

PLHIV Stigma Index:



QUESTIONNAIRE, POINTERS AND QUALITATIVE

Dr Laura Sharp

Dr Helena Paterson

Office for Psychosocial Research

41 Park Terrace Lane
GLASGOW G3 6BQ

t: +44 (0)141 333 0241

e: mail@researchoffice.co.uk

w: researchoffice.co.uk



THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX

Self-stigma

Health Settings

Rights and Laws

Themes in PLHIV Stigma Index

Exclusion

**Disclosure
Decisions**

**Disclosure
Experiences**

Diagnosis experiences

**Effecting
Change**

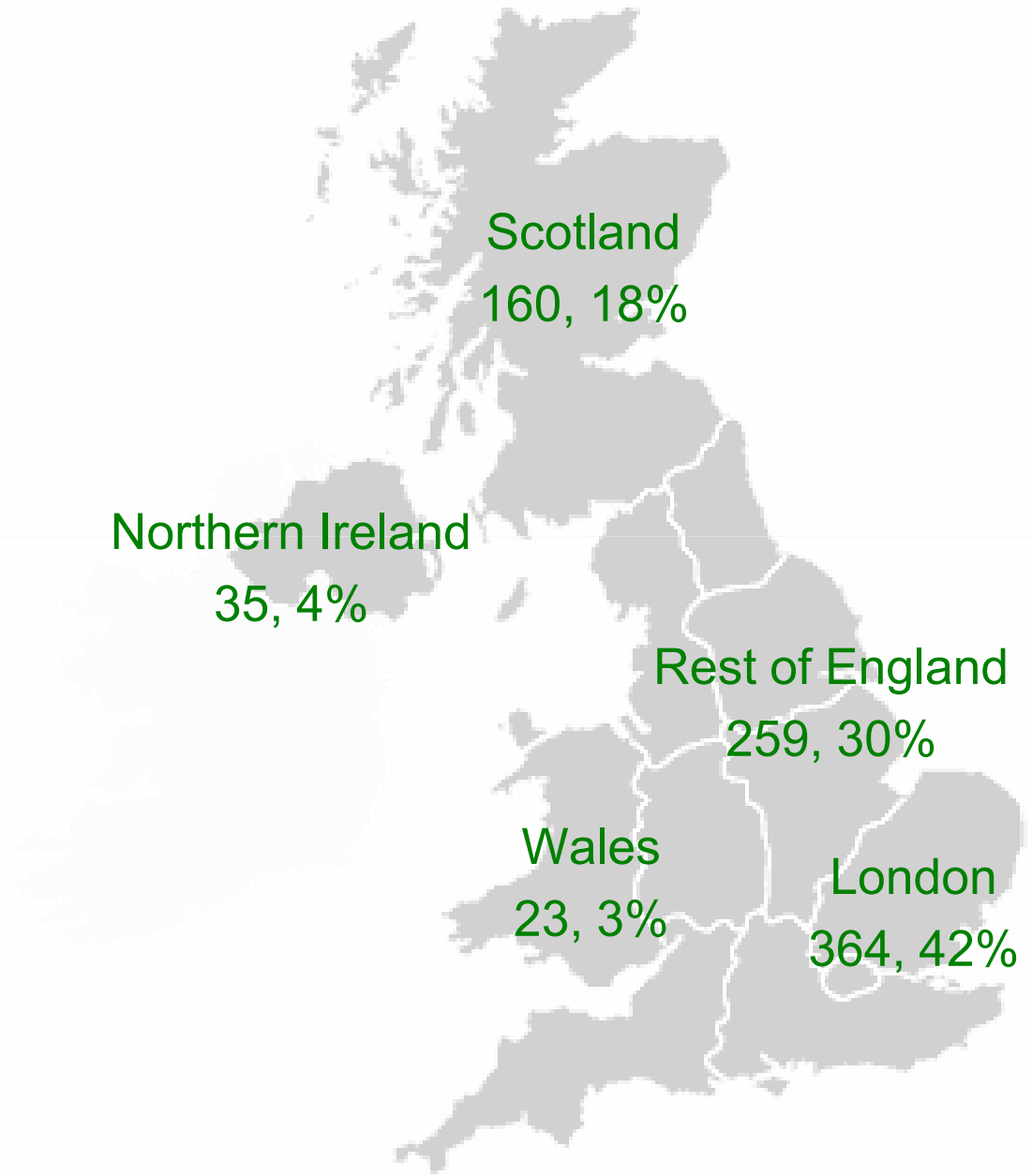
**All face-to-face research
was undertaken by
PLHIV:**

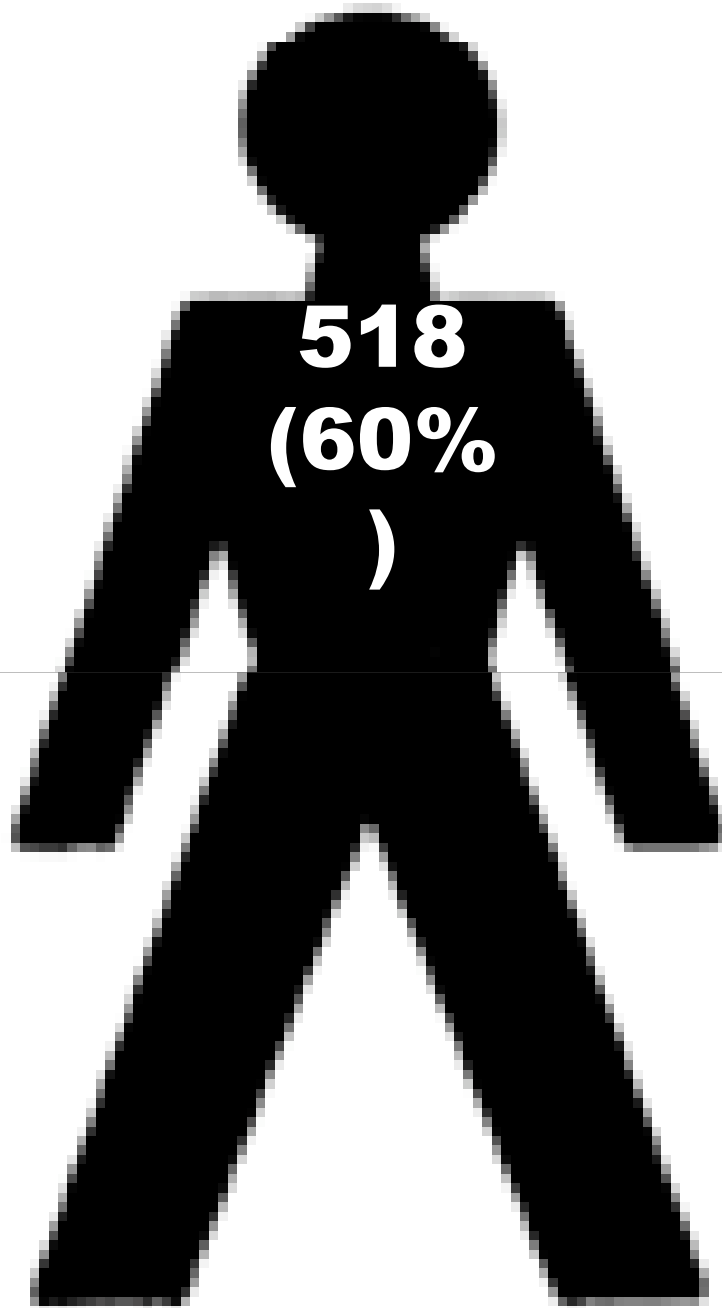
- **3 days training for Stigma Index**
- **1 hour top-up session for focus group facilitation**

867 Stigma Index
Questionnaires
completed around UK, in
more than 40 sites

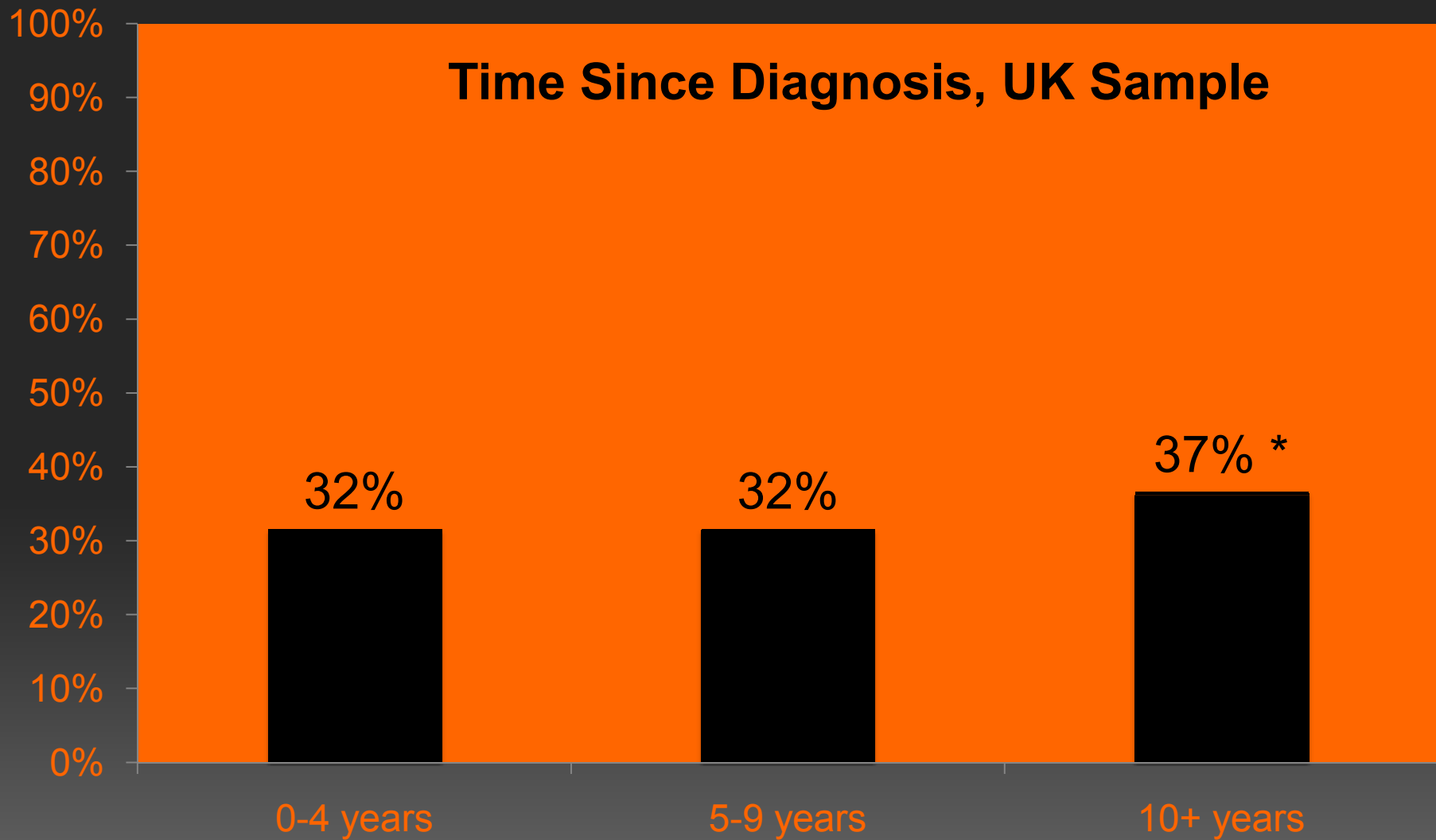


Stigma Index Questionnaire UK Location Participant Breakdown





Time Since Diagnosis, UK Sample



*** 20% had been living with HIV for 15+ years**

Data collected ... but what next???

Two main tasks:

- 1) Develop a tool that will give access to some of the more complex parts of the data (Pointers)
- 2) Explore some of the findings using qualitative approach to gain greater insight into the observations made.



Pointers: Introduction

- The people living with HIV stigma index is a very comprehensive and rich source of data
- Some of it is too complex to summarise and comprehend quickly
- Pointers allow us
 - to decide where we should direct sources to find interesting individual stories and relationships in the data.
 - To do more sophisticated statistical analysis

What are the pointers all about?

- The basic premise is:
 - Take the frequency data generated by many questions and sensibly combine it to make a single number
 - A way to summarise complex data in a sensible way

What are the pointers all about?

Pointers allow specific questions to be asked:

- A tool for comparison within a group
- A tool for comparison between different parts of the UK
- A tool for international comparison

Self-stigma

Discrimination

4 Pointers

**Reactions to
Disclosure**

Disclosure

**Each Pointer has Sub-Pointers
(more concise themes)**

**Total of 12 Sub-Pointers
(& 4 sub-themes)**

Discrimination (3SP + 4ST)

Sub-Pointers

Rights Abuse

Wider Community

Personal Relationships

Sub-Themes

Work & Education

Healthcare

Discrimination by other PLHIV

Assault

Disclosure (3 SP)

Close Relationships

Formal Relationships

Wider Community

Reactions to Disclosure (3 SP)

Close Relationships

Formal Relationships

Wider Community

Self-Stigma (3 SP)

Negative Feelings

Self-Stigmatising Behaviour

Fears

**Each of the 12 Sub-Pointers and
4 Sub-Themes is made up of a
number of questions from the
Stigma Index**

For example...

Example (1 of 12 Sub-Pointers):

POINTER: SELF-STIGMA

SUB-POINTER: FEAR


QUESTIONS:

1. Fear of being gossiped about
2. Fear of being verbally insulted, harassed and/or threatened
3. Fear of being physically harassed and/or threatened
4. Fear of being physically assaulted
5. Fear that someone would not want to be sexually intimate with you

QUALITATIVE WORK

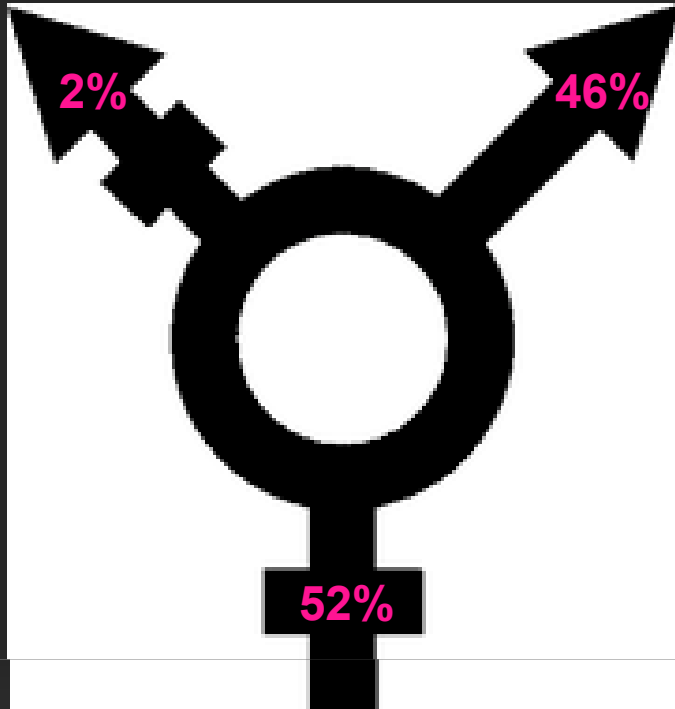
A 3D rendering of a crowd of white human figures, with one figure in the foreground highlighted in red, standing with arms raised. The background is a blurred, light blue and white environment, suggesting a large gathering or a virtual space.

Qualitative investigation offered an opportunity to collect the stories behind the quantitative findings. This process aimed to offer context to the main findings.

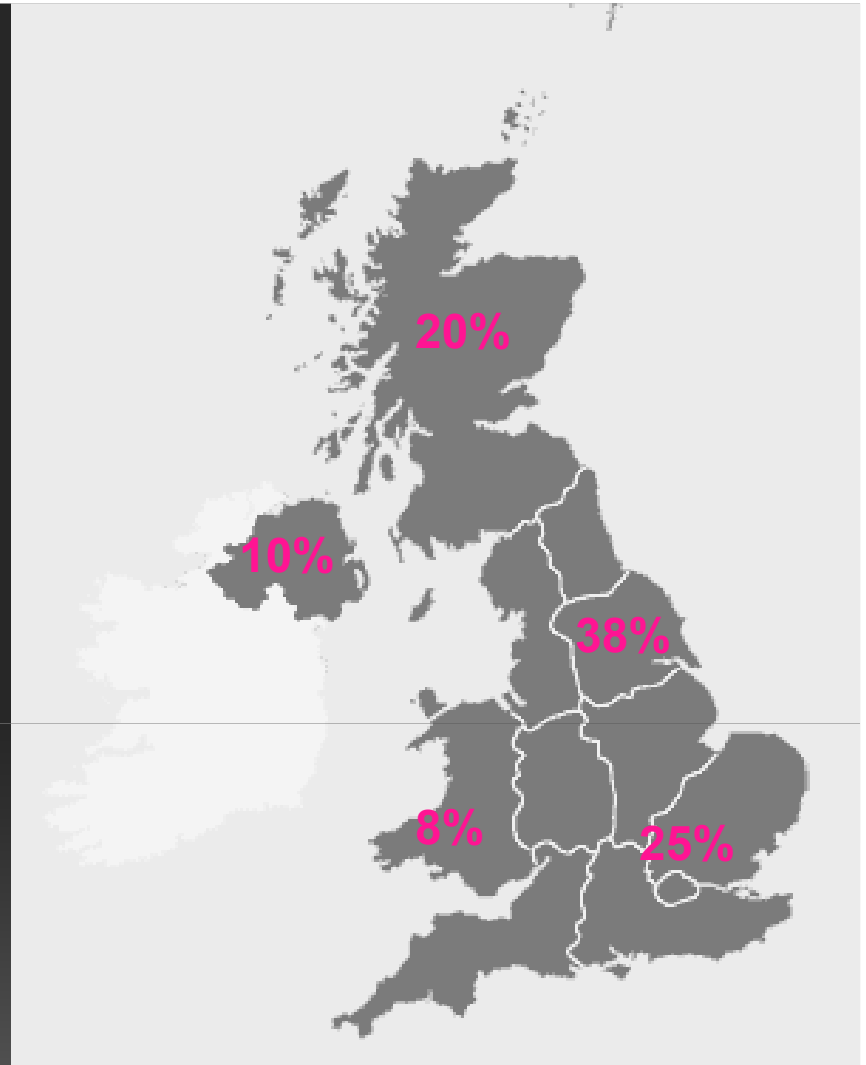
A map of the United Kingdom, including Great Britain and Northern Ireland, with white outlines delineating the regional boundaries. The map is positioned on the right side of the slide, partially overlapping the text area.

Qualitative 12 focus
groups completed in
across the UK

Total Qualitative Sample: n = 61



DEMOGRAPHICS FOR QUALITATIVE WORK SUMMARY



Focus Group Structure

Power Point presentation used as Interview Schedule.

Two Interview Schedules developed (6 groups did each)

Each slide offered a summary of some key findings.

Participants were invited to

- make comments,
- share personal experiences,
- discuss findings
- enquire about anything they didn't fully understand.

Focus Group Structure

Health, Self and Disclosure

Accessing Healthcare
Disclosure: Health Settings
Sexual Relations
Self-Stigma
How disclosure occurred
Was disclosure empowering?
Effecting Change
Priorities for addressing stigma

Rights, Support, & Disclosure

Experiences of discrimination
Stigma and discrimination
Employment
Coping with HIV
Effecting Change
Priorities for addressing stigma

HOW CAN WE MAKE SENSE OF IT ALL



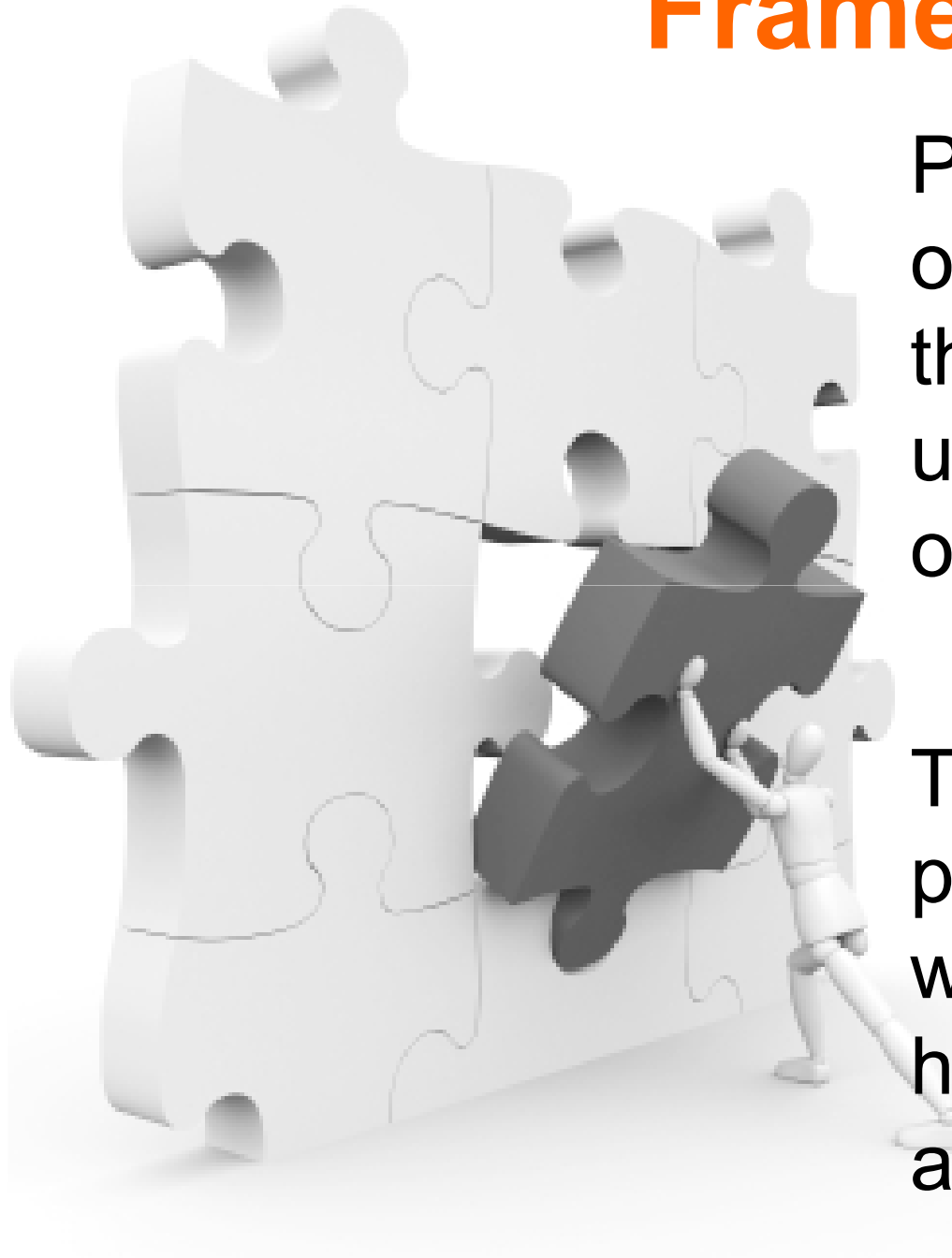
Overview of Structure

**Pointers
& Themes**

**PLHIV Stigma Index
Questionnaire (n = 867)**

Qualitative Focus Groups (n = 61)

Framework available



Pack includes overview of the potential areas that can be explored in using the different levels of data

The next three presentations will offer worked examples of how the findings can be applied

Point of Contact

www.stigmaindex.org
ahudson@ippf.org

Presentation 2

PLHIV Stigma Index:

Worked Example: TALKING ABOUT FEELINGS



THE PEOPLE
LIVING
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STIGMA
INDEX

Dr Helena Paterson
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Office for Psychosocial Research
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w: researchoffice.co.uk

• Stigma Index

- Demographics
- Discrimination and stigma
- Internal Stigma
- Rights, Laws & Policies
- Effecting change
- Testing and Diagnosis
- Disclosure
- Reactions
- Confidentiality
- Treatment
- Having Children

Overview of Structure

**Pointers
& Themes**

**PLHIV Stigma Index
Questionnaire (n = 867)**

Qualitative Focus Groups (n = 61)

- 4 Pointers Themes
 - 16 sub-pointers and sub-themes
 - Individual questions that relate to each
 - Qualitative quotes and themes that fill in the human element

Example (1 of 12 Sub-Pointers):

POINTER: SELF-STIGMA

SUB-POINTER: Negative Feelings

QUESTIONS:

- I feel ashamed
- I feel guilty
- I blame myself
- I blame others
- I have low self-esteem
- I feel I should be punished
- I feel suicidal



The Process of Calculating Pointers

- Deciding on Weights for different questions
 - With the help of interested judges
- Deciding on what questions should fit together
- Calculating and applying the weights

Self Stigma

- Weights:
 - Average of weights made by five judges

Feelings	Weight
I feel ashamed	0.60
I feel guilty	0.47
I blame myself	0.60
I blame others	0.53
I have low self-esteem	0.80
I feel I should be punished	0.53
I feel suicidal	0.93

Calculating Feelings Sub-Pointer

- Main pointer was calculated as follows for each participant
 - Weight applied to each question
 - Multiplied by 1 if the person experienced the feeling/and 0 if they did not
 - All summed
 - Summed score divided by maximum to form the proportionate score
- The higher the score for a person, the higher is the impact of HIV on their negative feelings

Pointers reflection

- After calculating the pointers some clear themes emerged
 - Pointer numbers become most meaningful in the context of comparing groups and sub-populations
 - Pointers are a very powerful tool for correlation (a type of statistical analysis)

UK Overall: .369

722 (85%) experienced negative feelings

286 (33%) 4 or more

Almost exactly the same for Men and Women

Fewest negative feelings for under 30's (pointer = .284, experienced by 73%)

Higher pointer for refugee Women (.379 vs .344 for other) and 36% more than 4 negative feelings (vs 28% other women)

Feelings Pointer

More Gay men than other men experienced negative feelings (76% vs 86%)

Low Self Esteem

63% (n=542)

What Feelings?

Low Self-esteem

“There are times when I really feel so low but that is as a result of a lot of other reasons, one is not being able to having sex actually. Not having a relationship sometimes, ... it can be very lonely... As I said HIV is just part of the jigsaw... There are times when you just sit and think ‘I can’t be bothered, that guy is asking me out and I can’t be bothered to go and disclose’ so it goes on like that.”

Low Self Esteem
63% (n=542)

Guilt

43% (n=372)

What Feelings?

Guilt

“I don’t know why I feel guilty, probably because the society doesn’t accept it, so I am guilty.”

“(I feel) Guilty. Because I shouldn’t have slept with that other guy. I was in a relationship and I feel a lot of guilt for that. He was an ex partner and he knew he was HIV but he didn’t tell me... So I have a lot of guilt for my partner. I am worried.”

“I can relate to feeling guilty and also feeling that I should be punished ... you are constantly being reminded, ‘if it wasn’t for you then we wouldn’t be in this situation, you know it’s your fault.’ When you hear it over and over again, you start to feel that actually it might be my fault.”

“I never felt guilty. I don't think I deserve any punishment, I didn't blame others for it. It's just like any other illness.”

Low Self Esteem
63% (n=542)

Guilt

43% (n=372)

Shame

44% (n=376)

What Feelings?

Shame

“I feel ashamed because I can’t even openly talk about it, so I’m still living another life.”

Low Self Esteem
63% (n=542)

Guilt

43% (n=372)

Shame
44% (n=376)

What Feelings?

Self Blame
48% (n=419)

Self-Blame

“I blame myself probably for not being well enough educated to know what this HIV was all about.”

“I blame myself, ... if only the bells were ringing that day... When I came to this part of this world (from Zimbabwe) I was so eager to just get my family over here, which I couldn't then, and all I did was work and sleep. And then you find this guy who lives in the same block of flats as you, who is very single, who drives a very nice car, who is really, really very nice and you think ‘Who says life is not good?’ ... If only someone were to slap me, that very moment I could have saved myself.”

“I blamed myself for being careless that's all.”

Low Self Esteem
63% (n=542)

Guilt

43% (n=372)

Shame
44% (n=376)

What Feelings?

Self Blame
48% (n=419)

Suicidal Feelings

25% (n=216)

Suicidal

“I am suicidal all the time, they’ve got me seeing a psychiatrist... I can’t even go out and buy myself clothes or I can’t go on holiday. It’s just a job to eat... The word ‘HIV’ is enough to drive me cuckoo. I can’t talk about it. I can’t read about it”

**2-4 years since diagnosis
has the highest rate of
suicidal feelings**

Men: 33%, Women: 27%

**>5 Years TSD more
women blame
others: 28% vs 16%
men**

**Trend reversed for
10-14 years TSD**

What Feelings?

**19% women vs 30%
men blame others**

**As do different age
groups**

**On average UK
men and women
have similar
feelings profiles**

**And also gay/msm and
refugee women**

What Feelings?

Suicidal Feelings

UK: 25% (n=216)

Bangladesh 10%

DR 8%

UK Overall: .369

**722 (85%) experienced
negative feelings**

Bangladesh: .446

96%

**experienced
negative feelings**

Women: .344

Men: .504

**Profile of feelings
different for men
and women**

International Feelings

**DR: .241 and 71%
experienced negative
feelings**

Women: .27

Men: .212

**Profile of feelings different
for men and women**

Training health workers and volunteers to spot signs of depression

Workshops to help build self esteem & self worth

Posters in volunteer centres/GP practices for Breathing Space or other organisations

Interventions

Education for PLHIV on how to help friends

Targeted Support Groups/counselling services/advertising

A specialist online dating service for PLHIV

Education about the stages of grief

Point of Contact

www.stigmaindex.org
ahudson@ippf.org

Presentation 3



HEALTH OVERVIEW



**THE PEOPLE
LIVING
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STIGMA
INDEX**

Dr Laura Sharp
Dr Helena Paterson

Office for Psychosocial Research

41 Park Terrace Lane

GLASGOW G3 6BQ

t: +44 (0)141 333 0241

e: mail@researchoffice.co.uk

w: researchoffice.co.uk

Health: Plan for session

Rights abuse

Discrimination: denial of health service

Testing experiences

Confidentiality

Reactions of health professionals to disclosure

Importance of education

Overview of Structure

**Health Related
Themes**

**PLHIV Stigma Index
Questionnaire Sections 2B,
2C, 3A, 3B, 3D**

**Relevant Quotes from Qualitative
Focus Groups (n = 61)**

RIGHTS ABUSE:

In last 12 months 92 participants (11%) reported that they had been forced to submit to a medical or health procedure.

“being forced into medicals and divulging our status ... is shocking ... where does that leave us?”


DISCRIMINATION:

In last 12 months 179 participants (21%) reported that they had experienced discrimination in health settings.

“My daughter ... didn’t like going [to the paediatric HIV clinic] because it reminded her that she was HIV positive... when the nurses took her blood they always put on two pairs of gloves and ... those dreadful yellow tape stickers ... ‘danger of contamination’ ... ‘high risk’ and that just reinforced the stigma she felt.”

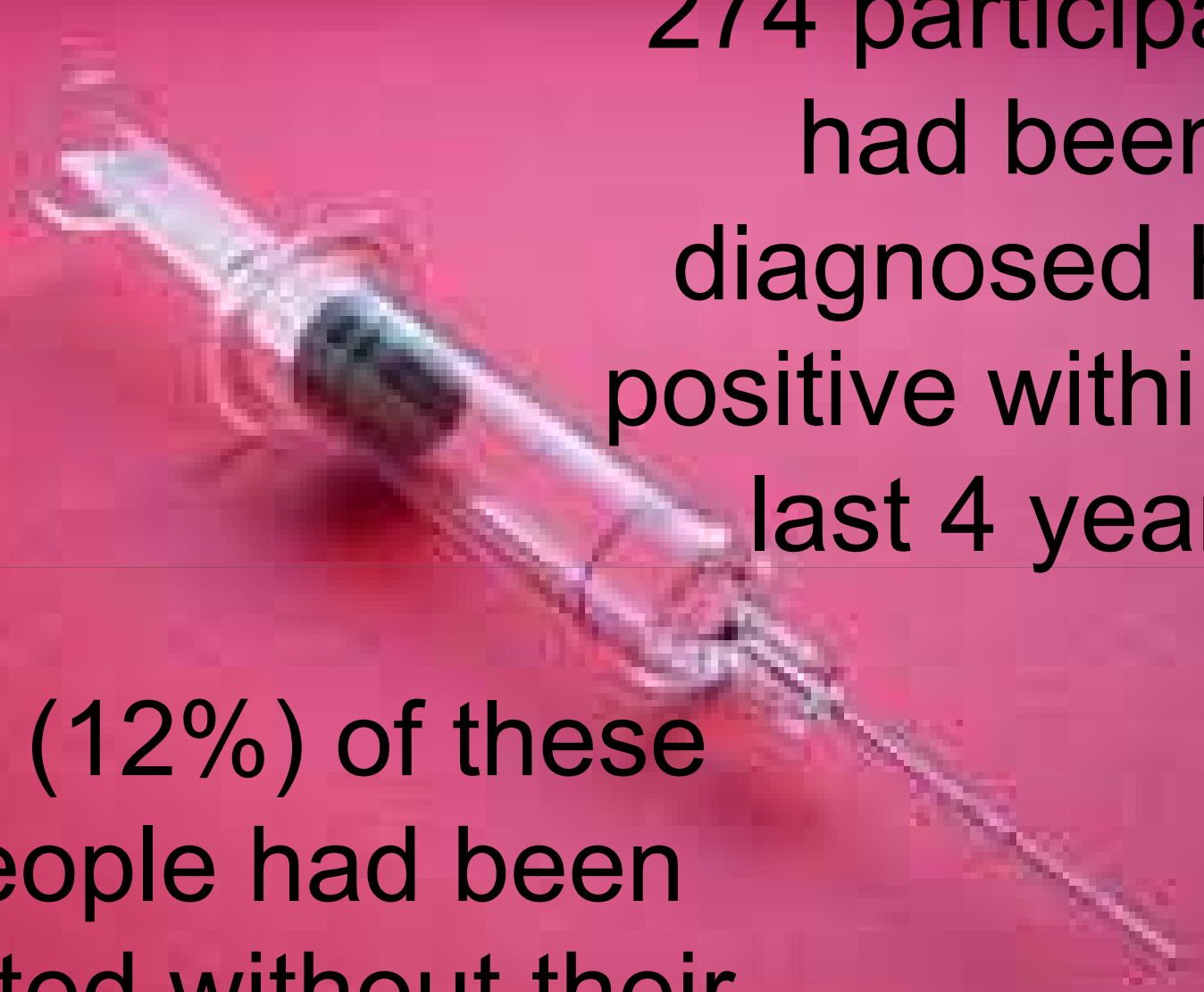
The majority (n=146, 81%) of people who had experienced discrimination in health settings had experienced denial of health service.

- **34** had been denied family planning services
- **23** had been denied sexual and reproductive health care



Of the women diagnosed in the last four years, who considered reproductive support applicable to them (n = 90), 64 (56%) had not received counselling on their reproductive options

“[PLHIV seeking] fertility treatment ... [have] been ... told, ‘well we can’t do that for you with HIV, you can’t be having children’.”

A syringe with a needle, set against a dark red background. The syringe is positioned diagonally, with the needle pointing towards the bottom right. The background is a solid, dark red color.

274 participants
had been
diagnosed HIV
positive within the
last 4 years

33 (12%) of these
people had been
tested without their
knowledge.

43% (n=118)

**Pre & Post test Counselling
BEST PRACTICE**

**32% (n=87) No
counselling
during testing
process**

**Reflection of current
practice (in those diagnosed
in the last 4 years)**

4% (12)

**Only Pre-test
Counselling**

20% (55)

**Only Post-test
Counselling**

Potential implications of not counselling when testing for HIV

The highest proportion of people reporting suicidal feeling is in the group 2-4 years after diagnosis.

Confidentiality

18% (157) reported it was clear that their medical records were not being kept confidential. A further 42% (361) were unsure if their records were confidential.

“I know that medical records aren’t kept completely confidential. Because I received somebody else’s blood records, with their name and address, in my medical file... just 6 weeks ago. They (the hospital) said that wasn’t in the medical file. I says ‘well, I’ve got it at home’. So they apologised.”

How would you describe the reaction of healthcare workers when they first heard about your HIV status?

Three options for response:

- Discriminatory
- No different
- Supportive

What reaction do people want?



Discrimination



Supportive



No different

Discriminatory Response



“My own doctor, if I asked him for heroin he would give it to me just to get me in and out. You know, one of them can’t even bear to look at me... He can’t get the prescriptions wrote out quick enough for me... Because (of) his upbringing, he’s stuck up. His father was a doctor, you know. Just think very anti-gay, but what can you do about it? ... I think he is afraid of my HIV. You know, I might sneeze on him.”

Supportive Response: Positive



“I needed to get my blood test done. There was a nurse who came in and ... I said ‘oh you better protect yourself’ ... she said, ‘thank you’. ... I said ‘you better put your gloves on, just to be careful.’ And she said ‘you know what, thank you very much, not many people would just say’... She was very kind to me.”

Supportive Response: Negative



“I went to have my bloods taken for diabetes at the GP practice the nurse knew I was coming... I got in there she had a red ribbon. ... it could be a positive thing that she’s in support but I would rather be treated like anybody else... I thought there was no need to wear a red ribbon. Are you trying to say something to me? Are you feeling sorry for me or it could mean “oh I’m in support with you”... But when go to a doctor’s surgery and nobody’s wearing a ribbon and they see me and they go and come back with a red ribbon... I don’t know what it meant but I thought she shouldn’t have worn it.”

“Every time ... I go to the GP, even if I am not going for HIV, ... they always talk to me about that ... making me feel very embarrassed.”

No Different Response



“I very reluctantly told my doctor (GP) ... there is a big generation gap. He was never brought up the way, he wouldn't know what the word “working class” would be... He wouldn't have had an idea what it was like when we grew up and I can't really relate to him... So when I told this doctor (GP), he was quite all right, just right.”

“When I go to my GP now, he doesn't ask me so many questions, he'll just say, “you are not breastfeeding”. He won't say “because you are HIV”.

Varying interpretations

A persons could have 99 positive experiences with health professional but one healthcare worker has reacted unprofessionally could tick:

‘Discriminated against’ to highlight this occurrence as unacceptable.

OR

‘Supportive’ or ‘No different’ to reflect the majority of their experiences.

For Example...

“Last time I was in hospital, I felt stigmatised ... It wasn't by the nurses and it wasn't by the consultant in the clinic but ... when I was in A & E, doctors in there. But even the junior doctor was alright, it was ... some higher doctor ... just his whole attitude”

Would this person have ticked ‘supportive’, ‘no different’ or ‘discriminatory’?

How would you describe the reaction of healthcare workers when they first heard about your HIV status?

Three options for responses:

Discriminatory

8% (55)

No different

14% (88)

Supportive

78% (506)

n.b. 213 participants indicated this was not applicable to them

Qualitative work offers large amount of insight into the frequency data!!

This presentation contains experiences of people about what is occurring in practice

In the Index participants were asked what they considered most important in addressing stigma and discrimination. They were offered five options. 29% considered:

‘Raising awareness and knowledge of the public about AIDS’

to be the most important intervention to target resources

RECURRENT THEME IN FOCUS GROUPS

‘Raising awareness and knowledge of the public about AIDS’

“Some nurses they don’t have the knowledge and when it comes to handling HIV it is a mess. But you don’t blame them because they don’t know. They think just touching somebody you can get it.”

“If people understood their rights with HIV that might help ... to empower them ... to be able to challenge [decisions to deny services].”

RECURRENT THEME IN FOCUS GROUPS

‘Raising awareness and knowledge of the public about AIDS’

“I had a client who phoned in the other day and she had started a new relationship and in this relationship she disclosed to her partner that she was HIV positive and then this partner phoned some nurse from some clinic and he was told that he could actually contract HIV from kissing. And so that meant that relationship was coming to an end completely. And this is a health professional telling this guy that you can contract HIV from kissing.”

These illustrate the role of the qualitative work in supporting observations and interpretations

Health Themes

PLHIV Stigma Index Questionnaire

Quotes from Qualitative Focus Groups

Point of Contact

www.stigmaindex.org

ahudson@ippf.org

Presentation 4



DISCRIMINATION: Targeted Reports

Dr Laura Sharp
Dr Helena Paterson

Office for Psychosocial Research
41 Park Terrace Lane
GLASGOW G3 6BQ
t: +44 (0)141 333 0241
e: mail@researchoffice.co.uk
w: researchoffice.co.uk

**Proposal to illustrate
how the information
could be used to
educate and enlighten
others....**

**Family Planning
/Pregnancy**

Mental Health

**Housing / UK
residency**

**Areas Discrimination
reported...**

Dental Health

General Practice

Employment

Family / friends

**Religious
Setting**

Identify theme to communicate

Consider data to address the positives / negatives: e.g.

1. Of those whose status was disclosed (642) to other adult family members 84% (512) found them to to be supportive or no different.

2. 100 participants reported discrimination related to employment.

Then compliment with qualitative findings.



WORKED EXAMPLE: RELIGIOUS SETTINGS



DATA EXTRACTION

From overall stigma index participants who recorded 'not applicable' to disclose to a religious leader were excluded from religion specific reporting.

259 participants included – assumed to be part of a religious community

**120 (47%) individuals had taken
the decision to disclose to a
religious leader**

“My church ... knows that I am HIV positive and it’s not an issue and they don’t talk about it. And when I meet them I am not worried that they are going to talk about my status.”

Own decision to disclose POSITIVE REACTION

“The priest from the church, he knows but he’s not said anything to anybody, not even his wife.”

“There is a need for more discussion of stigma in the churches or in religious communities.”

Own decision to disclose **NEGATIVE REACTION**

“(She) told her very supportive clergyman ... in confidence and after that he stopped her taking the communion ... he also suggested that she shouldn’t touch something else ... In a community where she felt she had been accepted and she felt absolutely dreadful that something that mattered to her spiritually became an issue for her because of her HIV”

Low Self Esteem
63% (n=542)

Guilt

43% (n=372)

What Feelings?

Shame

44% (n=376)

Suicidal Feelings

Self Blame

48% (n=419)

25% (n=216)

**6 (2%) reported their status had
been disclosed without their consent**

“If I disclose it to [the religious leader, he] will tell some people... He’ll [say] to the elder, ‘let’s pray for [her] ... she’s HIV’.”

6 (2%) reported their status had been disclosed without their consent

“The Pastor mentioned we have to pray for [someone] to chase away this curse of HIV.”

**139 (54%) of participants had
opted not to disclose their HIV
status to a religious leader**

“I have found out that protestant people ... don't have a lot of tolerance for people ... they seem to look down their noses on you ... if you seem to be gay they look down and that's (HIV is) God's punishment.”

What might influence the decision not to disclose?

“I think they wouldn't exclude me (from religious gatherings) if they knew. I am not taking the risk... Like anywhere else, some people would be alright with it but a lot of people wouldn't.”

Discrimination

Of the 120 individuals who disclosed to their religious leaders 16 individuals (14%) reported that they had been discriminated against.

“If you were HIV positive you weren’t welcome in the church any longer. I have met several people who have reported that as an absolute fact. ... Well, because they’d obviously sinned.”

EXCLUSION FROM RELIGIOUS ACTIVITIES

27 (10%) of the participants involved in a religious community reported being excluded from religious activities or places of worship due all or in part to their HIV status.

Of those, the majority 17 (63%) had disclosed their HIV status to religious leader. 10 (37%) had not disclosed.

EXCLUSION FROM RELIGIOUS ACTIVITIES

“I went to confession; I thought I’ve been diagnosed (HIV positive) maybe its time to speak to the Big One (God). I went in spoke to the priest and he pulled the curtain back and everything on me. Gave me verbal. ‘Why are you living your life like this? It’s against the Bible. ... Where is your conscience?’ The Sunday I goes to mass, ... (the priest) gives my dad communion, looks at me and just went like that (shake’s head) ... and gives it to the person next to me. ... He wouldn’t give me communion. That was years ago I still go to mass today but I do not go down to get communion anymore.” FG 2.

Assumption of celibacy

An observed assumption by parents with religious beliefs was that their offspring would not enter into sexual relations until they were married. Participants considered this assumption naïve, meaning that young people are deliberately not exposed to information about safe sex practices and therefore putting the young people at risk.

Assumption of celibacy

“I think certain religions don’t educate them young enough in their heart of hearts and their minds they (their children) don’t have relationships until they’ve got rings on their fingers and signed on a dotted line.”

Recommendation not to take medicine

Some participants reported that they had been advised that they should not take their medication as prayer will cure them of HIV. The recommendation to halt the medication regime is a risk to individuals' health.

Recommendation not to take medicine

“Why is it that the pastors tend to tell people to stop taking medication? ... I mean people end up dying.”

“I think the issue (is) that they regard it as a demon which can be exorcised and once it has been exorcised you are free of HIV which is a fallacy. It shows lack of understanding of how the HIV virus operates so they will need a lot of education so that they will not detract people from taking medication on the belief that the demon has been exorcised and they are now clear.”

“Pastor Chris said ‘I must stop medication, I’m healed.’ ... So what I'm saying is mostly don't listen to these churches, your medication is your life... I stopped for 2 weeks ... but I was having all these rashes and I went to a doctor.”



**PROPOSED LEAFLETS:
PLHIV NEED TO CONSIDER
THEIR VALUE AND HOW TO
APPLY THEM**

“I wish that I had been told more about disclosure when I was just diagnosed.”

**Family Planning
/Pregnancy**

Mental Health

**Housing / UK
residency**

**Areas Discrimination
reported...**

Dental Health

General Practice

Employment

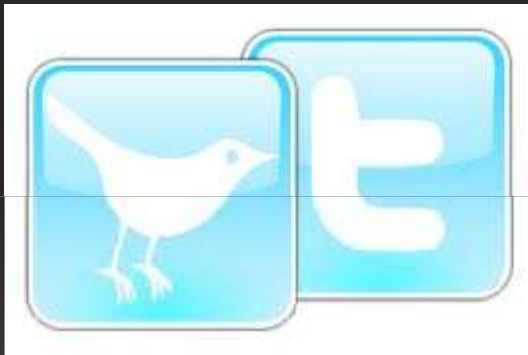
**Religious
Setting**

Family / friends

Dissemination



facebook®



How could we share the info?

Facebook

Twitter

Personal Networks

Official Organisations (e.g
Church Assembly, RCGP)

HIV and general charities

Target talks: London Mayor

Point of Contact

www.stigmaindex.org

ahudson@ippf.org