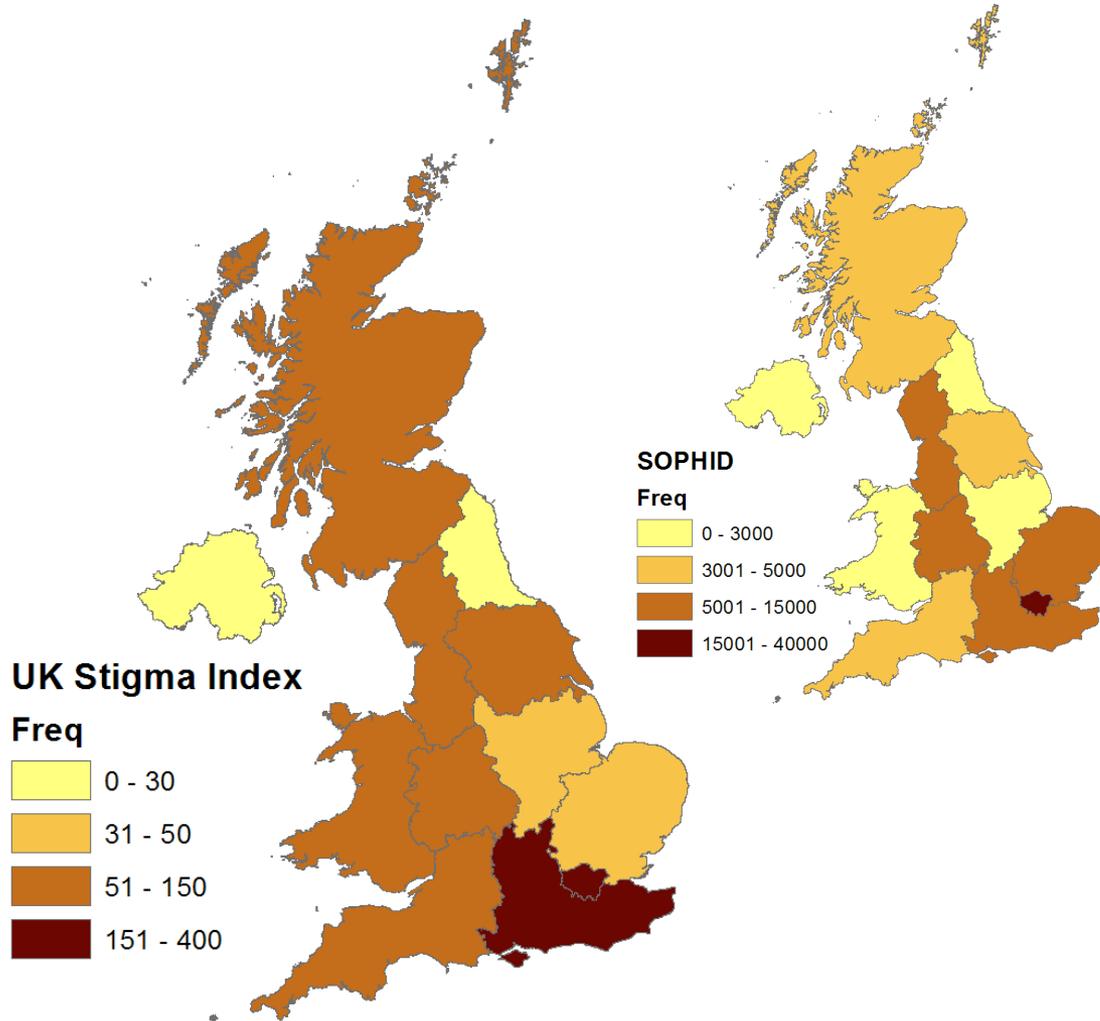


NHS Sample 55%



- Majority taking ART (**93%**)
- Mean **11** years since diagnosis (range <1-34 years)

Who took part?



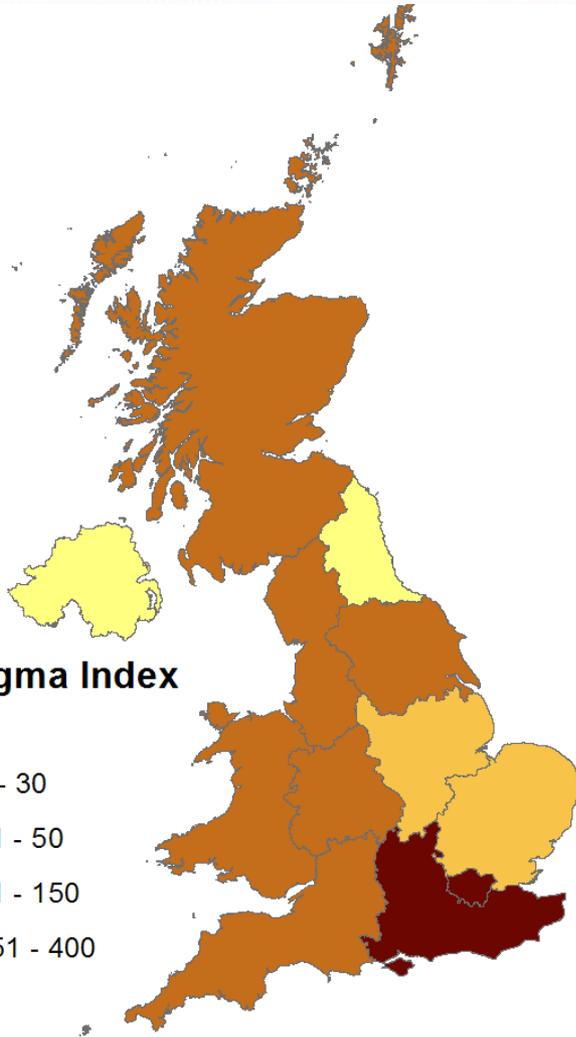
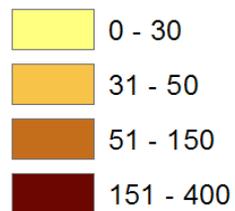
People living with HIV in England, Scotland and Northern Ireland

- Recruited from 120 cross sector organizations and 45 HIV clinics
- Between Jan-April 2015

Good geographical coverage

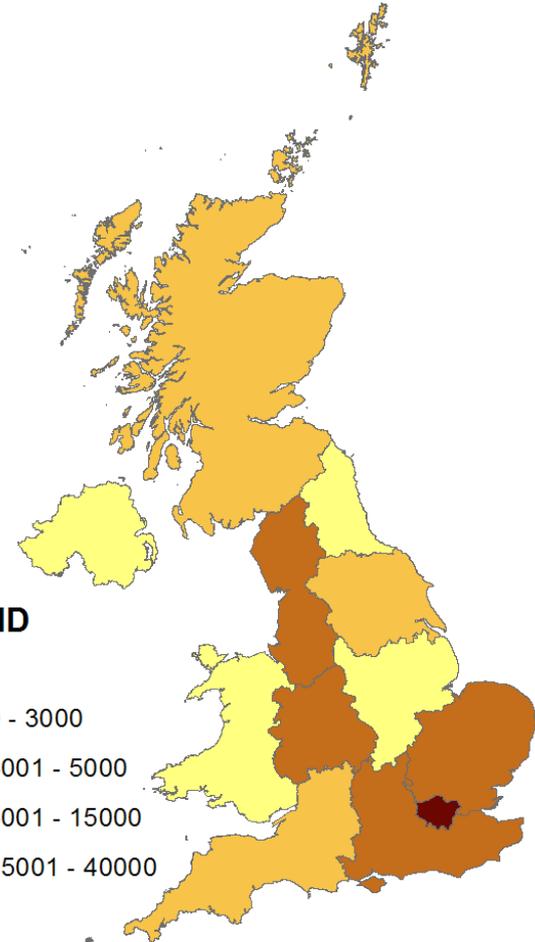
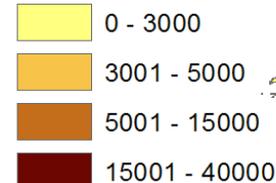
UK Stigma Index

Freq



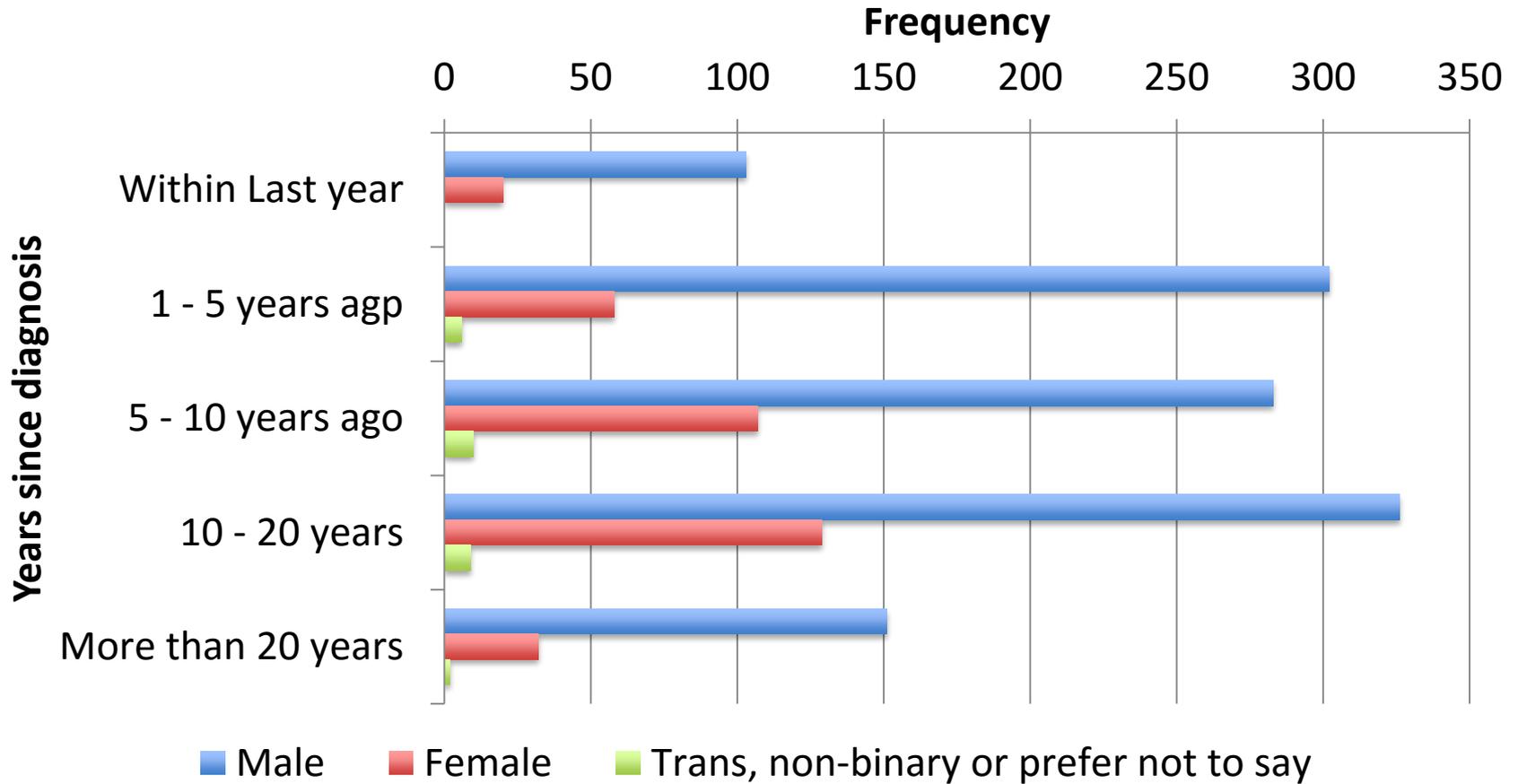
SOPHID

Freq



* Comparisons to UK population using the National HIV Surveillance data (SOPHID) 2013 (N=80,467)

Time since diagnosis



Feelings and experiences in relation to HIV status

Living with HIV in 2015

Q. In the last 12 months, have you experienced any of the following feelings in relation to your HIV status?

N=1576	YES
In control of my health	61%
Positive about life	64%
Positive about the future	62%
As good as anyone else	58%

Self-image

Q. In the last 12 months, have you experienced any of the following feelings in relation to your HIV status?

N= 1576	YES
Felt ashamed	48%
Felt guilty	45%
Blamed myself	48%
Had low self esteem	48%
Blamed others	23%
Felt suicidal	18%

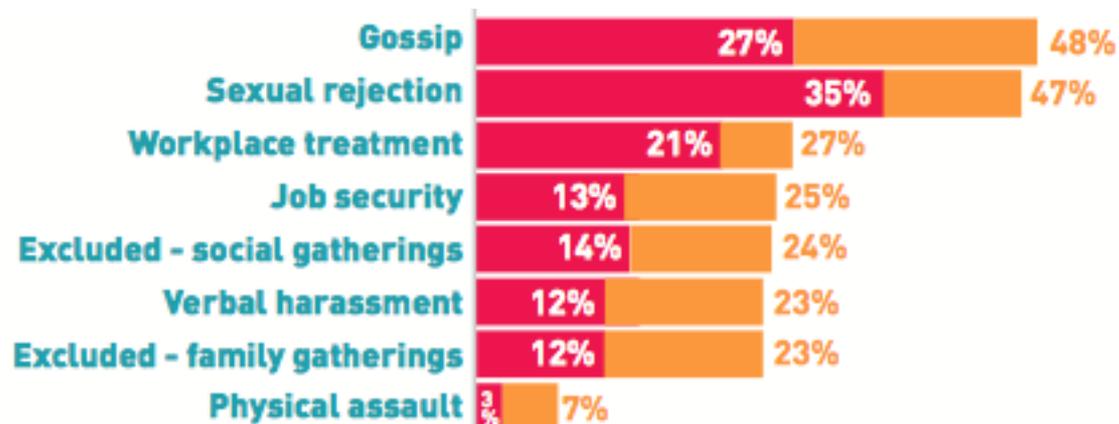
Almost a third of participants (28%) diagnosed in the last year reported suicidal ideation.

National experiences of HIV related stigma and discrimination in 2015

● % of all who report experience is due to HIV ● % of all who answered yes

In the last 12 months...

Have you worried about:

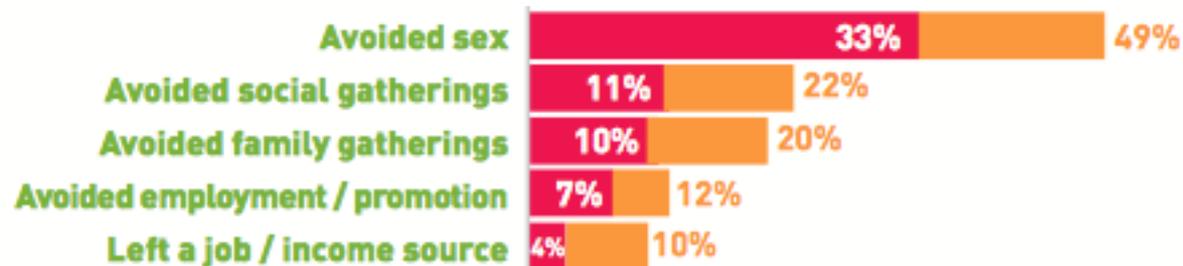


National experiences of HIV related stigma and discrimination in 2015

● % of all who report experience is due to HIV ● % of all who answered yes

In the last 12 months...

Have you:

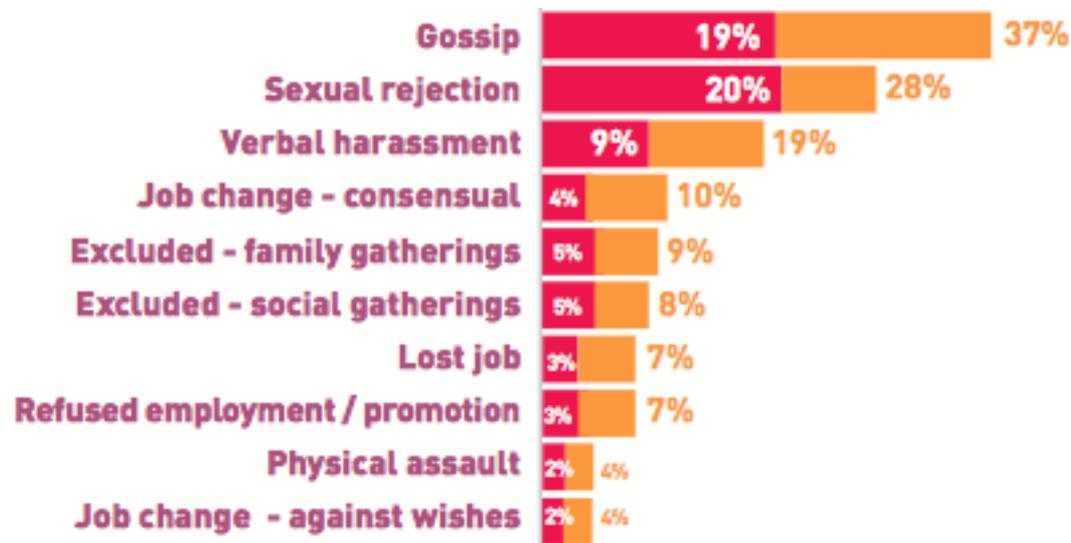


National experiences of HIV related stigma and discrimination in 2015

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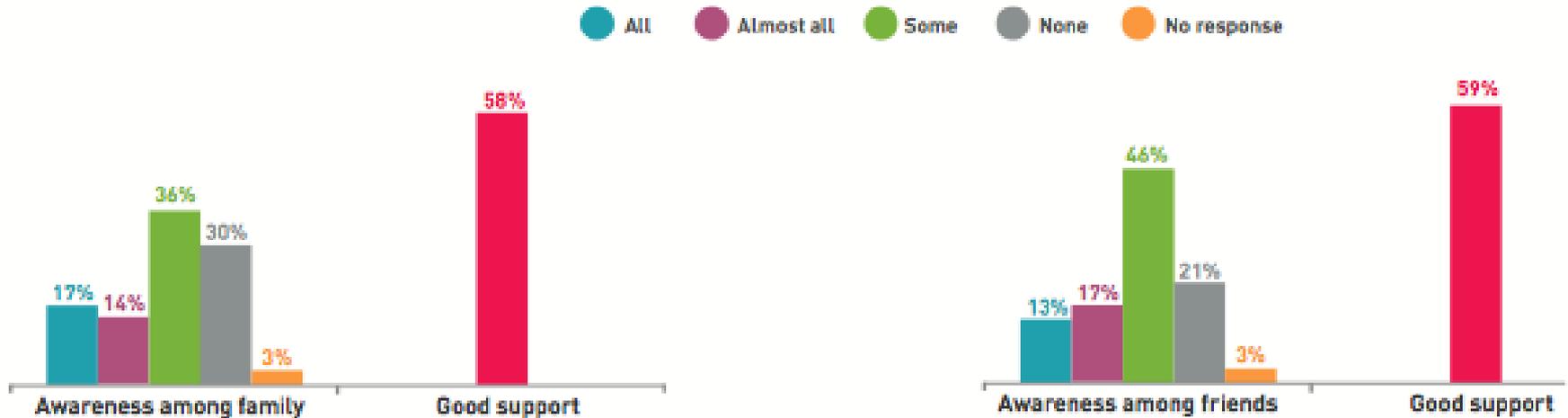
Have you experienced:



Experiences of disclosure of HIV status

The survey measures people's experiences of disclosing their HIV status in different settings. It also looks at **control, support** and **pressure** during and after disclosure of HIV

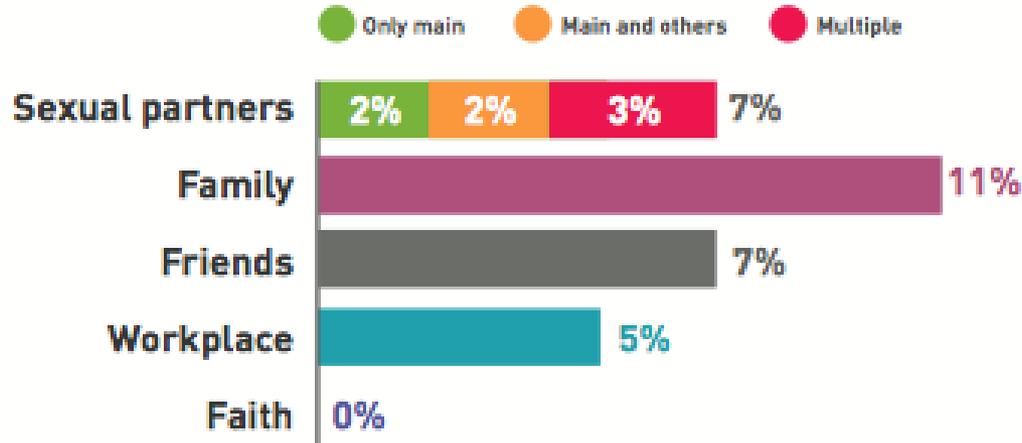
Awareness and support



“You are living with a secret that in itself has an impact on your health. You are constantly trying to hold things back.” Woman, 49 years old, white ethnicity and living in Bournemouth, diagnosed 2008

“I then went on to disclose to my brother and his wife... that was a really positive experience, and they were just a bit puzzled as to why I hadn’t told them before, which I thought was lovely.”
 Woman, 44 years old, white ethnicity and living in London, diagnosed 2003

Pressure to tell others



“I actually told my boss. That made life much easier, so instead of inventing what I needed to when I needed to go to the hospital or clinic, I could just say where I was going. It makes a difference, it made me feel better”
 Man, 41 years old, white ethnicity and living in Southampton, diagnosed 2012

Disclosure in different settings

- About half (55%) of people found disclosing their HIV status to be an empowering experience
 - *there were differences found among participants and settings however...*

“It’s a small part of my life and I don’t want to make it the whole of my life. I’m also not other peoples’ entertainment.”

Black African Woman aged 24 living London, born with HIV.

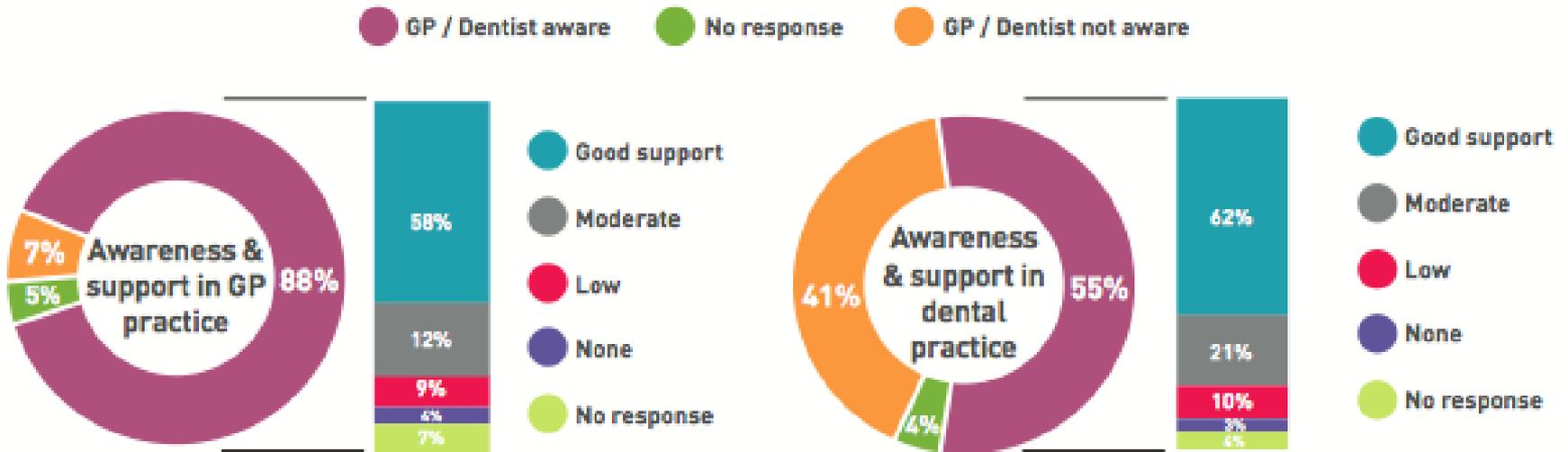
“I don’t feel positive about finding and maintaining a relationship because of my status.” White British MSM aged 37 living in Wales. Diagnosed in 2006.

Disclosure in Faith Setting

- 628 (40%) people had ever practiced a religion
 - About half had practiced in the last 12 months
 - Most considered themselves Christian (85%)
 - About one in four people (23%) said that someone in their faith community was aware
- *63% of these had found disclosure to be an empowering experience*

“I never at any point considered telling my family. And I’m really grateful that I decided not to. My parents are Muslim, my family are Muslim” Man, 36 years old, Asian ethnicity and living in Brighton, diagnosed 2010

Awareness and support in primary care



“[Whenever] under pressure to disclose to a new GP, I often feel judged and ashamed”

Trans woman of black African ethnicity living in the North West, 37 diagnosed 2006

“Even medical and dental professionals (both doctors and nurses) behave differently once I tell [them my HIV status]” Woman, 54 years old, black British Caribbean ethnicity and living in London, diagnosed 2009

Negative self-image and seeking care

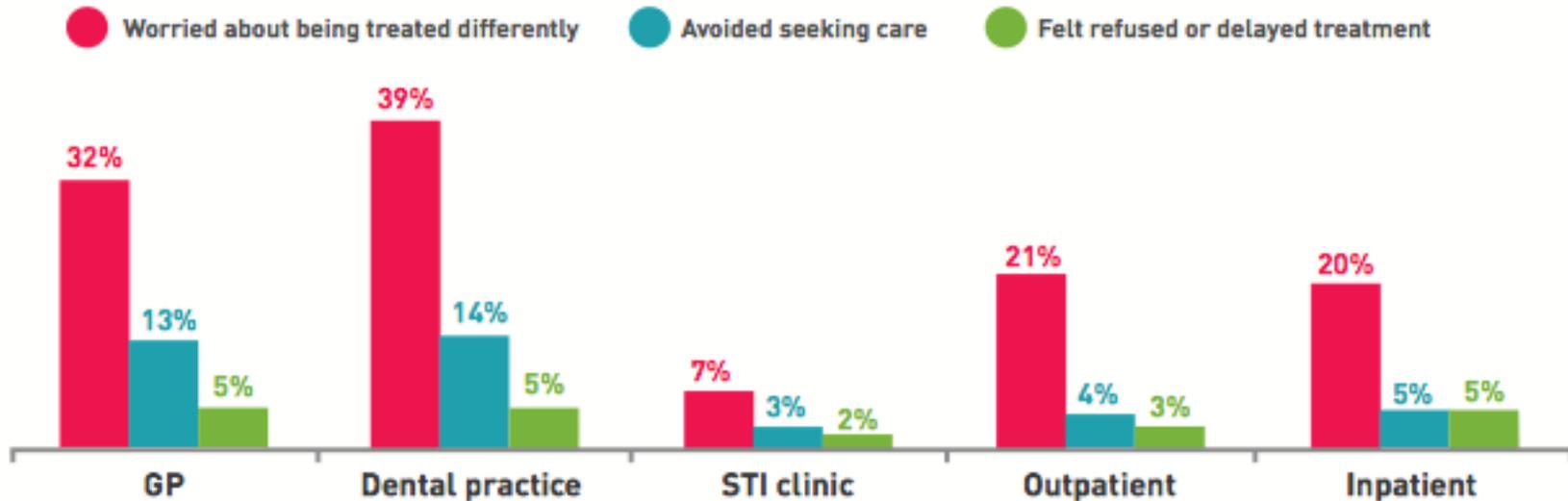
General Practice

- 13% of all participants reported avoiding their GP
- 74% of participants avoiding their GP had a negative self image score

Dental practices

- 14% of all participants reported avoiding dental practices
- 66% of participants avoiding dental practices had a negative self image score

Healthcare setting experiences



Had negative comments from a healthcare worker about your HIV status or PLHIV ?	13%
Felt there was excess attention to using barrier protection (i.e. gloves, masks)?	21%
Been given the last appointment of the day not by choice?	12%

HIV and the law

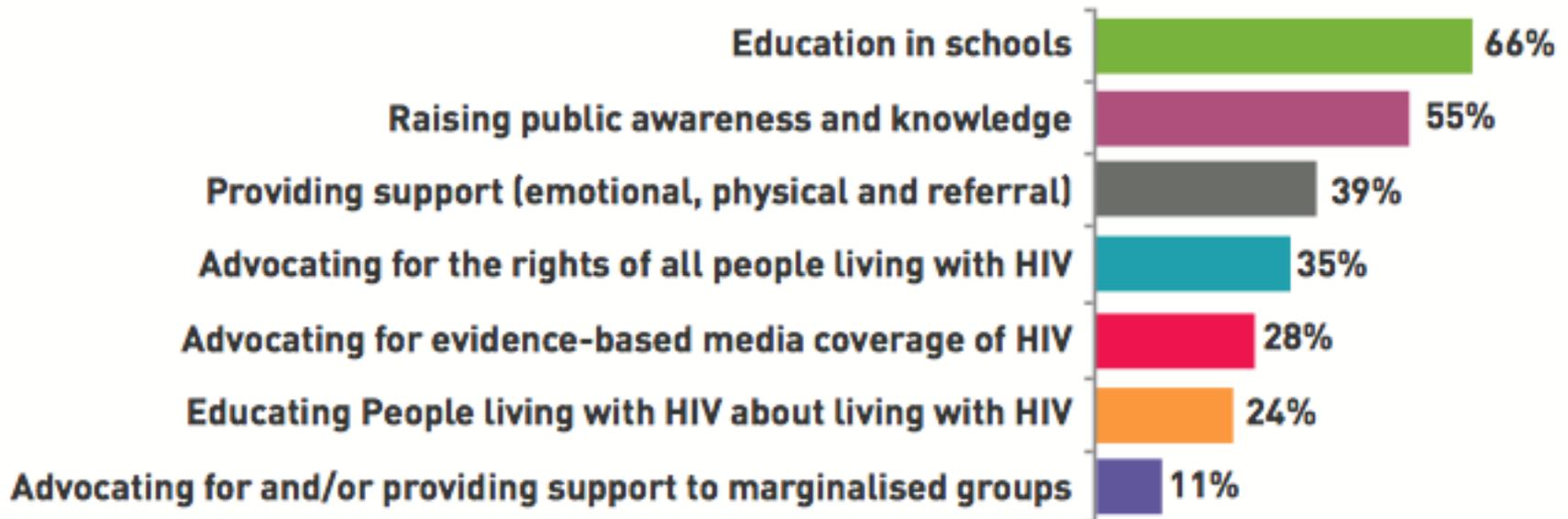
Q. In the last 12 months, have the following things happened to you?

	Yes
I had to disclose my HIV status to apply for residence or nationality	5%
I had to disclose my HIV status in order to enter another country	4%
I was detained, quarantined, isolated or segregated because of my HIV status	1%
I was denied insurance products (e.g Health, dental, life, job protection) because of my HIV status	11%

Criminalisation of HIV

- 85% of people were aware of prosecutions for recklessly transmitting HIV to sexual partners in the UK
- 46% had read the content of the law against reckless or intentional transmission of HIV
- 20% felt transmission of HIV should be a criminal offence (40% disagreed and 37% said 'I don't know')

Addressing stigma and discrimination



“Generally when I tell guys about my HIV status they are usually supportive. But (they) don't understand what undetectable is and only think back to the tomb stones of the 1980's information campaign. We need another nation-wide mass campaign to update people.” Man, 41 years old, White Irish diagnosed in the last 5 years.

Conclusions

- The UK has well-established anti-discrimination laws and policies and excellent health care
- The majority of people living with HIV in the UK feel positive about their lives and health

However,

- Half of people living with HIV has a negative self image in relation to their HIV and almost one in five felt suicidal
- Better identification and support for people with negative self image is required
- A significant number of people continue to feel or experience stigma in a range of settings including health care settings
- These feelings can be reduced when people feel in control of the decision to disclose their HIV status

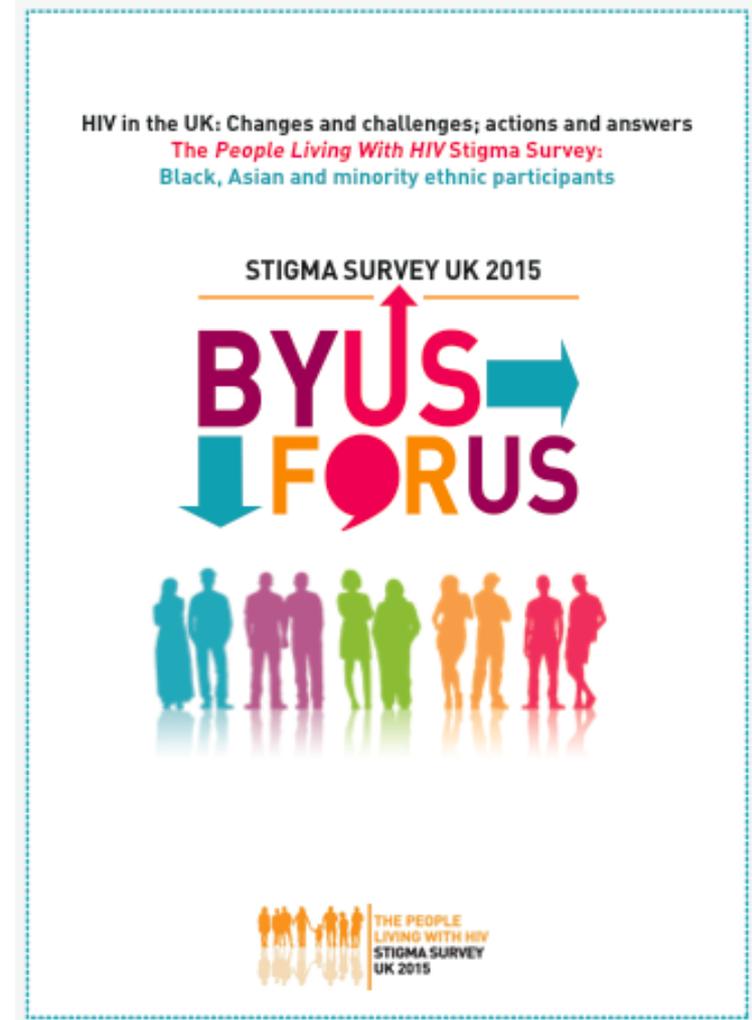
Next steps

- International dissemination/knowledge exchange
 - 6 abstracts accepted for poster presentation and a booth in the Global Village at IAS Durban this July
 - Academic Papers and Publications
- Regional dissemination and advocacy
- Activist Training
- Further qualitative analysis
- Further analysis on healthcare settings
- BAME qualitative study – 2016/17
- Young People's Study - 2016/17
- Development of CPD/educational/awareness resources 2016/17

Report cards

- 11 report cards focusing on regions and key populations:
 - ✓ National
 - ✓ England
 - ✓ Scotland
 - ✓ Wales
 - ✓ Northern Ireland
 - ✓ London
 - ✓ MSM
 - ✓ BAME
 - ✓ Women
 - ✓ Trans Non Binary
 - ✓ People who inject drugs

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Thank you



Thank you to all our participants who took part in the study!

