

A close-up photograph of a person's hands. The left hand is open, and the right hand has a white bandage wrapped around the index finger. The index finger of the right hand is pointing towards the word 'INDEX' in the main title. The person is wearing a dark, ribbed sweater.

# GIVE STIGMA THE INDEX FINGER!

INITIAL FINDINGS FROM THE PEOPLE  
LIVING WITH HIV STIGMA INDEX IN  
THE UK 2009



THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX

# HANDS UP FOR COMMUNITY RESEARCH



Eight hundred and sixty seven people living with HIV have been interviewed around the UK, by their peers, about their experiences of stigma and discrimination in the last 12 months.

**THEY FOUND THAT 46% OF PARTICIPANTS REPORTED THAT THEIR RIGHTS MAY HAVE BEEN ABUSED IN SOME WAY OVER THE LAST YEAR:**

**60%** Are not sure if their medical records are being kept confidential

**31%** Have not had a constructive conversation with a health care professional about their reproductive health, sexual relationships, drug-use and emotional well-being

**PEOPLE LIVING WITH HIV PLAY A LEADING ROLE IN CHALLENGING AND OVERCOMING STIGMA:**

**45%** of people living with HIV have challenged, confronted or educated someone who was stigmatizing them

**84%** have supported other people living with HIV

Living with HIV in the UK today is a different experience for every individual. For some, taking treatment, seeking support, and accessing health services is routine and part of a wide selection of services and choices available. For others, information is limited, support insufficient, or choices denied because of fear or marginalization. For all, stigma relating to HIV still remains a significant challenge in the UK because it has an impact on the accessibility and orientation of services (not only health, but also legal, care and support services) as well as on the self-esteem and general quality of life of people living with HIV.

**The results in this report reveal some of the realities of people living with HIV in the UK in 2009 and have implications for current policy and priorities for future actions.** Understanding and addressing stigma related to HIV can guide our individual and collective responses to overcoming wider issues of discrimination, marginalisation, racism, homophobia and other social injustices. It is clear that people living with HIV are at the forefront, not only living through, confronting and overcoming devaluing attitudes and behaviours, but also speaking out against prejudice, supporting their peers and advocating for positive social change.

The implementation of *The People Living with HIV Stigma Index*<sup>1</sup> in the UK is the first robust attempt to establish a baseline for documenting the stigma and discrimination experienced and overcome by people living with HIV. Further reports will be published in 2010 to provide more in-depth analysis according to group identity, length of time since diagnosis, gender, age and geographic location.

<sup>1</sup> The initiative is the product of a partnership between two international networks of people living with HIV (GNP+ and ICW), IPPF and UNAIDS.

## WHAT IS STIGMA?

Stigma is commonly understood as a process of devaluation.

It can have many outcomes (such as discrimination, which is also known as enacted stigma) and in the context of HIV can adversely affect how and when someone accesses services (including testing, support and treatment), how people interact with each other (including friendships, intimate partnerships and professional relationships), and how someone perceives themselves and their self-esteem.

*“For me, HIV is a diagnosis not a lifestyle choice. With medication and support I just get on with it. This research will shake things up a bit and give people’s fears and opinions a timely makeover”*

**PARTICIPANT, LONDON, SEPTEMBER 2009**

*“It’s a big rollercoaster for me – it’s a journey I will never ever forget. I am not alone. I have been hiding – for what?”*

**RESEARCHER, LONDON, MAY 2009**

## WHAT IS THE PEOPLE LIVING WITH HIV STIGMA INDEX?

*The People Living with HIV Stigma Index is a community research and advocacy initiative that has been developed by and for people living with HIV.*

It documents how people have experienced—and been able to challenge and overcome—stigma and discrimination relating to HIV over a 12 month time period. Championing a community research model, the core principle underpinning *The People Living with HIV Stigma Index* is as a research and advocacy initiative by and for people living with HIV—the process being just as important as the product.

The power of the research process lies in the community of people living with HIV—those interviewing as well as those participating—in completing the questionnaire and driving each stage of implementation. This peer-interviewing approach puts people living with HIV at the centre of the process, the interviews aspire to be empowering not only for the participants, but also for the interviewers.

The product is a collection of responses to an in-depth questionnaire. The data from the Index can be used as: a) a monitoring tool to analyse and compare changes in stigma over time; and b) to better understand the experiences of stigma for different groups of people according to location, time since HIV diagnosis, group identify, gender and/or age. Driven by the priorities identified by people living with HIV, the results will be used to inform and re-energise debate about the complex social, care and support needs of people living with HIV.

**WWW.STIGMAINDEX.ORG**

## PROCESS = PRODUCT

Thirty-five community researchers were trained from around the UK to guide peer-interview sessions.

Participants completed a standard questionnaire that touches on the causes of stigma and discrimination; access to work and services; self stigma; rights, laws and policies; effecting change; disclosure and confidentiality; treatment; having children; the criminalisation of HIV transmission and overcoming stigma.

*"You're all positive too? OK count me in"*

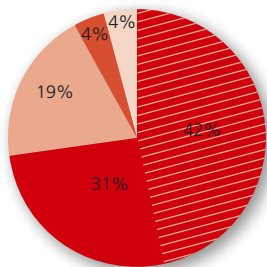
PARTICIPANT, MANCHESTER, JUNE 2009

## STIGMA IN THE UK

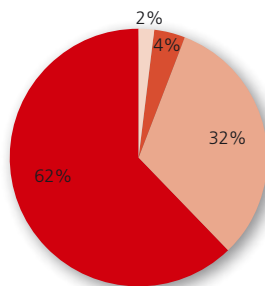
HIV-related stigma is one of the primary hurdles in addressing prevention and care issues and creates a stumbling block in ensuring access to essential services.

The UK National Strategy for Sexual Health and HIV (2001) highlighted the need to improve and modernise sexual health services. This included a specific objective to reduce stigma associated with HIV and sexually transmitted illnesses. In 2009, the Department of Health (DH) suggests that the outlook has improved—there are treatment options, some laws have changed (such as the Disability Discrimination Act in 2005), and public opinion seems to be shifting so it is less acceptable to discriminate

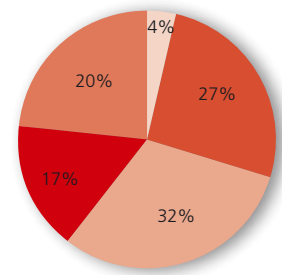
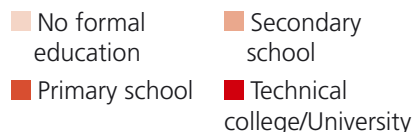
## BACKGROUND INFORMATION



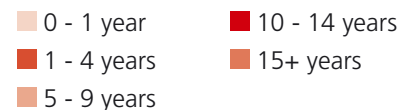
### LOCATION OF PARTICIPANTS



### LEVEL OF EDUCATION



### TIME SINCE DIAGNOSIS

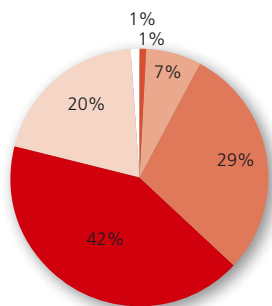


# KEY FINDINGS

against people due to their colour, disability, race or sexuality. Yet stigma remains significant in the UK and the DH suggests that despite these improvements there is still much to be done. In 2007, a survey by the National AIDS Trust indicated that 71% of people agree more needs to be done to tackle prejudice, and that attitudes such as rejection by family and friends, blame, and guilt relating to HIV transmission remain and are highly stigmatizing (NAT 2007). The UK Department for International Development (DFID) calls for “urgent attention” and action to tackle stigma, and argues that one of the “best ways to do this is to empower people living with HIV and vulnerable groups to act on their own behalf and in their own interests” (DFID 2008, p. 28). This is also just as essential for the response in the UK as in any country in the world.

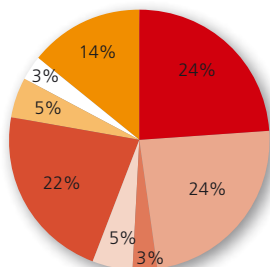
## EXPERIENCES OF STIGMA RELATING TO HIV IN 2008 - 2009

This section highlights five of the main findings from *The People Living with HIV Stigma Index* in the UK—research to comprehensively document experiences of HIV-related stigma that has been done by and for people living with HIV.



**AGE**

- 18 - 19 years
- 20 - 24 years
- 25 - 29 years
- 30 - 39 years
- 40 - 49 years
- 50+ years



### GROUPS PARTICIPANTS IDENTIFIED WITH AT ANY TIME (TICK MORE THAN ONE)

- Men who have sex with men
- Gay or lesbian
- Sex worker
- Injecting Drug User
- Refugee or asylum seeker
- Other
- Prisoner
- I do not belong to, and have not in the past belonged to, any of these categories

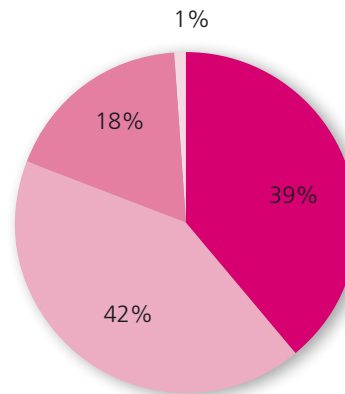
# 01. HEALTH



Issues relating to confidentiality in health settings, disclosure of HIV status without consent, comprehensive consultations and provision of information remain a challenge for people living with HIV in the UK.

One hundred and forty-six people (17%; 78 male, 68 female) reported having been denied health services at least once because of their HIV status in the last 12 months.

Twenty percent of participants (171 responses) have not had a constructive discussion with their health care professional about HIV-related treatment options in the last 12 months, and 31% (262 responses) have not had a constructive discussion on other subjects such as sexual and reproductive health, sexual relationships, drug-use and emotional well-being.



## HOW CONFIDENTIAL DO YOU THINK THE MEDICAL RECORDS RELATING TO YOUR HIV STATUS ARE?

- I am sure that they will be kept completely confidential
- I don't know if they are confidential
- It's clear to me that they are not confidential
- Non-response

### 2010:

Analysis and action will focus on improving the quality of service provision in different areas, including primary health care and promoting the sharing of best practice between HIV specialists and other health service providers such as dentists, general practitioners, nurses and receptionists.

*"When the nurse put on two gloves I was so humiliated, I mean who taught her to do that? If this is going to make a difference you can ask me anything you like."*

PARTICIPANT, LONDON, MAY 2009

# 02. SELF

"I have an undetectable viral load and know my status, how many guys on the scene can honestly say that. I just wish I was able to disclose without so much fear."

PARTICIPANT, MANCHESTER, AUGUST 2009

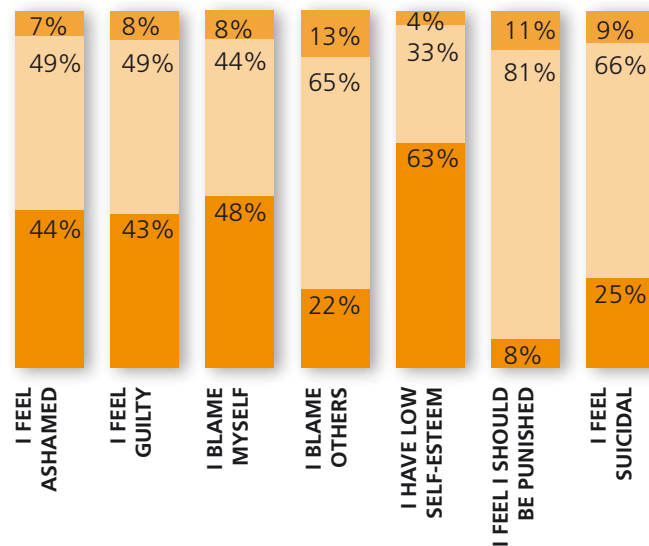
Recognising the complexity of individual lives framed by emotions and experiences, past and present, internalized stigma is apparent among people living with HIV in the UK in 2009.

Internal stigma involves a process whereby someone internalizes any judgements or gossip or prejudice they experience, and devalue themselves. This can lead to low self-esteem, depression, isolation and/or self-exclusion from social events or accessing services.

Living with HIV is one aspect of many in someone's life - but it is undoubtedly one that may positively or negatively affect, influence and shape self identity and image. Self-perception is influenced by the perceived, anticipated or experienced impact of stigma. For example in the last 12 months in the UK, of the participants who identified as gay or lesbian (283 responses), 46% said that they had experienced stigma or discrimination because of their sexual orientation rather than relating to their HIV status. Twenty-nine percent of the participants who identified as being refugees or asylum seekers (253 responses) experienced discrimination because of their immigration status in the last 12 months.

Participants were asked about their feelings in relation to their HIV status and nearly half of participants reported feeling ashamed or guilty, and almost two-thirds reported having low self-esteem in the last 12 months. Consideration should be given to the services available to support people in coming to terms with a positive diagnosis—32% of participants (274 responses) never received pre- or post-test counselling on receiving their HIV positive diagnosis.

## IN THE LAST 12 MONTHS, HAVE YOU EXPERIENCED ANY OF THE FOLLOWING FEELINGS BECAUSE OF YOUR HIV STATUS?



■ Yes      ■ No      ■ Non-response

### 2010:

Analysis will explore trends between experiences of internal stigma, how people experience stigma from others, and how other aspects of identity (such as sexuality, income or immigration status) interact with experiences of stigma relating to HIV. Follow-up qualitative research and further analysis will also explore the relationship between internal stigma, disclosure, and learned behaviour from past experiences. Action will focus on more effectively supporting people living with HIV to feel empowered, live positively and access services that meet their specific and diverse needs.

# 03. SUPPORT



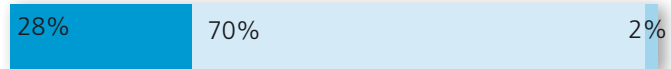
There is a gap between awareness of services to address issues of stigma for people living with HIV and the uptake of these services. Although 88% of people know of organizations they can go to for support, only 29% have sought support from these services.

Are the services provided meeting the identified and diverse needs of people living with HIV in 2009? Have services kept adequate pace with the changing realities of people's lives? And if available, are they accessible to all people living with HIV in the UK?

## DO YOU KNOW OF ANY ORGANIZATIONS OR GROUPS THAT YOU CAN GO TO FOR HELP ...?



## HAVE YOU SOUGHT HELP FROM ANY OF THE ABOVE ORGANIZATIONS OR GROUPS?



## IN THE LAST 12 MONTHS HAVE YOU SUPPORTED OTHER PEOPLE LIVING WITH HIV?



■ Yes    ■ No    ■ Non-response

*"I don't need an HIV support group; I need understanding, people to understand I am not going to die from this."*  
PARTICIPANT, SOUTH YORKSHIRE, JUNE 2009

### 2010:

Analysis and action will explore the relationship between people who are reporting higher levels of internal stigma and the uptake of services. Consideration will be given to how services can be effectively tailored to meet the needs of people newly diagnosed with HIV, as well as people who have been living with HIV for many years. Recommendations will be made about improving the quality and comprehensiveness of service provision to meet the diverse needs of people living with HIV on issues such as health, support, immigration, housing and employment.



# 04. RIGHTS

“There is a need to educate about people’s rights. For one to identify that they have been discriminated against they need to know their rights”

RESEARCHER, LONDON, MAY 2009

In the UK there are three key legislative frameworks that affect the human rights of people living with HIV:

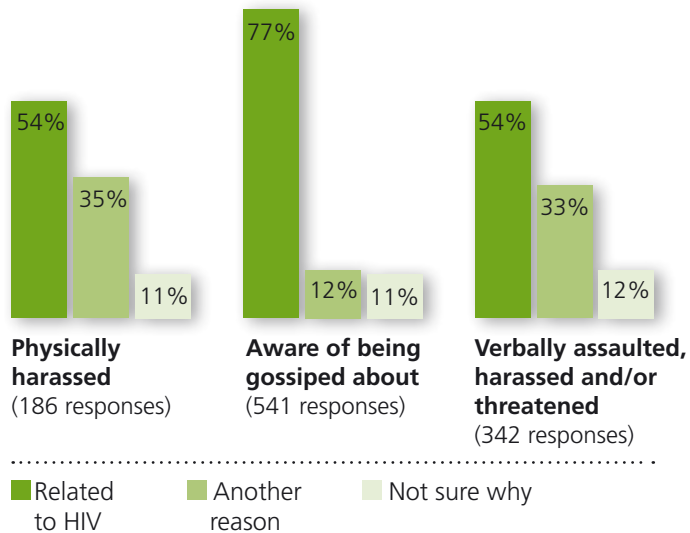
- 01 United Nations General Assembly Special Session dedicated to HIV/AIDS (UNGASS): Declaration of Commitment on HIV/AIDS** (International, 2001)—An international human rights framework that outlines time-bound commitments and a regular process to review country progress in meeting those commitments. The UK was one of 189 countries to endorse the UNGASS Declaration of Commitment in 2001.
- 02 The Disability Discrimination Act (DDA)** (UK, 1995, 2005)—An act that provides the potential access to benefits for people living with HIV.
- 03 The Offences Against the Person Act (OAPA)** (UK, 1861)—An Act that provides the potential criminalization of HIV transmission.

For all three frameworks—two promoting the human rights of people living with HIV, the DDA and UNGASS; and one undermining those rights, the OAPA—knowledge is limited to around half the participants and even fewer have read the specific details of the legislation.

Almost half (46%) of the participants identified that their rights had been abused (167 responses) or were not sure if these had been abused (233 responses) in the last 12 months.

- **One hundred and eighty six participants (22%)** reported being physically harassed in the last 12 months—54% said this was at least in part related to their HIV status

**PARTICIPANTS REPORTING HARASSMENT IN THE LAST 12 MONTHS—PERCEPTIONS OF THE REASON**



- **Five hundred and forty-one participants (63%)** reported being aware of being gossiped about in the last 12 months—77% said this was at least in part related to their HIV status
- **Three hundred and forty-two participants (40%)** reported being verbally assaulted, harassed and/or threatened in the last 12 months—54% said this was at least in part related to their HIV status

## 2010:

Analysis and action will focus on improving the understanding of human rights and the relevant legislative frameworks, and accessing legal services and support, targeted to meet the needs of specific groups of people living with HIV.

# 05. CHANGE



## FUTURE PLANS:

People living with HIV are at the forefront of effecting change—in terms of overcoming fear and isolation, cultivating self-esteem and living positively, as well as in terms of championing non-discrimination, protecting human rights and educating others about how not to stigmatize or discriminate.

### 45%

of participants (383 responses) of people living with HIV have confronted, challenged or educated someone who was stigmatizing or discriminating against them in the last 12 months.

### 61%

of participants (535 responses) reported that they felt that they had the power to influence decisions relating to legal matters, local or national government policies, or programmes that affect their lives.

#### TOP PRIORITIES:

When asked to choose one action for the future, the top three priorities identified by the 867 participants were:

- 01** Raise public knowledge and awareness about HIV (35%)
- 02** Advocate for the rights of people living with HIV (27%)
- 03** Provide support to people living with HIV by providing emotional, physical and referral support (25%)

#### 2010:

Analysis and action will focus on using the specific findings from the Index to promote public debate, targeting information to fill the gaps and support effective change. By continuing to be a community-led research and advocacy initiative the Index will also support people living with HIV to be - and to become - the change they want to see in the world and support service users to ensure that services are tailored to meet their needs.

#### FROM RESEARCH TO ACTION

In 2010 in-depth analysis, discussion, reporting and qualitative research will help us to explore key issues that have emerged from the findings.

The information presented in this document is a brief snapshot of a huge dataset documenting the experiences of people living with HIV in 2009. The community research team will continue to partner with local agencies and further bulletins will be published that consolidate regional and thematic analysis. The bulletins will generate debate and lead to informed and targeted recommendations to improve and update the services, policies and political priorities to meet the diverse needs of people living with HIV in the UK.

*"It's about what we ourselves are going to do about it and that the Government is interested in the results that makes me feel I am being listened to."*

STAKEHOLDER, SCOTLAND,  
AUGUST 2009

## RESEARCH DESIGN AND METHODOLOGY

### RESEARCH DESIGN AND METHODOLOGY

The information available from the Survey of Prevalent HIV Infections Diagnosed (SOPHID) database, which collects data on individuals diagnosed with HIV accessing care across England, Wales and Northern Ireland ([www.hpa.org.uk](http://www.hpa.org.uk)), was used to provide recommendations for recruiting a diverse group of participants to participate in the research. This model was then extended for the Scottish sample. A research design was developed to reflect the nature of HIV in the UK and to ensure good representation from across the UK. Eight hundred and sixty-seven interviews were completed in total, with 83% from a large town or city, 13% from a small town or village and 4% from rural areas, with men and women from diverse ages, backgrounds, professions and religions around the UK. Interviews were conducted across the UK, including Aberdeen, Birmingham, Belfast, Brighton, Cardiff, Dundee, Edinburgh, Glasgow, Leeds, London, Manchester, and Wolverhampton. This is the initial report from the total UK sample; regional variation will be analysed in 2010.

While recognising the limitations—a baseline study implemented for the first time in the UK with community researchers new to the initiative—we celebrate the passion, commitment and successful implementation of the research by and for people living with HIV. It has been a valuable opportunity for all involved to reflect on and at times confront individual memories, perceptions and beliefs and to shape advocacy based on the research findings. Future work with *The People Living with HIV Stigma Index* in the UK will build on the success of the 2009 baseline study by aiming for even more expansive participation in rural areas and people not otherwise engaging with any service organizations.

## ACKNOWLEDGEMENTS

### ACKNOWLEDGEMENTS

This report is the product of a myriad of efforts—most notably the passion and commitment of the community research team and the partner agencies that have supported the process. These have included AB Plus, AIDS Trust Cymru, the African HIV Policy Network, Barnardos, Body & Soul, Body Positive Chester, Body Positive North West, Body Positive Tayside, Brunswick Centre, Begin, Crusaid, Fife Men, Gay Mens Health, GMFA, George House Trust, HIV Carers Scotland, The HIV Centre Belfast, HIV Scotland, HIVine, Look Ahead, Manchester Pride, MesMac, National AIDS Trust, National Children's Bureau, Naz Project, NHS Health Scotland, Plus Me, Positive Action, Positive East, Positive Living, Positively Women, PozFem, The Positive Place, River House Trust, Scotsgay Magazine, Office for Psychosocial Research, Terence Higgins Trust, Waverley Care, Winkfield Resource Centre, YMCA and the Zimbabwe Women's Network.

The UK roll out is part of the international initiative coordinated by the International Planned Parenthood Federation (IPPF), in partnership with the Global Network of People Living with HIV (GNP+), the International Community of Women living with HIV (ICW) and the Joint United Nations Programme for HIV and AIDS (UNAIDS), and has been supported by the M.A.C. AIDS Fund and the Scottish Government.

**We are grateful to each participant who gave their time and energy to participate in the research journey—we hope that this process will contribute to improving our individual and collective efforts to overcome stigma relating to HIV in the UK.**

\*\*note unless otherwise stated, all %s are proportionate according to the number of responses to each question.

## RESOURCES

### RESOURCES

- Disability Discrimination Act (DDA)
  - [www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG\\_4001068](http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068)
- Offences Against the Persons Act (OAPA)
  - [criminalhivtransmission.blogspot.com/search/label/UK](http://criminalhivtransmission.blogspot.com/search/label/UK)
- UNGASS Declaration of Commitment on HIV/AIDS (UNGASS)
  - [www.ua2010.org/en/UNGASS](http://www.ua2010.org/en/UNGASS)

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- National AIDS Trust (NAT) (2009). [www.nat.org.uk](http://www.nat.org.uk)
- Department of Health (DH) (2001) The National Strategy for Sexual Health and HIV implementation plan
- DH (2007). Tackling HIV Stigma and Discrimination
- DH (2009). Moving Forward: Progress and Priorities—working together for high-quality sexual health [www.dh.gov.uk](http://www.dh.gov.uk)
- *The People Living with HIV Stigma Index* [www.stigmaindex.org](http://www.stigmaindex.org)

BETWEEN MAY AND SEPTEMBER 2009, **867**  
**PEOPLE LIVING WITH HIV** HAVE BEEN  
INTERVIEWED BY THEIR PEERS ABOUT EXPERIENCES  
OF **LIVING WITH HIV**, ACCESSING HEALTH AND  
OTHER SERVICES, **EXPERIENCES OF STIGMA AND**  
**DISCRIMINATION**, SOURCES OF SUPPORT, AND  
**LIVING POSITIVELY**. THIS IS THE FIRST REPORT OF  
THE FINDINGS FROM THE PEOPLE LIVING WITH HIV  
STIGMA INDEX IN THE UK.



THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX