

STIGMA SURVEY UK



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NHS Trust



Public Health England



#zerodiscrimination: UNAIDS



Stigma Survey UK – 2015

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.

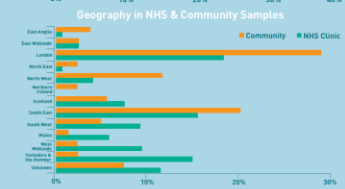
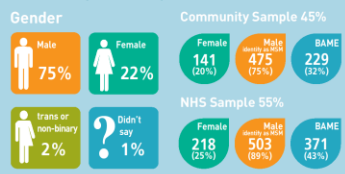
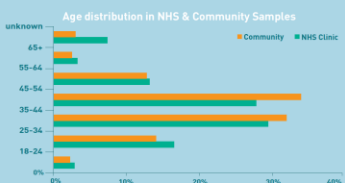
Method

- 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



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.

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

Measures

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)
- Anticipated (avoiding situations)
- Enacted (treated differently)*
- Disclosure control & support
- Pressure to disclose

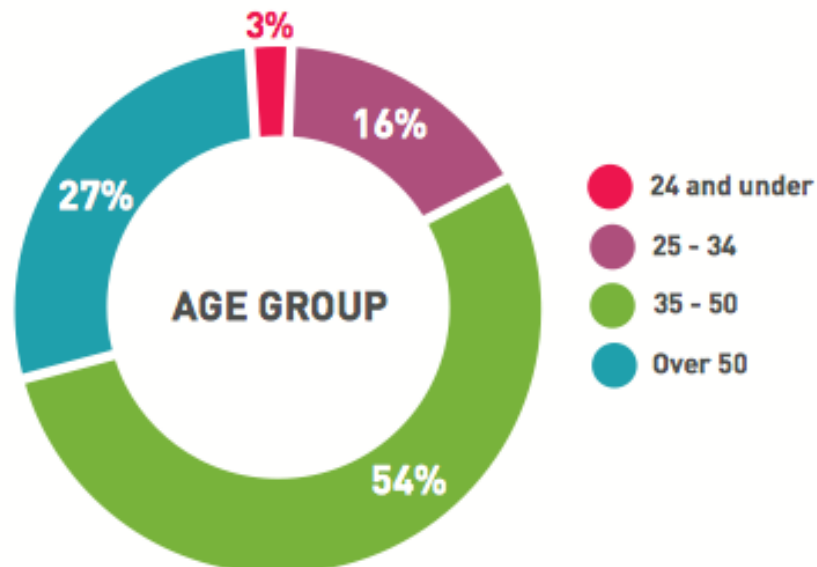
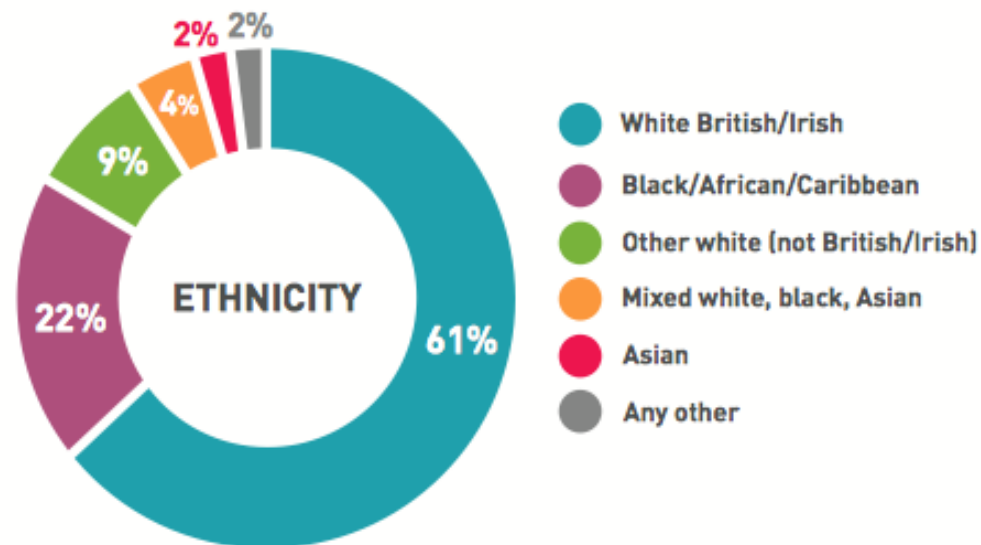
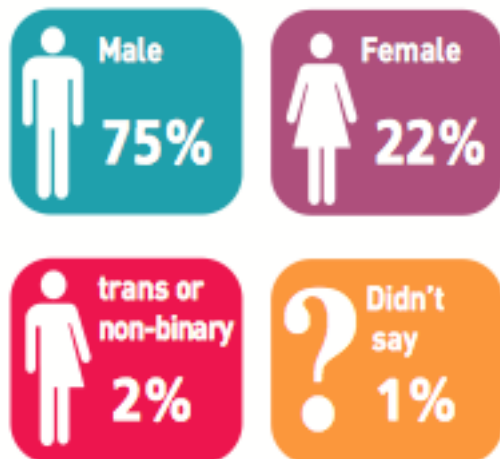
Participant information:

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

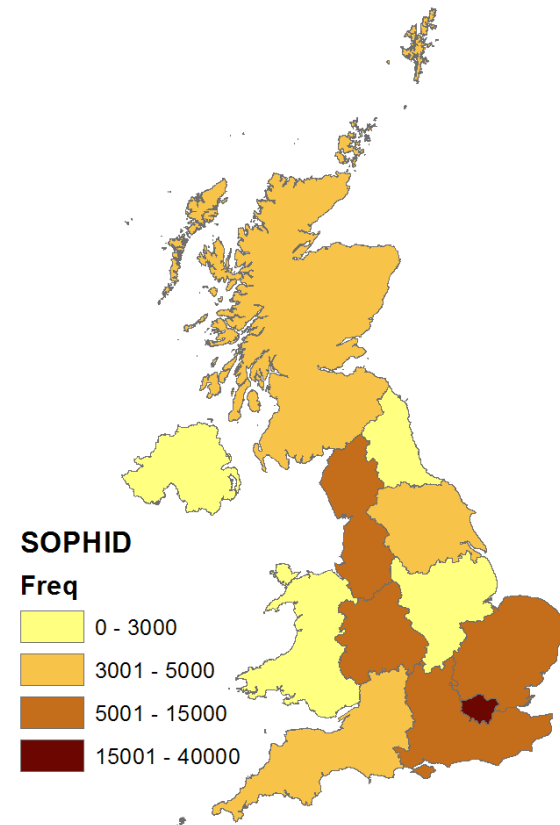
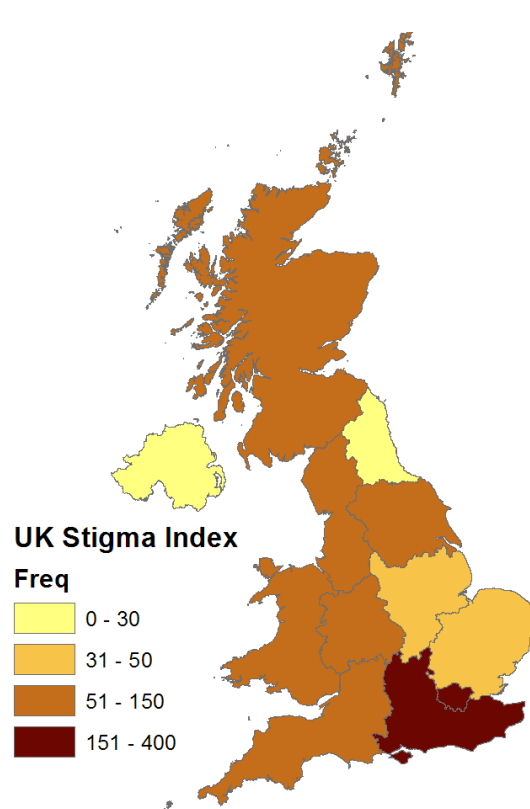
Who took part?

Total: **1,576** participants

Gender

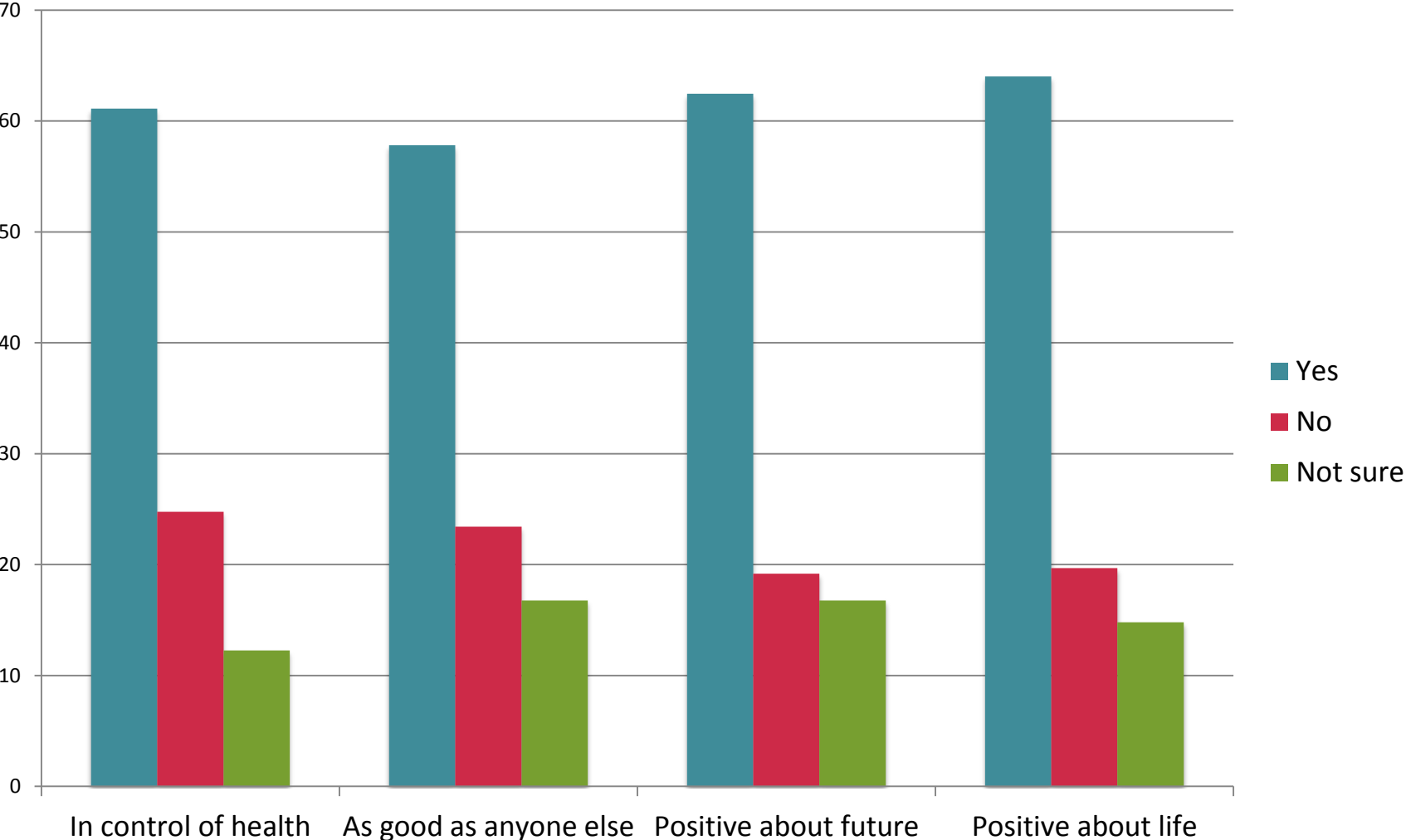


Who took part?

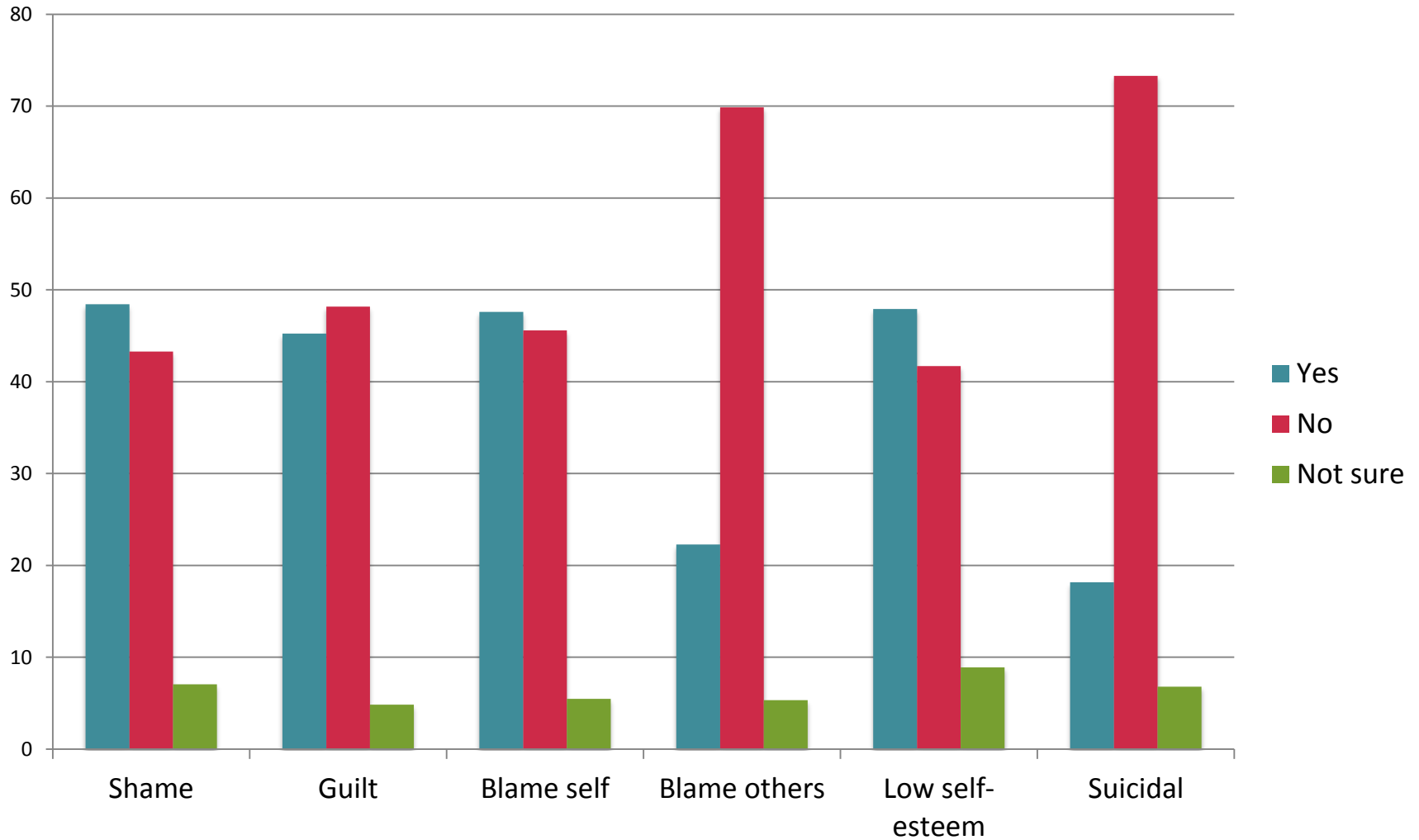


- Majority taking ART (**93%**)
- Mean **11** years since diagnosis (range <1-34 years)

Positive Feelings



Negative Feelings



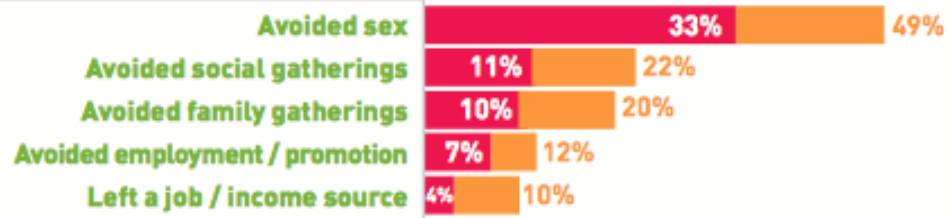
Experiences of stigma & discrimination

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

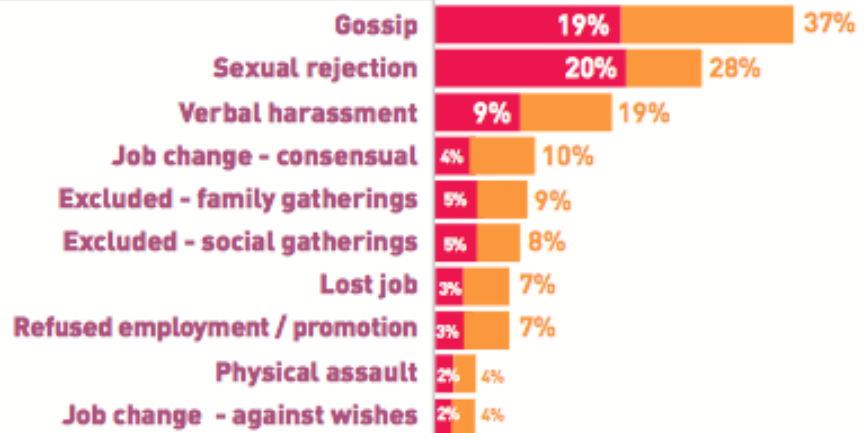
In the last 12 months...



Have you:

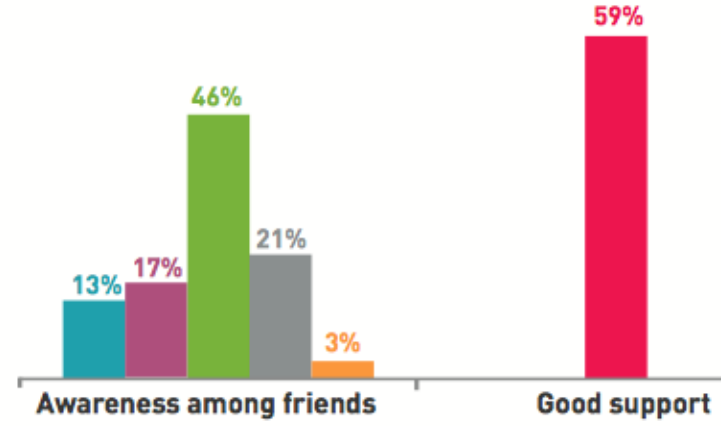
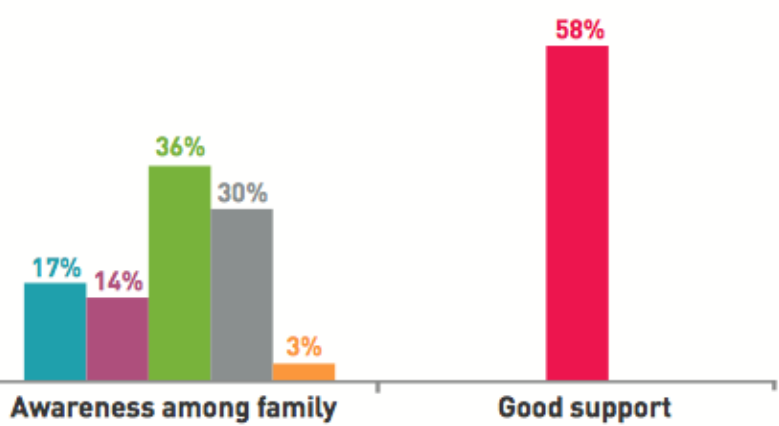


Have you experienced:

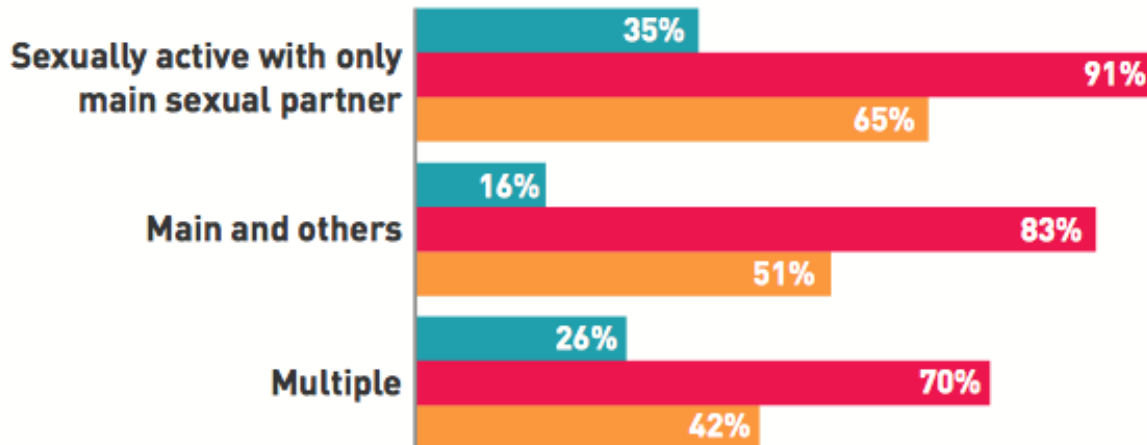


Awareness of HIV and support

● All
 ● Almost all
 ● Some
 ● None
 ● No response



● Percentage of people
 ● Percentage of partners aware
 ● Percentage reporting good support



Getting personal

“I am a trans woman. People are still afraid of things they do not understand.”

**White non-British, Trans woman
aged 50, diagnosed 2000**

“None of my kids know that I’ve got HIV.”

**White, aged 36, diagnosed
2014**

“In my church, I’ve never really alluded to having HIV, because I don’t know how they would think.”

**Black woman aged 60, diagnosed
2003**

“I haven’t felt comfortable not being open about it,... I’ve found it really hard not being able to be completely honest with people.”

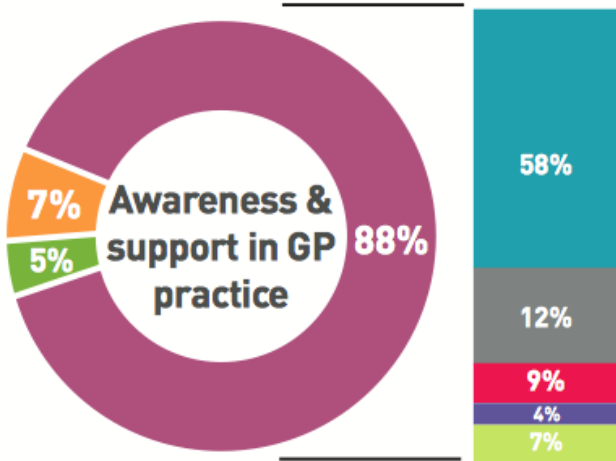
White, aged 36, diagnosed 2014

Healthcare

● GP / Dentist aware

● No response

● GP / Dentist not aware



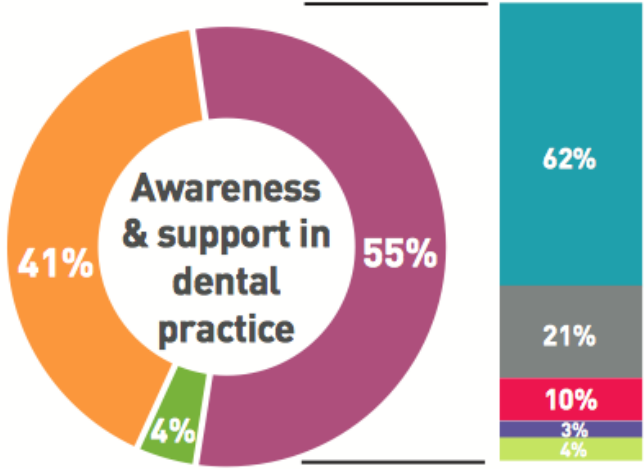
● Good support

● Moderate

● Low

● None

● No response



● Good support

● Moderate

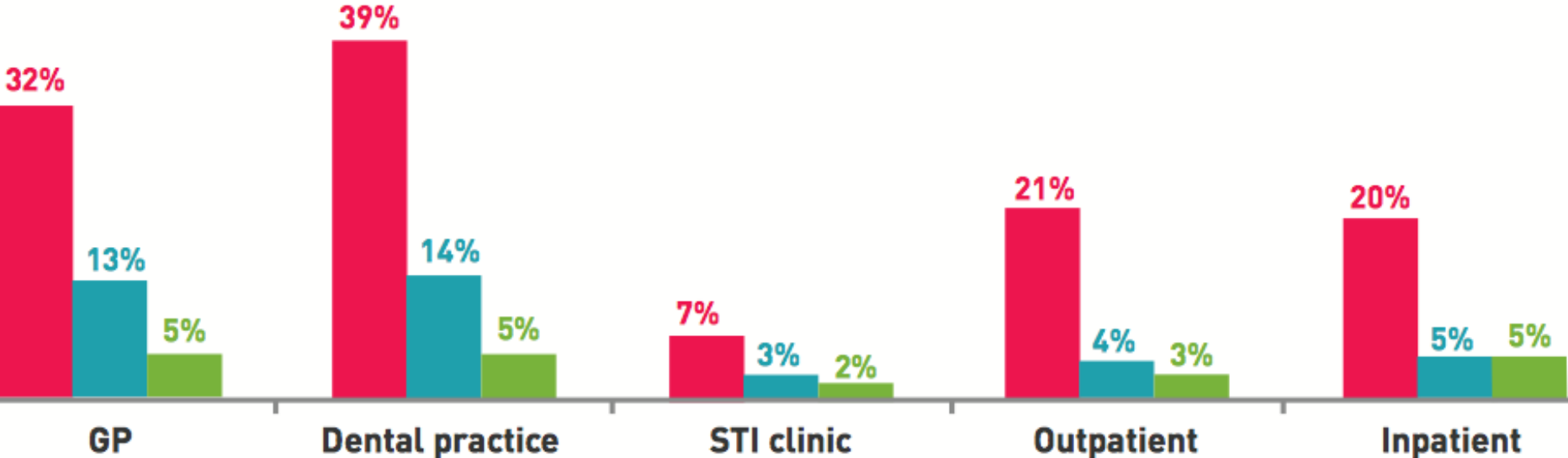
● Low

● None

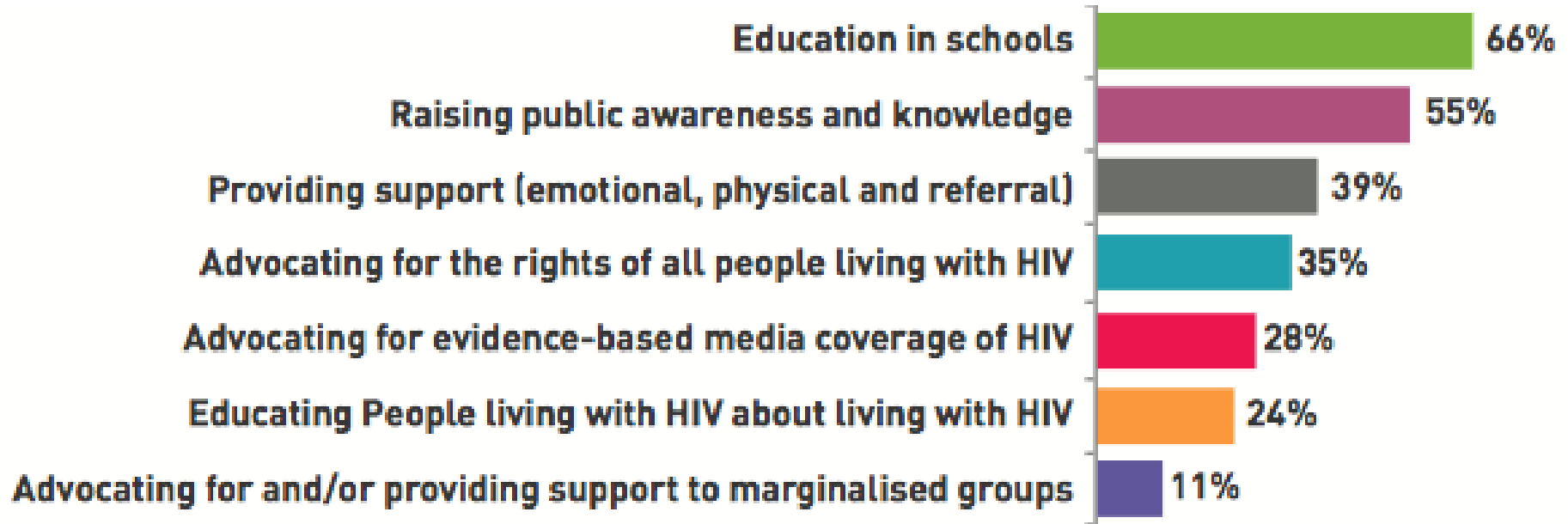
● No response

Healthcare

● Worried about being treated differently ● Avoided seeking care ● Felt refused or delayed treatment



Actions to Address Stigma



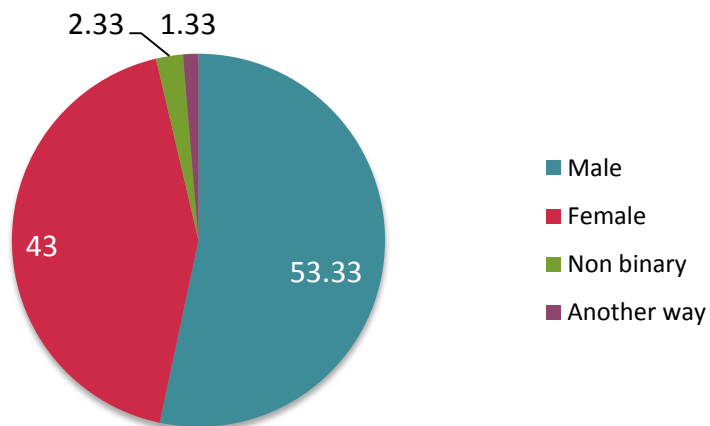
Conclusions & Reporting

- Stigma, and discrimination continue to impact the lives of HIV positive people in the UK
- Many worried about negative treatment, and some experienced HIV-related discriminatory treatment
- Half of participants reported feelings of internalised stigma, and many had a poor self-image
- Our data has been used as evidence by a range of stakeholders including local authorities, policy organisations (ie. APPG, NAT, HIV Scotland) for resource mobilisation, advocacy efforts, programme development and policy change
- We have presented findings at national and international conferences
- **Full findings can be found at www.stigmaindexuk.org**

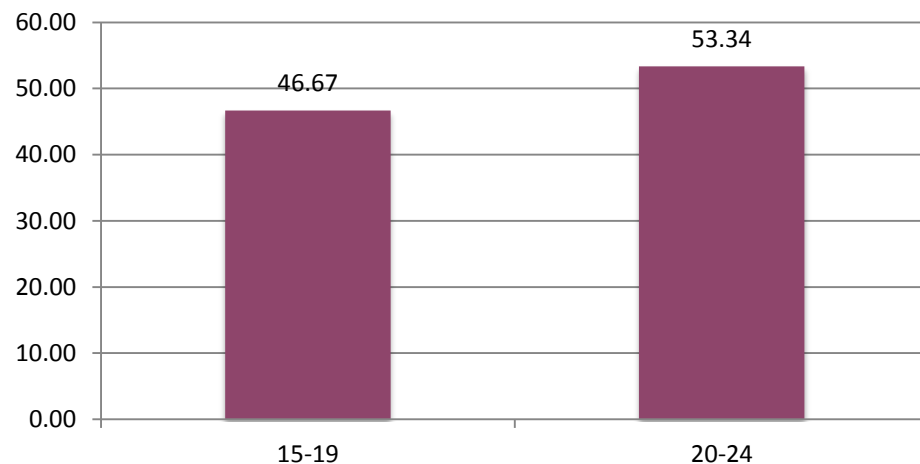
Young People's Stigma Survey UK – 2017

Who took part? (n=300)

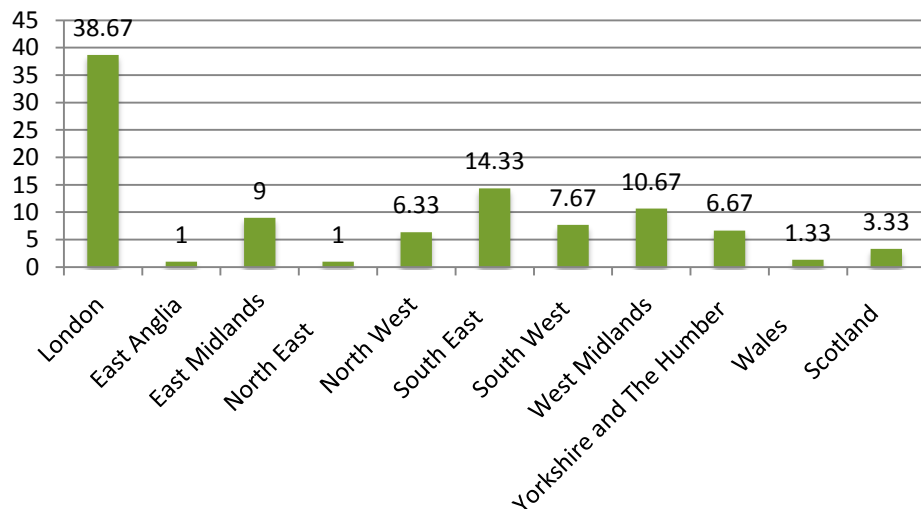
Gender



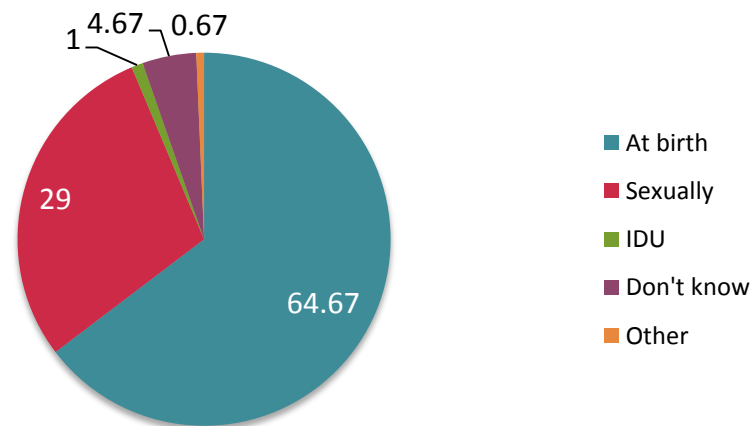
Age



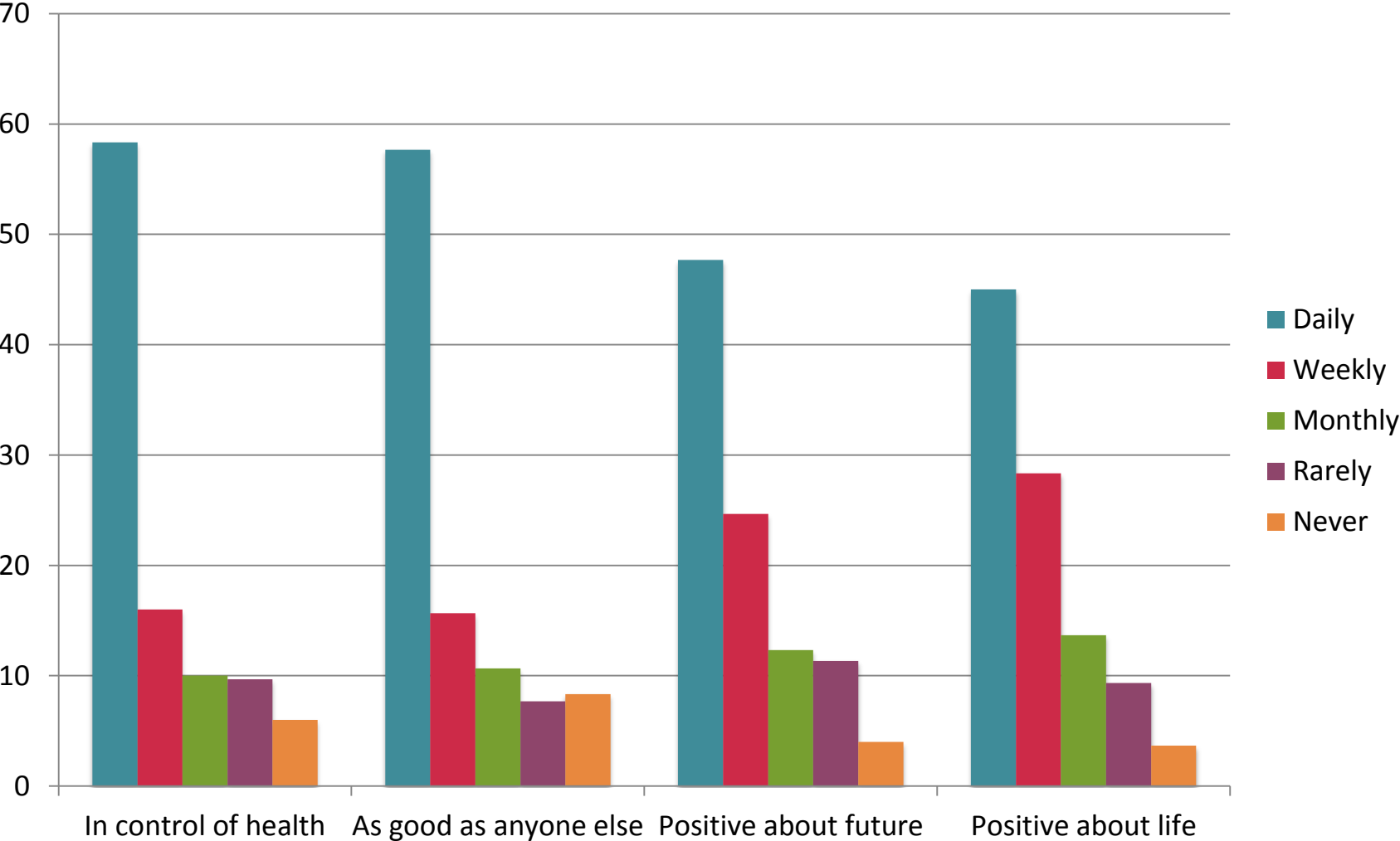
Region in UK



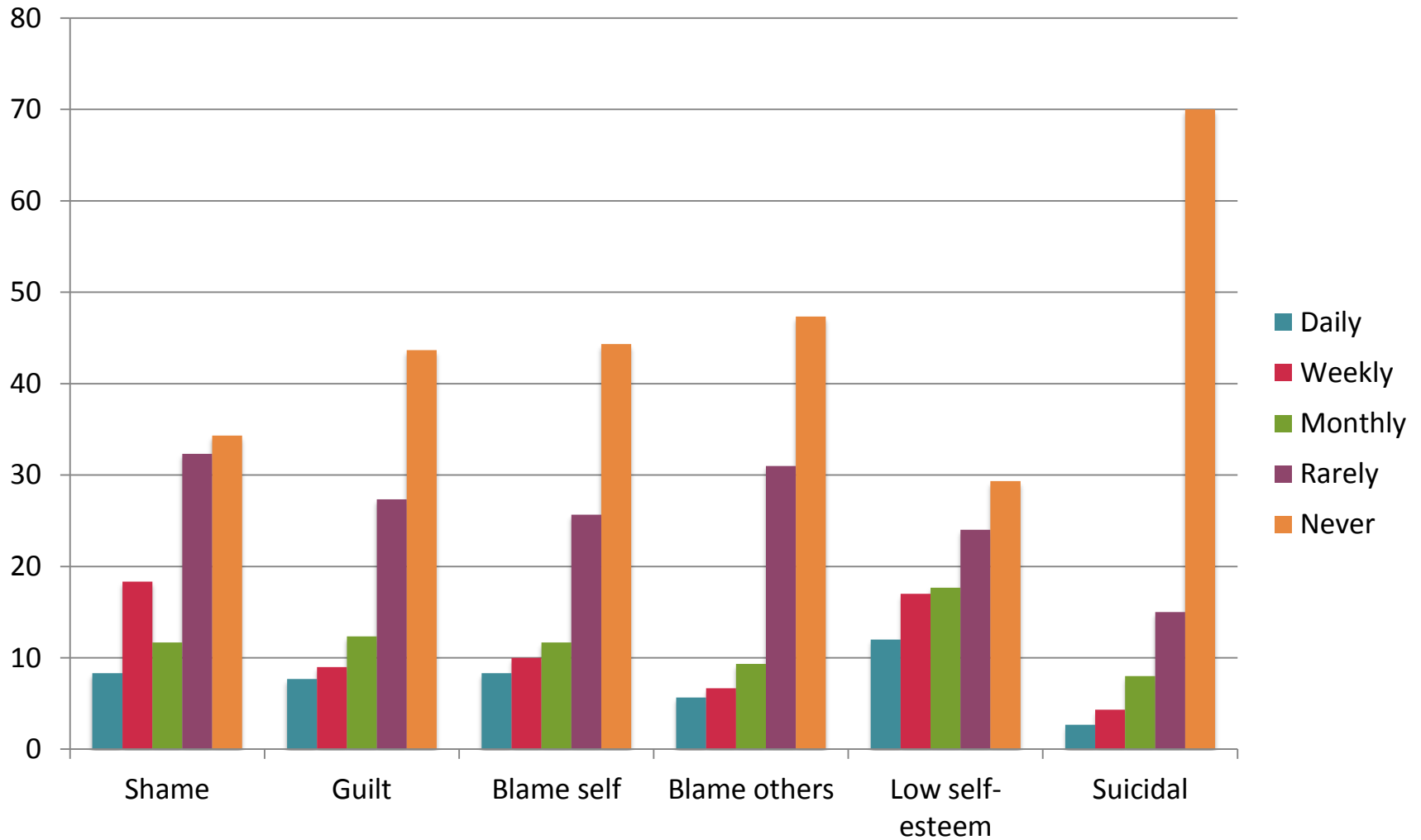
HIV acquisition



Positive Feelings



Negative Feelings



Dissemination & Next steps

- International dissemination/knowledge exchange
 - Preparing abstracts for submission to national and international conferences
 - Academic papers and publications on both the 2015 adult and 2017 YP study datasets
- Analysis of Young People's Stigma Survey UK data
- Dissemination of final report and leaflets to participating sites
- Regional advocacy

Thank you



the sexual health charity

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

