

# GIVE STIGMA THE INDEX FINGER!

SCOTLAND REPORT 2009

*THE PEOPLE LIVING WITH HIV STIGMA INDEX*

“PEOPLE **don't want to TEST** DUE TO STIGMA OF  
A POSITIVE RESULT”

“**Fear** OF THE UNKNOWN LONG-TERM”

“**My HIV diagnosis saved my life!** GOD KNOWS  
HOW I WOULD BEHAVE TODAY IF I HAD NOT BEEN STOPPED IN MY  
TRACKS.”

“**HIV** IS A DIAGNOSIS NOT A LIFESTYLE CHOICE...

... WITH MEDICATION AND SUPPORT, **I just get on with it.**”

## ACKNOWLEDGEMENTS

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Others in the UK have included AB Plus, AIDS Trust Cymru, the African HIV Policy Network, Barnardos, Body & Soul, Body Positive Chester, Body Positive North West, Brunswick Centre, Begin, Crusaid, GMFA, George House Trust, The HIV Centre Belfast, HIVine, Look Ahead, Manchester Pride, MesMac, National AIDS Trust, National Children's Bureau, Naz Project, Plus Me, Positive Action, Positive East, Positive Living, Positively Women, PozFem, The Positive Place, River House Trust, Terrence Higgins Trust, 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.

*"Use me how you will, I have had such a laugh meeting you guys. I refuse to be afraid or a victim of this disease."*

– Participant, Glasgow, July 2009

The main audience for this report is the Scottish Government and core organisational partners who supported the implementation of *The People Living with HIV Stigma Index*. A summary of key findings will be produced in 2010 to communicate the Scottish specific results to a wider audience. The findings outlined in this report reflect (as closely as possible) the wording of the questions as they were asked, and the responses as they were given in the open-ended sections. It is neither a damning nor a celebratory report, but rather an accurate presentation of the responses from the 163 people living with HIV who participated in this initiative in Scotland in 2009.

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## ACRONYMS

ART	Antiretroviral treatment
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV and AIDS
IPPF	International Planned Parenthood Federation
OI	Opportunistic Illness
PLHIV	People Living with HIV
SRHR	Sexual and Reproductive Health and Rights
UNAIDS	Joint United Nations Programme on HIV and AIDS

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## EXECUTIVE SUMMARY

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

In Scotland, 163 people living with HIV were interviewed between August and September 2009. This included men and women representing key groups, including men who identified as MSM, asylum seekers, sex workers, prisoners and people who use drugs. Interviews were conducted in Glasgow, Edinburgh, Tayside and Aberdeen.

Overall, the results show that in the last 12 months:

- **Stigma and discrimination remain a challenge in Scotland.** Of the 163 participants, forty-four percent (71 participants) reported that their rights either have been abused or are not sure if their rights have been abused, and seventeen percent (28 participants) reported having been denied health services.
- **People living with HIV in Scotland are showing leadership in the response to stigma.** In Scotland forty-four percent (71 participants) reported challenging someone stigmatising them in the previous twelve months, and ninety percent (146 participants) reported supporting other people living with HIV to overcome stigma.
- **Services need to be improved and updated to meet the changing needs of people living with HIV.** Although eighty-seven percent (142 participants) of people know of services available to them, only twenty-five percent (41 participants) have used these services for support relating to stigma and discrimination in Scotland.

The report contributes to and builds on the re-energised attention and focus generated by the HIV Action Plan launched by the Scottish Government in December 2009. The community research team involved with *The People Living with HIV Stigma Index* are committed to working with the evidence generated from this initiative to support action that generates change in the lives of people living with HIV in Scotland.

**Key recommendations** emerging from the initiative include:

- 1) Implement the HIV Action Plan in partnership with and informed by people living with HIV.
- 2) Develop a rights-based information campaign for the general public about HIV.
- 3) Develop a rights-based information campaign for specific key groups of people living with HIV.
- 4) Build on the key issues identified in follow-up and in-depth research with under-represented communities of people living with HIV and on key issues.

In many ways, this report builds on and colours-in some of the priorities already identified by the Scottish Government in the HIV Action Plan (2009) as well as the Strategy and Action Plan for Improving Sexual Health (2005).

‘Give Stigma the Index Finger’ provides both an opportunity to better inform and support policies and practices to address stigma related to HIV by listening to the voices and real life experiences reported by people living with HIV, as well as amplifying the ongoing challenge to transform good policies into better practice that generates a demonstrable benefit for the lives of all people living with HIV in Scotland.

*“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”*

--Stigma Index Participant, Glasgow, September 2009

## INTRODUCTION

Stigma and discrimination remain a significant issue in Scotland and in the UK. 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 the majority, stigma relating to HIV still remains a significant challenge in Scotland 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 implementation of *The People Living with HIV Stigma Index* in Scotland is the first robust attempt by and for people living with HIV to establish a baseline for documenting the stigma and discrimination experienced and overcome by people living with HIV.

The results outlined in this report reveal some of the realities for people living with HIV in Scotland in 2009 and have implications for service delivery and priorities for future action. The priority areas analysed and outlined in this report were identified in consultation with key partners in Scotland as well as in a 'research roundtable' (hosted at IPPF, 3 February 2010) with people living with HIV, members of the community research team and research advisors.

Understanding and addressing stigma related to HIV can guide 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 experiencing, confronting and overcoming devaluing attitudes and behaviours. It is our hope that process of implementing *The People Living with HIV Stigma Index* as well as the products of the community based research support, energise and connect people living with HIV to continue their leadership in challenging and overcoming HIV related stigma.

*"I did not think anyone was interested in what people think about living with HIV anymore... this is not the sexy issue it was in the 80's. Can you really get these stories out there? I would hate to think I was just wasting time ticking someone else's boxes. This is my life..."*

— Stigma Index Participant, Glasgow, August 2009

*"I was diagnosed with this [HIV] two years ago. In that time I have been told what hospital and what doctor to see, what pills to take and what to do to live "effectively with my diagnosis". Being involved in this wee group has helped me voice for myself what I feel really about it... the process of being able to talk to other people with HIV like this has been so liberating. This is the first time I have done something like this"*

— Stigma Index Participant, Edinburgh, September 2009

## WHAT IS STIGMA?

In Scotland, as in every country in the world, stigma can create barriers to testing and to the uptake of HIV and sexual health services. Stigma and discrimination are associated with a lower likelihood of adopting health-seeking behaviours, delayed testing and a decreased quality of life for people living with HIV.

Stigma is commonly understood as a process of devaluation (Goffman, 1963). It can have many outcomes such as discrimination, which is also known as enacted stigma. In the context of HIV, stigma can have many outcomes and 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 (Maman *et al*, 2009; Genberg *et al*, 2009; Simbayi *et al*, 2007). Stigma is layered and complex and can feed off other attitudes or prejudices relating, for example, to homophobia, racism or sexism (Mahajan *et al.*, 2008; Nyblade 2006; Dodds, 2006).

In the context of HIV, there are three key ways that stigma can undermine human rights and the achievement of universal access to prevention, care, treatment and support. Research and literature reviews from around the world indicate that:

- 1) Internalised stigma can negatively affect the quality of life and self-esteem of people living with HIV and can create barriers to realising other human rights (Li *et al*, 2009; Simbayi *et al*, 2007). Self-perception is influenced by the perceived, anticipated or experienced impact of stigma (Link and Phelan, 2001). Stigma has been shown to be associated with stress, depression, and lower perceived quality of life among people living with HIV (Simbayi *et al.*, 2007). People living with HIV can feel dirty, ashamed, or guilty because of their HIV status (*ibid*) and it is uncontroversial and well-evidenced that stigma exacerbates the already-heavy burden experienced by people living with HIV (Li *et al*, 2009).
- 2) Stigma creates barriers for accessing health and other services (Maman *et al*, 2009). For example research has indicated that stigma affects HIV prevention and treatment efforts, including the use of condoms, HIV testing uptake, and uptake of prevention of mother to child transmission programs (Maman *et al*, 2009; Genberg *et al*, 2009; Simbayi *et al.*2007). Anticipated stigma relating to the fear of a positive result has been identified as a factor contributing to the refusal to return for the results among people who have tested, to low HIV disclosure rates and to affect adherence to antiretroviral therapy (ART). Research has also found that experiences of stigma in a healthcare setting limits the uptake of these services by people living with HIV (DH, 2007).
- 3) Stigma can re-enforce power inequalities and processes of social marginalisation (Mahajan *et al.*, 2008; Parker and Aggleton, 2003). It touches on intimate behaviours, decisions and moralities that are cut across and stretch personal and societal attitudes, perceptions and principles (Dodds, 2006; Cornwall and Welbourn, 2002). As such, stigma relating to HIV is often conflated with others such as racism, homophobia or sexism (Herek, 1999; Nyblade, 2006).

*"I've lived with HIV for 22 years now and have seen it at its worst for myself and others. We need to work together to stamp out the stigma and discrimination, as in our health it takes its toll to live two lives".*

– Stigma Index Researcher, Glasgow, July 2009

Stigma in relation to HIV remains significant in Scotland and in the UK. For example in 2007, a survey by the National AIDS Trust discovered that the majority (71%) of people agree more needs to be done to confront prejudice. The results from the Ipsos MORI survey (1,981 adults over the age of 16 were interviewed between 15th and 22nd November, 2008) show mixed messages on stigma. Even though there was support for people living with HIV (over two-thirds of people saying if a family member or neighbour was HIV positive it would not affect their relationship) it seems that a culture of blame was still evident (NAT, 2008). The survey also identified that poor knowledge persists about the transmission of HIV with more than 90% not fully understanding how HIV is transmitted (NAT, 2008). For example, the survey found that people in Scotland, and London, were comparatively poor at identifying each of the key HIV transmission routes (p 5). Another recent report, in-depth qualitative research with a small group of gay men living long-term with HIV, identified that stigma was still a pressing concern in Scotland in 2008 as it was in the 1990s (Wells, 2008).

In the context of international efforts to monitor and respond to HIV, stigma and discrimination are consistently mentioned as a major challenge for achieving the goals outlined in the Declaration of Commitment agreed by the UK and 189 countries around the world at the Special Session on HIV and AIDS of United Nations General Assembly (UNGASS) in 2001. Within this framework, the Interim Country Report for the UK, prepared by the Department of Health (DH), indicates that stigma remains a primary challenge that demands (and to some extent has been receiving) remedial action (DH, 2006, p 6; DH, 2008, p 7).

In Scotland, the recently launched 'HIV Action Plan' identifies that HIV is major public health challenge' (Scottish Government, 2009). As outlined in the HIV Action Plan, stigma is an underlying factor that impacts on every aspect of responses to HIV, cutting across layers of identity and other social determinants of health (p 10). This further builds on the prioritisation of tackling stigma and discrimination in all Scottish Executive policies as part of the ongoing health improvement agenda (Scottish Government, 2005, p 5).

Engaging communities most affected by HIV are just as essential in Scotland as in any country in the world, and the UK Department for International Development (DFID) also 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). For the UK as whole, both the DH and DfID are aligned in identifying the importance of working with and empowering people living with HIV in the response to stigma, which in turn is central to a national response to HIV and addressing the underlying structural determinants of health (WHO, 2008; Mann; 1999). While the HIV Action Plan prioritises the need to address stigma, unlike the UK wide policy documents referred to above (DfID, 2008, p28; and DH, 2006, p6; and DH 2008, p7) there is no explicit reference or actions identified that prioritise working to engage and empower communities of people living with HIV (Scottish Government, 2009).

The results from *The People Living with HIV Stigma Index* in Scotland provide further evidence that indicates that stigma and discrimination relating to HIV remain a significant challenge. This initiative has engaged community researchers and participants who represent different realities of living with HIV in Scotland and has documented their experiences of HIV-related stigma and discrimination over the 12 months preceding September 2009.

The findings are outlined in this report and illuminate areas where:

- access to and tailoring of services could be improved,
- people need to be supported to overcome internalised stigma,
- people living with HIV are supporting each other and advocating for change, and
- further research is needed to update our collective understanding of the nuances and diverse needs of people living with HIV.

*“We also have a responsibility in Scotland to challenge the stigma and discrimination that is associated with HIV. While we recognise that attitudes can not be changed overnight, this will be a focus of our work for the foreseeable future. This however is not only a challenge for the Scottish Government but for other statutory and voluntary organisations. “*

Shona Robison, MSP for Public Health and Sport (Ministerial Forward in Wells, 2008)

The report contributes to and builds on the re-energised attention and focus generated by the HIV Action Plan launched by the Scottish Government in December 2009. The community research team involved with *The People Living with HIV Stigma Index* are committed to working with the evidence generated from this initiative to support action that generates change in the lives of people living with HIV in Scotland.

## 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<sup>6</sup>. It documents how people have experienced – and have been able to challenge and overcome – stigma and discrimination relating to HIV over the preceding 12 month time period. Championing a community research model, the core principles underpinning *The People Living with HIV Stigma Index* are that it is a research and advocacy initiative that is by and for people living with HIV. The process is 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 for the interviewers and for the participants.

The research results have been collected by questionnaire-led peer-interviews conducted by people living with HIV. The results are a collection of responses to an in-depth questionnaire developed as a monitoring tool (IPPF et al, 2008). The questionnaire was developed in consultation with ‘experts’ from around the world (including people living with HIV, statisticians, psychologists and social scientists, human rights researchers, government and UN representatives and civil society) and was piloted in 2006 (India, Kenya, South Africa, Trinidad and Tobago) (IPPF et al, 2007). The questionnaire was revised and finalised in 2007, and translated into key languages including Arabic, Chinese, French, Kiswahili, Portuguese, Russian and Spanish. The first country to implement *The People Living with HIV Stigma Index* was the Dominican Republic (in 2008). The UK was the first country in Europe to implement the Index, in 2009 (see [www.stigmaindex.org](http://www.stigmaindex.org)).

By ‘walking the talk’, as an initiative by and for people living with HIV working in an inclusive and non-stigmatising way with diverse individuals within their own historical and lived experience with HIV. *The People Living with HIV Stigma Index* strove to model GIPA principles<sup>7</sup> in action, working in an inclusive and non-discriminatory way with people of diverse age, background, sexual orientation and life experiences. As such, the Index could be seen as part of an evolving research paradigm—performative social science—that essentially seeks to perform the desired outcomes of the research while also reporting on the process and results (Haseman, 2006). In so doing, the Index directly acts as an anti-stigma intervention in its own right, modelling GIPA principles. By actively seeking to empower people living with HIV in every stage of a research and advocacy intervention to measure and overcome stigma, the process of implementing the Index has been just as important as the products of the research.

This questionnaire enquires about:

- triggers 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.

Drawing on theoretical conceptualisations of stigma (cf. Link and Phelan, 2001; Parker and Aggleton, 2003), the questionnaire aims to measure and document experiences of stigma in different settings (e.g. in social, religious, workplace, educational, community and family settings), the internalisation of stigma (e.g. feelings of guilt, blame or

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<sup>6</sup> See the *User Guide* (IPPF et al, 2008) available for download at [www.stigmaindex.org](http://www.stigmaindex.org) for further details

<sup>7</sup> Greater Involvement of People Living with HIV and AIDS, see [www.unaids.org/en/policyandpractice/gipa/default.asp](http://www.unaids.org/en/policyandpractice/gipa/default.asp)

punishment, and enacted isolation), as well as different types of stigma (perceived stigma, stigma by association, and enacted stigma and discrimination). The questionnaire is primarily a quantitative research tool. It also provides opportunities for qualitative responses. Some of the qualitative areas include free-text questions asking participants to comment on what they see as the main problems and challenges in relation to health services (specifically testing and diagnosis and treatment), disclosure and confidentiality, and having children. Other opportunities are given in the questionnaire for participants to elaborate with qualitative responses referring to how they have tried to resolve an issue relating to stigma or discrimination, layers of stigma and other disabilities not relating to HIV.

The recently appointed Executive Director of UNAIDS, re-affirmed the commitment of UNAIDS to support the work with the Index and emphasised the imperative of addressing stigma for promoting human rights and achieving universal access to prevention, treatment, care and support.

*“It is essential that the global response to the AIDS epidemic is grounded in human rights and that discrimination and punitive laws against those most affected by HIV are removed”*

-- Michel Sidibé, Executive Director of UNAIDS, June 2009

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, between May and September 2009, 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 in a large part of the UK, including Aberdeen, Birmingham, Belfast, Brighton, Cardiff, Edinburgh, Glasgow, Leeds, London, Manchester, and Wolverhampton. 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 UK research. This model was then extended for the Scottish sample. See Annex 1 for further details.

Thirty-five community researchers who are living with HIV were trained from around the UK. Their role was to guide peer-interview sessions where participants complete *The People Living with HIV Stigma Index* questionnaire. Ten people were trained at a two day Scotland specific workshop in Glasgow in June 2009 delivered by a Dr Laura Sharp (Office for Psychological Research), Kevin Osborne (Senior HIV advisor IPPF), Alastair Hudson (Ayedear.com), Lucy Stackpool Moore (HIV Officer IPPF), Catherine Murphy (THT) and Roy Kilpatrick (HIV Scotland). The majority of interviews were self-completed questionnaires in a group setting, supported and facilitated by representatives of the community research team of people living with HIV. Each session included referrals as requested, information about the initiative in a national and global context, and appreciation of the time and contribution of each participant.

Frequency data has been extracted for all questionnaire responses. Co-occurrences have been explored across different UK regions; gender; time since diagnosis; age and different identity groups. Hypotheses generated through consultation with people living with HIV have and will be further explored. A regression analysis was performed on proportionate scores for responses to all questions related to stigma and discrimination collected from Scotland compared to the rest of the UK. The results show that UK frequencies were a strong predictor for those in Scotland [ $t_{545} = 177.2, p < .0005$ ] with the regression fit being near one [ $R^2_{adj} = 98\%$ ] and significant [ $F_{1,545} = 31365.36, p < .0005$ ]. This means that changes in frequencies for Scotland, closely matched changes in frequencies for the rest of the UK, showing that experiences for those living in Scotland closely matched experiences for those living in the rest of the UK. In terms of policy, this suggests that Scotland can address issues with stigma and discrimination in a joint initiative with England, Wales and Northern Ireland. The qualitative responses have been thematically explored. The combined results have sign-posted areas for more in-depth and follow-up research in 2010.

As a community research initiative led by and for people living with HIV, the 2009 implementation of *The People Living with HIV Stigma Index* in Scotland and in the UK has successfully built foundations for new models of community research. An evaluation workshop was held in December 2009 (hosted by Body Positive Northwest, in Manchester) that included 16 representatives from the community research team including 3 of the researchers from Scotland. The representatives from the team who participated in the evaluation workshop generated some suggestions for how the process could be improved when it is next implemented, identified key areas of success (such as the supportive working environment and leadership of people living with HIV), and were proud of what the team has been able to achieve collectively. Additional ideas for local discussion events were developed, such as 'taking the T out of stigma' tea parties (supported by partners such as the Church of Scotland), where some of the team will use the leaflet and resources from the Index results in 2009 to support their own local efforts to challenge stigma. A film, 'Give Stigma the Index Finger!' has been produced that documents the journeys of different individuals as part of the initiative, and will be released in various public screenings in 2010.

Some limitations relating to the research design and results include:

- Participants were recruited through referrals and membership lists of partner organisations in Scotland as in the whole of the UK. While some general publicity was shared through magazines and leafleting, the

majority of participants came through the established networks relating to HIV agencies. This has limited outreach to people living with HIV not currently engaging with any services.

- The high number of people who identified as unemployed may also relate to participants who are currently claiming benefits and to the proportion of participants who identified as refugees or asylum seekers.
- Individuals under eighteen were not approached for the current study<sup>8</sup> and young people were under-represented in this sample.
- Specifically in Scotland, the interviews were conducted between August and September 2009. The research design and timing made it difficult to engage people living with HIV in rural communities. This is also in part related to the research design to recruit through referrals and membership of partner organisations in Scotland. Initial efforts were made to include participants in rural areas near Aberdeen, The Borders, Inverness and The Highlands. For ethical reasons it was not possible to pilot test or develop telephone adapted interviewing approaches at this time, which would have facilitated outreach to more remote areas.

Future research will aim to more effectively reach out to the communities under-represented in this sample.

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. The results from the UK rollout in 2009 provide a baseline that will be able to be compared in future years when the Index is implemented again. The results will be useful for monitoring change over time and the data can be processed to monitor the experiences of stigma for different groups of people according to variables such as: location, time since HIV diagnosis, group they identify with, 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.

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<sup>8</sup> The ethical guidance and piloting of the questionnaire and process of *The People Living with HIV Stigma Index* has always been limited to people over the age of 18. Conversations have been ongoing with the National Children's Bureau in the UK to develop a complimentary approach specifically targeted and adapted to engage young people living with HIV.

In Scotland, 163 people living with HIV were interviewed between August and September 2009. We spoke to 104 men (64%) and 59 women (36%), who were ...

... representatives from key groups, including sixty men who identified as MSM (37%), thirty-two asylum seekers (20%), eight sex workers (5%), fourteen prisoners (9%) and twenty people who use drugs (12%).

... of different ages, including one hundred (61%) over 40 years and seventeen (10%) under 30 years.

... well educated, with eighty-eight (54%) having completed higher education and (sixty) 37% having completed secondary school.

... and almost half were single (n=74, 45%).<sup>9</sup>

Interviews were conducted in Glasgow (n=84, 52%), Edinburgh (n=66, 40%), Tayside (n=9, 6%) and Aberdeen (n=4, 3%). Most individuals were from a large town or city (n=128, 82%) and twelve percent (n=18) were from a small villiage or town, while those from rural areas were underrepresented by six percent (n=9) of respondents.

Nearly two-thirds of participants were over forty (n=100, 61%) with twenty-nine (18%) of these were over fifty. The least well represented age group were those under thirty (n=16, 14%) with six persons under twenty-five.

### Reaching out to diverse groups

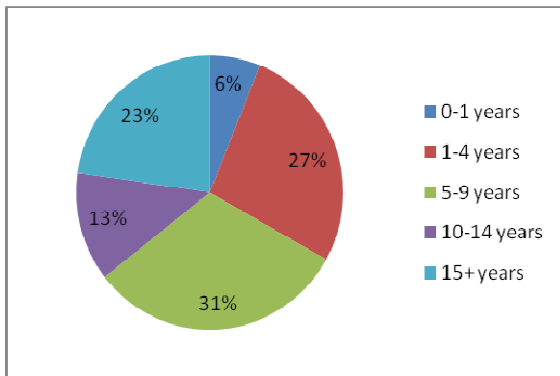
Participants were asked to highlight any groups that they felt identified them and only twenty percent (n=34) indicated that none of the choices were appropriate to them. Thirty-seven percent (n=60) identified themselves as men who have sex with men, and as a group is well represented when compared to the SOPHID database. Refugees or asylum seekers comprised twenty percent of the sample (n=32) while injecting drug users were less well represented (n=20, 12%). The groups that participants identify themselves with are summarised in the table below.

<b>Group Identity*</b>	<b>n</b>	<b>% of N</b>
Men who have sex with men	60	37%
Gay or lesbian	52	32%
Sex worker	8	5%
Injecting drug user	20	12%
Refugee or asylum seeker	32	20%
Migrant worker	5	3%
Prisoner	14	9%
No Group	34	21%

*\*n.b. participants could identify themselves with more than one group*

**Table 1: Group identified with at any time in life**

<sup>9</sup> for the remainder of the report, n represents the group of individuals under discussion and N represents all the 163 participants in Scotland



**Graph 1: Time since diagnosis (years)**

Participants were asked how long they had been living with HIV (see graph) and six percent (n=10) had been living with HIV for a year or less, twenty-seven percent (n=44) had been living with HIV for one to four years, thirty-one percent (n=51) for five to nine years, thirteen percent (n=21) for ten to fourteen years and twenty-three percent (n=37) for fifteen or more years. Overall the sample represents a good range of people who have known they have been living with HIV for different amounts of time.

In terms of education, fifty-four percent (n=88) of participants had finished higher education and thirty-seven percent (n=60) had completed secondary school. However unemployment amongst this group was high at sixty percent (n=98), this was also the case in the rest of the UK (comprising England, Wales and Northern Ireland) where unemployment was at sixty-four percent. Of those in any form of employment in Scotland (n=63, 39%), thirty-one stated that they worked or volunteered in a project related to HIV.

### **Sample in relation to HIV prevalence in Scotland**

Compared with the prevalence rates outlined in the SOPHID database of HIV modelled for Scotland<sup>10</sup>, the sample reflects a seven percent discrepancy with a higher proportion of women, an over representation of individuals in the age group 39-49 and over fifty; and an under representation of those in age groups under thirty. Further details are outlined in Annex 1. The nature of this sample compared to the HIV prevalence should be taken into account when considering the ongoing policy development and implementation in Scotland of the findings outlined in this report.

While recognising these limitations in the sample, many groups are well represented, for instance those living with HIV for over ten years (a third of respondents), gay men and the proportion of women to men is close to the prevalence rates in the SOPHID database.

*"I never knew there were so many flavours of HIV and I don't just mean colours. I learned a lot just sitting in that wee group at the end with people from other African countries... and I thought I was being brave!"*

– Stigma Index Researcher, Glasgow, May 2009

<sup>10</sup> Health Protection Agency Centre for Infections and Health Protection Scotland (2009).

## Evidence for action

The initial findings of the UK wide project were launched in Scotland at two events: 1) a community event (at Inspace, New Media Centre, Edinburgh University) and 2) a meeting of the Cross Party Group of the Scottish Parliament, 2 December 2009. Highlights included a presentation by Shona Robison, MSP for Public Health and Sport, describing the importance of addressing stigma as part of the HIV Action Plan in Scotland and responses to the initial findings from Dr Gordon Scott (NHS Lothian), Phil Eaglesham (NHS Health Scotland), Roy Kilpatrick (HIV Scotland) and partners and members of the community research team.

*“I have been waiting 22 years to ask that question. I have wanted to ask a politician about healthcare and pregnancy based on my own experiences with my son. Today I had that opportunity.”*

—Stigma Index Researcher, to Shona Robison at Edinburgh Scottish Parliament CPG Launch event,  
December 2009

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

Overall, and further details are describe below, the results show that:

**Stigma and discrimination remain a challenge in Scotland.** Of the 163 participants, forty-four percent (n=71) reported that their rights either have been abused or are not sure if their rights have been abused and seventeen percent (n=28) reported having been denied health services.

**People living with HIV in Scotland are showing leadership in the response to stigma.** In Scotland forty-four percent (n=71) of participants reported challenging someone stigmatising them in the previous twelve months, and ninety percent (n=146) reported supporting other people living with HIV to overcome stigma.

**Services need to be improved and updated to meet the changing needs of people living with HIV.** Although eighty-seven percent (n=142) of people know of services available to them, only twenty-five percent (n=41) have used these services for support relating to stigma and discrimination in Scotland.

The findings are reported according to five key sub-sections:

- 1) Health: including experiences with family planning, reproductive health, testing and diagnosis, treatment and self-perceptions of health.
- 2) Self and internalised stigma: including feelings, anticipated stigma, disclosure, sex and intimacy and intersecting layers of stigma relating to complex lives and complex identities.
- 3) Support: including knowledge of and accessing support and clinical services, peer support for other people living with HIV, and experiences (or lack) of counselling.
- 4) Human rights: including knowledge and use of legal mechanisms to redress experiences of discrimination, reporting of rights that have been abused, and the criminalisation of HIV transmission or exposure.
- 5) Effecting change: including priorities identified for the future and influencing policy debates, effective commissioning and programme implementation targeting people living with HIV across Scotland.

Data comparisons have been made with the rest of the UK and unless otherwise stated the experiences of people living with HIV are similar in Scotland as elsewhere in the UK. Generally, differences under five percent have not been reported.

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<sup>11</sup> Please note: unless otherwise stated, all % are proportionate according to the total number of individuals who completed *The People Living with HIV Stigma Index* in the Scotland.

## 1) HEALTH

In this section key findings relating to health are outlined. Overall, even though fifteen people (9%) did not identify any problems and many commented that the healthcare system is generally excellent, significant gaps were identified—most notably in the area of provision of counselling at testing, mental health, non HIV specific healthcare settings (e.g. GP’s and Dentists) and holistic care about living with HIV (beyond HIV treatment options).

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 Scotland. Many participants reported that a healthcare professional had disclosed their HIV status without permission in the previous 12 months. In addition many people also reported not having confidence in the discretion of those who hold and access their medical records, which could be a barrier for access and warrants further investigation.

In Scotland participants indicate that overall they have had constructive consultations with a healthcare provider regarding their HIV treatment options. Eighty-one percent (n=132) of individuals reported having had a constructive discussion about HIV treatment options in the previous 12 months. There was a trend that people who had been living with HIV for longer had had such a discussion in the previous 12 months, perhaps reflecting an increased need for antiretroviral treatment in this group and/or a need to change treatment regimes for people who have been on treatment for longer. Antiretroviral treatment and other medication for opportunistic illnesses appear to be accessible in Scotland, with only two percent reporting that they do not have access to needed medication. However participants did recognise the barriers in place for others in Scotland accessing treatment.

Further research is needed to identify specific sites of healthcare provision (e.g. dental care, HIV specialist care, general practice, support staff and reception) where fears relating to breaches of confidentiality are concentrated. Follow-up research could explore the extent to which people living with HIV feel informed and empowered to initiate conversations and their ability or desire to challenge their healthcare providers about their treatment options. Of the few facing challenges with accessing treatment a high proportion were asylum seekers or refugees.

Details are provided in the tables and summary sections below, covering participants’ specific experiences in unspecified health settings, access to health services, access to family planning and sexual and reproductive rights, experiences of testing and diagnosis, treatment and self perceptions of own health.

### EXPERINCES OF HEALTH SERVICES

<b>How confidential do you think the medical records relating to your HIV status are?</b>	<b>n</b>	<b>% of N</b>
I am sure that my medical records will be kept completely confidential	62	38%
I don’t know if my medical records are confidential	68	42%
It is clear to me that my medical records are not being kept confidential	31	19%
Non-response	2	1%
TOTAL	163	100%

**Table 2: Confidence in confidentiality of medical records**

Twenty-one percent (n=35) of participants reported that a healthcare professional had disclosed their HIV status without consent since they were diagnosed. This trend was similar in those who had been diagnosed within the previous four years (n = 11, 20% of those diagnosed in the last four years).

<b>Has a healthcare professional ever disclosed your HIV status without consent</b>	<b>n</b>	<b>% of N</b>	<b>% of Men</b>	<b>% of Women</b>
Yes	35	21%	18%	27%
No	64	39%	39%	39%
Not sure	64	39%	42%	34%
Non-response	0			
<b>TOTAL</b>	<b>163</b>	<b>100%</b>		

**Table 3: Experienced disclosure of HIV status by healthcare professional without consent and gender breakdown**

Non-consented disclosure affected over a quarter of women (n=16, 27%) compared to eighteen percent of men (n=19).

<b>In the last 12 months have you been denied health services including dental care because of your HIV status?</b>					
	<b>Never</b>	<b>Once</b>	<b>A few times</b>	<b>Often</b>	<b>Not Applicable</b>
<b>n</b>	123	21	6	1	12
<b>% of N</b>	75%	13%	4%	1%	7%

**Table 4: Experienced denial of health services due to HIV status**

Seventeen percent (n=26) reported having been denied health services at least once because of their HIV status in the previous 12 months. Denial of health service was reported by twenty-five percent of women (n=15), compared to thirteen percent of men (n=13).

<b>In the last 12 months have you had a constructive discussion regarding Sexual Reproductive Health, emotional wellbeing etc</b>	<b>n</b>	<b>% of N</b>
Yes	108	66%
No	54	33%
Non-response	1	
<b>TOTAL</b>	<b>163</b>	

**Table 5: Experienced constructive discussion with healthcare provider re SRHR, emotional well-being etc**

Of there thirty-three percent (n=54) of individuals reported that they have not had a constructive discussion with healthcare providers on other subjects such as sexual and reproductive health, sexual relationships, drug-use and emotional well-being; thirty-seven percent were women (n=22) compared to thirty-one percent of men (n=32). While some groups were represented by relatively low numbers in the survey, about half of all sex workers, injecting drug users, refugees, migrant workers and prisoners (totalling thirty-eight of the fifty-four individuals) had not had such a discussion with health-care providers. This may be because they are not accessing health services on a regular basis.

## FAMILY PLANNING AND SEXUAL AND REPRODUCTIVE RIGHTS

Since diagnosis, have you received counselling about reproductive options?	Yes	No	Not applicable	Non-response	TOTAL
n	40	62	58	3	163
% of N	25%	38%	36%	1%	100%
n (Men)	17	37	47		
% of Men	32%	36%	45%		
n (Women)	23	25	11		
% of Women	48%	42%	19%		

**Table 6: Experienced counselling re reproductive options**

More than half of the women who felt counselling would be appropriate for them (n=25, 42% of all women) had not received any. Almost half of the men (n=47, 45%) reported that these discussions were not appropriate for them and of this number twenty identified themselves as gay, leaving a further twenty-six percent (n=27) of men perhaps feeling that a discussion regarding reproductive options was not relevant to them.

Six (4%) individuals, two men and four women, reported having been coerced into sterilisation by a healthcare professional since they were diagnosed and four of them identified themselves as refugees or asylum seekers. In the twelve months preceding the survey, five (3%) participants reported that they had been denied family planning services. A further seven (4%) reported having been denied sexual and reproductive health services.

Nine women (15%) reported receiving anti-retroviral treatment to prevent vertical transmission of HIV during pregnancy. Six did not have access to this treatment, one was denied it, and two were unaware of its existence. Five of these nine individuals were migrant workers, refugees or asylum seekers, and four did not identify themselves in a group. All the women who are undergoing ART were given information about healthy pregnancy and motherhood as part of the programme to prevent mother-to-child transmission of HIV.

From the sample it is unclear how many women were pregnant or had given birth in the 12 months preceding the survey. In a few individual examples, healthcare professionals were reported to coerce women's decisions in relation to abortion (n=1), method of giving birth (n= 2) and infant feeding practice (n=1). This coercion may have taken place in the UK or elsewhere. Three of the women who reported having been coerced (either relating to having an abortion, method of giving birth, or infant feeding practices) also identified as being refugees or asylum seekers.

## TESTING AND DIAGNOSIS

Was the decision to be tested for HIV up to you?	N	% of N
Yes, I took the decision myself to be tested (i.e. it was voluntary)	113	69%
I took the decision to be tested, but it was under pressure from others	24	15%
I was made to take an HIV test (coercion)	10	6%
I was tested without my knowledge – I only found out after the test had been done	15	9%
Non-response	1	1%
TOTAL	163	100%

**Table 7: Decision to be tested for HIV (who)**

Within the participants diagnosed in the last four years, eight reported that they had been tested without their knowledge and two reported that they had been coerced into testing.

Why Were you tested?	n	% of N
Employment	0	0%
Pregnancy	2	2%
To prepare for a marriage/sexual relationship	7	6%
Referred by a clinic for sexually transmitted infections	13	12%
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	21	19%
Husband/wife/partner/family member tested positive	13	12%
Illness or the death of husband/wife/partner/family member	15	13%
I just wanted to know	44	39%
Other	23	20%

*\*n.b. participants could identify more than one response*

**Table 8: Decision to be tested for HIV (why)**

Participants provided free text responses about what they felt were the main barriers that prevented people from being tested for HIV. Fifteen people did not identify any problems and many commented that the healthcare system is generally excellent e.g. “the testing & diagnosis is freely available on the NHS, it would be in the interest of those engaged in active sex to be tested as soon as possible.”

Common themes emerged from the qualitative responses<sup>12</sup>:

- **Concern about the experience of stigma and discrimination** was identified by twenty-eight individuals (17%) as a reason to avoid testing, such as “people don’t want to test due to stigma of a positive result”. Sixteen people highlighted concern about disclosing to others if they were to be diagnosed as HIV positive. The threat of legal action if someone was to knowingly transmit HIV to another person was a reason offered by six individuals to explain reluctance to be tested. In contrast to the other explanations, one individual highlighted that there is a myth that living with HIV is not a serious problem and therefore people don’t feel a need to be tested. One person outlined the shame they perceived to be associated with a positive diagnosis.
- **Fear of a positive result, including fears relating to death and coming to terms with an HIV positive diagnosis.** Thirty-seven participants suggested that people are reluctant to be tested because they are afraid of the result being positive e.g. “people would rather not test. They say they are better off not knowing”. Four participants reported a fear of death which some people may associate with a positive diagnosis. Twenty individuals highlighted that coping with the diagnosis was a concern, particularly in relation to depression e.g. “if you get tested then it becomes a reality and when you are diagnosed you go into denial. Sometimes it is difficult to accept the diagnosis”.
- **Timing and regular access to testing.** Six people felt that testing should be undertaken earlier as a late diagnosis can be detrimental to health and successful treatment. E.g. “people tend to present themselves late for testing diagnosis”. Eleven participants felt it would be beneficial to increase testing so that more people are aware of their status - the majority identifying that this would benefit society in general, reduce transmission rates and increase the uptake of treatment. A further eleven suggested that general population testing should be undertaken at regular intervals (e.g. every 3, 6 or 12 months).
- **Location of GUM clinics and access to testing.** The location of testing clinics, knowledge of testing availability and the possible negative association of GUM clinics were identified as challenges by ten participants e.g. “having to go to a GUM clinic is not ideal” and “stigma attached to the venue / clinic” were statements included in some of the responses. Eleven participants also highlighted that accessing testing could be challenging if appointment times are inconvenient and/or waiting times too long.
- **Limited access to and/or availability of knowledge and information** e.g. “the main problem I think is lack of information and knowledge which makes people find it difficult to go and get tested for HIV”. Two individuals stated that a lack of knowledge of the treatment options available may make people reluctant to

<sup>12</sup> Note the numbers and examples reported to describe the qualitative responses are indicative and provide an overview of the responses. The numbers indicate common themes although in some cases the specific words were different. The quotes included are examples to illustrate the kinds of responses that were coded under the general theme.

be tested e.g. “more education is needed to encourage people to test themselves as often as possible”. Seven people said that perceptions of the treatment regime and side effects of the drugs could make people cautious about testing e.g. “people need to know advantages of testing and disadvantages of not knowing their status”. Thirteen people suggested continuing to improve the information available about the realities of living with HIV would be beneficial in encouraging people to be tested.

- **Counselling availability.** Twenty-three individuals considered access to pre- and post-testing counselling essential. Similarly, an awareness that support was available and necessary was considered by nine participants to be likely to encourage individuals in opting for testing.

*“Post test counselling... are you having a laugh? Surely that needs to be done by someone who knows what they are talking about”*

– Stigma Index Participant, Dundee, September 2009

## TREATMENT

Almost all participants reported that they have access to the medication that they need and only two percent (n=3, including a refugee/asylum seeker and a migrant worker) said that they did not have access to the antiretroviral medication while six percent (n=10, including five refugees/asylum seekers or migrant workers) did not have access to medication for opportunistic infections. In terms of uptake, eighty-five percent (n=137) of participants were taking antiretroviral medications. Of the fifteen percent (n=25) that were not taking the medication twenty live in Glasgow and almost all but one were men. Considerably fewer individuals were taking medication for other illnesses (n=59, 36%) even though within this group there were twenty-six individuals (17% of respondents) in fair health and seven individuals (4%) in poor health.

Do you have access to antiretroviral treatment?	Yes	No	Don't know	Non-response	Total
n	151	3	4	5	163
% of N	93%	2%	2%	3%	100%

**Table 9: Access to ART**

Are you currently taking anti-retroviral treatment?	Yes	No	Non-response	Total
n	137	25	1	163
% of N	84%	15%	1%	100%

**Table 10: Currently taking ART**

Do you have access to medication for opportunistic infections	Yes	No	Don't know	Non-response	Total
n	139	10	9	5	163
% of N	85%	6%	6%	3%	100%

**Table 11: Access to medication for OIs**

Are you currently taking any medication to prevent or treat opportunistic infections?	Yes	No	Non-response	Total
n	59	103	1	163
% of N	36%	63%	1%	100%

**Table 12: Currently taking medication for OIs**

In the preceding twelve months eighty-one percent (n=132) of individuals reported to have had a constructive discussion with their health-care providers regarding HIV related treatment options. Of the eighteen percent (n=29) who had not had such a discussion, one reported their health to be poor and nine were in fair health with the remaining nineteen being in good to excellent health. Additionally the group who had not had a constructive discussion, included almost a quarter of all the women (n=14, 24% of women) compared to fourteen percent (n=15) of men. Additionally there was a trend for people who had been living with HIV for longer to have had such a discussion recently. Seventy-four percent (n=40) of those diagnosed within the previous four years had discussed their HIV treatment-related options in the previous twelve months, compared to eighty-two percent (n=42) who had been living with HIV for five to nine years and eighty-six percent (n=50) of those living with HIV for ten or more years.

In the last 12 months have you had a constructive discussion with healthcare professionals on the subject of your HIV related treatment options?	Yes	No	Non-response	Total
n	132	29	2	163
% of N	81%	18%	1%	100%

**Table 13: Experienced constructive discussion with healthcare provider re HIV treatment options**

Participants were asked about the challenges faced with antiretroviral drugs. Twenty individuals said that they did not have any problems with their medication e.g. “to be honest I would be lying if I said I’ve had problems with treatments. Everyone has been really supportive e.g. my consultant and every health worker I’ve worked with”. Five stated that they were not on medication.

Common themes from the qualitative responses the following emerged:

- **Fear of adverse reactions to medication**, noted by eighty-seven people, including physical e.g. “damage to a persons body long-term ... they (ART drugs) carry many painful side effects”, with three people highlighting the bad press or media representation about medication as a problem. Emotional and mental reactions to ART were a concern for twelve people. The impact of side effects on individuals’ ability to work was a concern identified by three participants e.g. “taking meds at work (can be) difficult as the side effects interfere with quality of life”.
- **Disclosure**. Taking medication was perceived to increase the risk of disclosure by four participants e.g. “finding the privacy to take medication at a specific time when in public”.
- **Expense**. Seven people identified the cost of medication as a challenge e.g. “some meds (are) not prescribed due to cost”. Although almost all the respondents reported having access to treatment they noted that others living in the UK who do not have residency status or leave to remain, and people living in other countries, may not have access to treatment for financial, legal or other reasons.
- **Clearer advice from healthcare providers**. Eight emphasised that they would benefit from clearer advice and information about medication and from additional input from health professionals e.g. “there is not enough quality information given with the bottle of tablets ... you don't know what to expect or how to react when certain things happen”.
- **Long-term effects**. Twenty-three explained that they had concerns that their drugs would not be effective or that long-term immunity would develop e.g. “in case I develop resistance” or “fear of the unknown long-term”.
- **Quantity of pills**. Seven people still highlighted the quantity of medication as a challenge “there is always an emotional effect on taking so many tablets each day. I look forward to taking the pill a week the day!” This was also highlighted as a problem for one person when travelling.

## SELF PERCEPTIONS OF OWN HEALTH

The majority of participants in the sample consider their state of health to range from good to excellent (72%), with around a quarter describing it as fair (26%) and a small proportion considering it poor (6%).

General State of Health	Excellent	Very good	Good	Fair	Poor	Non-response	Total
N	23	38	49	43	10	0	163
% of N	14%	23%	30%	26%	6%	%	100%

**Table 14: Reported general state of health**

Almost a third (n=45, 28%) of participants indicated a disability other than HIV and some offered additional qualitative details from which a number of themes emerged. Eight people reported mental health concerns, some offered a specific diagnosis, these included depression, anxiety, post-traumatic stress disorder and bipolar disorder, and others offered a general statement relating to mental ill health. Seven individuals reported co-morbid infection with Hepatitis, the majority identifying this as Hepatitis C. Fifteen individuals identified mobility problems, six specified back problems as a challenge and eight individuals reported having arthritis. Three or fewer individuals reported the following difficulties: hearing problems, cancer, problems with their lungs or breathing, diabetes, epilepsy, tiredness.

## 2) SELF

While keeping in mind the complexity of individual lives framed by emotions and experiences, past and present; internalized stigma is apparent among people living with HIV in Scotland in 2009. Internal stigma involves a process whereby someone internalizes any judgements or gossip or prejudice they experience, and devalues themselves (USAID, 2006). This can lead to low self-esteem, depression, isolation and/or self-exclusion from social events or accessing services (Simbayi, et al 2007).

Living with HIV is one aspect of many in someone's life. It may positively or negatively affect, influence and shape self-identity and image and is not the only way in which a person may define themselves. For example in the 12 months preceding the survey thirty-three percent (n=17) of the participants in Scotland who identified themselves as gay (total n=52, 33% participants in Scotland), reported experiencing stigma or discrimination because of their sexual orientation, some of them attributed both their sexual orientation and HIV status as the cause.

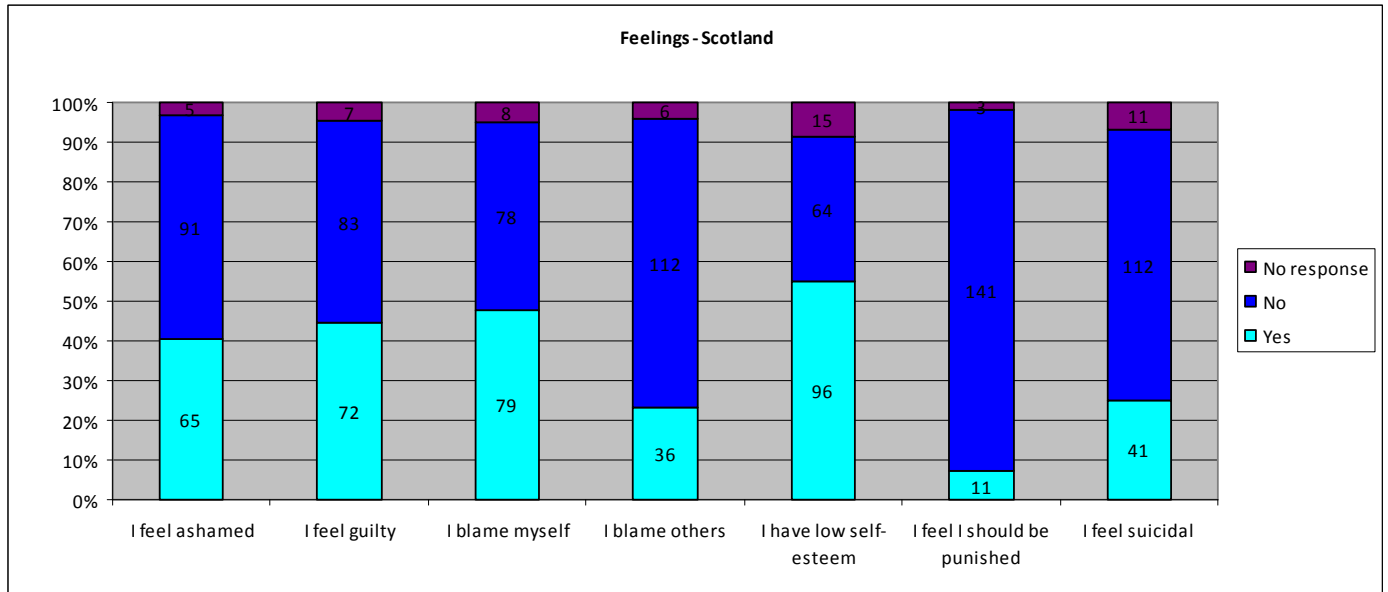
The need for enhanced outreach and support services is evidenced by the levels of internalized stigma reported by the participants. Fifty-nine percent of participants reported experiencing low self-esteem and 25% reported having felt suicidal in the previous 12 months. Over a third of individuals had isolated themselves from friends and family and a similar number reported avoiding social gatherings. Self-exclusion from social gatherings appeared to increase with time since diagnosis.

The results outlined in this section as well as the following section relating to accessing support services indicate that more attention needs to be paid to tailoring support services and enhancing the diversity of conversations with healthcare providers to include issues such as mental health, well being and reproductive rights.

To gain a better insight into how individuals stigmatised themselves and the role that stigma and discrimination play in their well-being, participants were asked to consider negative feelings associated with stigma; self-stigmatising behaviour; report on their fears of harassment and sexual rejection and to identify sources other than HIV status that contributed to discrimination, such as their sexual orientation or refugee status. The results of each of these are reported in the following sections.

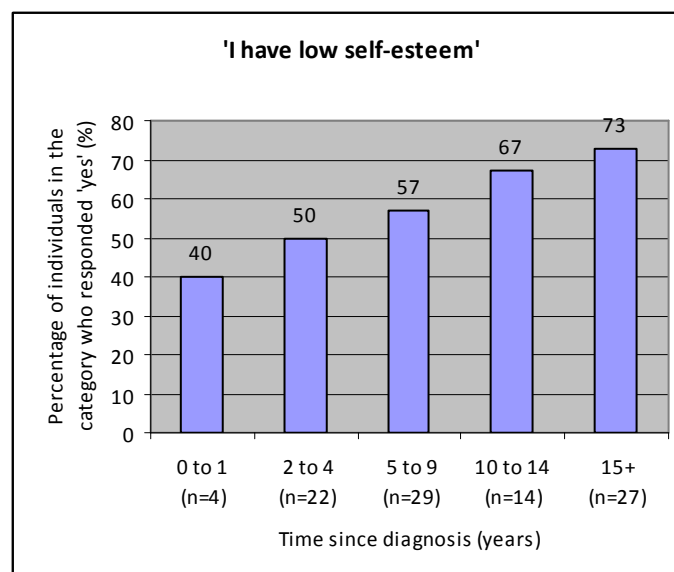
## FEELINGS

Participants were asked to report on the negative feelings they felt in the twelve months preceding the survey relating to their HIV status. Forty percent (n=65) reported feelings of shame and forty-four percent (n=72) felt guilty. Forty-eight percent (n=79) blamed themselves for their status and twenty-two percent blamed others. Seven percent (n=11) felt that they should be punished. However almost two-thirds (n=96, 59%) had low self esteem and a quarter (n=41) had suicidal feelings.



**Graph 2: Self-reported feelings**

As evidenced in the chart below, there was a trend for more individuals to describe feelings of self-perceived low self-esteem as the time that they have been living with HIV increased. For instance forty percent (n=4) of individuals living with HIV for up to one year suffered low self esteem compared to seventy-three percent (n=27) of those living with HIV for fifteen or more years. For other negative feelings, no clear trends were evident in relation to time since diagnosis.



**Graph 3: 'I have low self-esteem' self-reported responses according to time since diagnosis**

## ANTICIPATED STIGMA

Participants were asked about their experiences of anticipating stigma during the preceding twelve months.

<b>In the last 12 months have you been fearful of any of the following things happening to you – whether or not they actually happened to you?</b>	<b>n</b>	<b>% of N</b>
Being gossiped about	96	59%
Being verbally insulted, harassed or threatened	75	46%
Being physically harassed and/or threatened	61	37%
Being physically assaulted	55	34%

*\*n.b. participants could identify more than one response*

**Table 15: Anticipated stigma**

Of these individuals thirty-four percent (n=53) reported being aware of being gossiped about because of their HIV status, seventeen percent (n=27) reported that they had been verbally harassed because of their HIV status, eight percent (n=12) were physically harassed and three percent (n=5) were assaulted because of their HIV status.

## SELF-DISCRIMINATION

Participants were asked about whether in the preceding twelve months they had avoided any social situations, opportunities for enriching their lives or health settings because of their HIV status. Over a third of participants (n=60, 37%) reported that they had decided not to attend social gatherings because of their HIV status. There was a trend for participants who have been living with HIV for longer towards reporting isolating themselves from social gatherings. For instance twenty-six percent (n=11) of those diagnosed in the previous four years, reported that they did not attend social gatherings, compared to forty-seven percent (n=27) of those diagnosed ten or more years ago.

<b>In the last 12 months have you done the following because of your HIV status*</b>	<b>Yes</b>	<b>No</b>
I have chosen not to attend social gathering(s)	37%	61%
I have isolated myself from family and/or friends	39%	61%
I took the decision to stop working	12%	85%
I decided not to apply for work or a promotion	21%	76%
I withdrew from / refused opportunity of education	17%	80%
I decided not to get married	15%	81%
I decided not to have sex	36%	63%
I decided not to have (more) children	24%	71%
I avoided going to local clinic when I needed to	12%	85%
I avoided going to local hospital when I needed to	7%	90%

*\*n.b. participants could identify more than one response*

*\*Reported as % of N (percent of the whole sample)*

**Table 16: Self-discrimination and internalised stigma**

As evident in the table below, about two-thirds of individuals disclosure was reported as an empowering experience (n=95, 58%).

Did you find disclosure of HIV empowering?	Yes	No	Not applicable	Non-response	Total
n	95	53	15	0	163
% of N	58%	33%	9%	0%	100%

**Table 17: Empowering experiences of HIV disclosure**

About the same number of participants indicated that the risk of criminal prosecution relating to HIV transmission does (n=66, 40%) and does not (n=67, 41%) influence their decisions around their disclosure of their HIV status. These responses are summarised in the table below. There was a slight difference between the findings from Scotland and those in the rest of the UK: in the UK (excluding Scotland), 44% (+4%) of participants (n=312) said that the risk of criminal prosecution relating to HIV transmission influenced their decisions to disclose their HIV status and 33% (-8%) of participants (n=235) said it did not.

Does the risk of criminal prosecution relating to HIV transmission influence decisions you make regarding disclosure of your HIV status?	Yes	No	Not sure	Non-response	Total
n	65	68	26	4	163
% of N	40%	42%	16%	2%	100%

**Table 18: Influence of criminal law on decisions re HIV disclosure**

Participants gave free text responses about issues relating to disclosure and confidentiality a number of themes were identified. One individual was concerned about travel and immigration restrictions. Another person explained that they did not want people to be overly sympathetic when they chose to disclose.

Common themes included:

- **Stigma and fear of rejection.** Forty-one participants highlighted concerns about stigma and discrimination e.g. "I am unclear that sufficient rules are in place (relating to disclosure) and that people are guaranteed to follow them". A further forty-one explained that they feared rejection or adverse reactions from others e.g. "the social fear of backlash from bigoted uneducated people is the main reason for non-disclosure".
- **Choosing when, to whom and how to disclose.** Finding an appropriate time to disclose and informing partners, family, friends and others within the culture were particular concerns.
- **Anticipated discrimination.** Eighteen individuals highlighted concerns about unemployment and disclosing to employers e.g. "stigma is still rife ... especially in the workplace."
- **Fear of criminalisation.** Three participants highlighted concerns about the legal implications if they infect another person.
- **Concern about confidentiality.** Eight people explained that they were cautious about the confidentiality of their medical records with a further six specifically stating that they feared disclosure without their consent e.g. "(the) main (HIV) treatment centres' confidentiality appears (to be) better than the GP's, dentist's, etc".
- **Avoidance.** Eight individuals stated that they avoid disclosure and only inform people when it is essential e.g. "sometimes confidentiality is the simplest and safest course".

## SEX AND SEXUAL INTIMACY

As shown in the table below, fifty-eight percent (n=94) of participants reported that they are currently sexually active. Of these, almost twice as many of the men as women reported being sexually active (men: n=71, 68%) as women (n=23, 39%). Such a large difference between men and women may reflect a different approach to sexual attachment, as sixty-seven percent of women (n=40) reported that they were not in relationship, in other words single, separated/divorced or a widower. This group of women comprised most of those not sexually active (n=32, 54% of women; women not sexually active: n=36, 61% of women). While most of the women not in a relationship were also not sexually active, only half of the men who were not in a relationship were also not sexually active. There were sixty single, divorced, separated or widowed men (56% of men) and twenty-nine (26% of men) of them were not sexually active (men not sexually active: n=33, 32% of men).

Are you currently sexually active?	Total		Male		Female	
	N	% of N	N	% of Men	N	% of Women
<b>Yes</b>	94	58%	71	68%	23	39%
<b>No</b>	69	42%	33	32%	36	61%
<b>Non-response</b>	0	0%				
<b>Total</b>	163	100%				

**Table 19: Breakdown of gender and self-reported sexual activity**

Sixty-eight percent (n=110) of participants feared that someone would not want to be sexually intimate with them because of their HIV status in the preceding twelve months and of these thirty-one (19% of all participants) were married or in a long term intimate relationship while forty-six (29%) were single.

Forty percent (n=65) reported that they had suffered sexual rejection one or more times in the previous twelve months because of their HIV status, as summarised in the table below.

Frequency of Sexual Rejection in the previous 12 months	Never	Once	A few times	Often	Non-response	Total
<b>N</b>	94	18	36	11	4	163
<b>% of N</b>	58%	11%	22%	7%	2%	100%

**Table 20: Frequency of sexual rejection in last 12 months**

Of those that reported having been sexually rejected:

- twenty-five (18% of participants) were in a long-term intimate relationship
- thirty-two (20%) were single,
- thirty-five (22%) regarded themselves as currently sexually active, and
- thirty-one (20%) reported that they were not sexually active.

## LAYERS OF STIGMA

Stigma is just as complicated as the lives of the participants are diverse; and many people living with HIV reported having experienced stigma for reasons not relating to HIV in the previous 12 months such as sexual orientation (21%), asylum status (10%) or another reason (29%). Of the reasons identified for triggering stigma relating to HIV, the results suggest that efforts need to focus on public education campaigns that inform about the routes of transmission. The results indicate that the highest reasons for HIV stigma relate to fear of transmission (33%) or

misinformation about transmitting HIV through casual contact (34%). Another key reason identified was the association of shame with HIV (23%) which highlights the need for the sharing of information in a non-stigmatising and accessible way.

Many individuals reported other reasons for discrimination apart from HIV and their reasons for discrimination are summarised in the table below.

<b>Other reasons for discrimination (other than HIV)</b>	<b>N</b>	<b>% of N</b>
Sexual orientation (men who have sex with men, gay or lesbian) <sup>13</sup>	35	21%
Sex worker	3	2%
Injecting drug user	2	1%
Refugee or asylum seeker	17	10%
Migrant workers	5	3%
Prisoner	1	1%
None of the above – it was because of an(other) reason(s)	48	30%
	Non-response	52
		32%
	<b>Total</b>	<b>163</b>
		<b>100%</b>

**Table 21: Reasons other than HIV for experiences of discrimination**

Participants were asked to explain the source of any discrimination that they had not identified in other sections of the questionnaire. Recognising that the number of responses is small, other themes identified include:

- **Disability.** Five individuals reported having experienced discrimination as a result of a physical or mental disability.
- **Race or religion.** Three individuals had been discriminated against as a result of their race or religion
- **Age.** Four because of a cultural issue and two had experienced ageism.
- **Workplace environment.** One individual reported that they experienced discrimination because of the environment where they worked.

Participants were also asked to highlight other reasons that they thought others were discriminating against them or stigmatising them and these responses are summarised in the table below.

<b>Reason for HIV related stigma / discrimination</b>	<b>N</b>	<b>% of N</b>
People are afraid of getting 'infected' with HIV from me	53	33%
People don't understand how HIV is transmitted and are afraid I will 'infect' them with HIV through casual contact	55	34%
People think that having HIV is shameful and they should not be associated with me	38	23%
Religious beliefs or "moral" judgements	35	21%
People disapprove of my lifestyle or behaviour	26	16%
I look sick with symptoms associated with HIV	17	10%
I don't know/I am not sure of the reason(s)	18	11%

*\*n.b. participants could identify more than one response*

**Table 22: Reasons identified for HIV-related discrimination**

*"I am so annoyed when people refer to us as 'Poor Africans', poor Africans cannot afford plane tickets. We are not all 'Poor Africans'"*

*– Stigma Index Researcher, Glasgow, July 2009*

<sup>13</sup> This category in the questionnaire also includes 'transgender' however none of the participants in Scotland in the 2009 study identified as transgender.

### 3) SUPPORT

Even though many people living with HIV know of support networks and organisations that they can approach to help overcome stigma and discrimination, few people reported they are actively engaging with these services. There is a gap between awareness of support services to address issues of stigma for people living with HIV and uptake of these services.

As indicated above, a third of individuals in the 4 Scottish interview sites stated they had not had a recent discussion with their health care provider regarding sexual health, relationships, reproduction, drug use or mental well being in the last 12 months. In addition, it appears that even though participants reported having constructive conversations with healthcare providers about HIV treatment options, this was not the case in regard to more holistic aspects of mental health, general well being, and reproductive health and rights.

#### ACCESSING SUPPORT SERVICES

In the UK, although 88% of people know of organisations they can go to for support, only 29% have sought support from these services. This pattern was similar in Scotland, where although 87% of people know of organisations they can go to for support only 25% have sought support from these services. Of the participants in Scotland reported that they had sought support over the previous 12 months, seventeen were women (29% of all women) compared to twenty-four men (23% of all men). The identified groups that most often sought help were asylum seekers or refugees (n=10, 31% of this group) and prisoners (n=5, 36% of this group). Although small numbers, it is important to report the different responses from individuals identifying with other specific groups. Individuals who sought help the least were sex workers (n=1, 13%) and people who identified as gay or lesbian (n=9, 17%). Of those under thirty years old, eighteen percent (n=3) sought help, compared to twenty-six percent of those over thirty (n=38).

What kind of organisation do you know about (that you can go to for help if you experience stigma or discrimination)?	N	% of N
People living with HIV support group	142	87%
Network of people living with HIV	96	59%
Local non-governmental organization	70	43%
Faith-based organization	22	13%
A legal practice	26	16%
A human rights organization	37	23%
National non-governmental organization	29	18%
National AIDS council or committee	38	23%
International non-governmental organization	16	10%
UN organization	14	9%
Other	12	7%

*\*n.b. participants could identify more than one response*

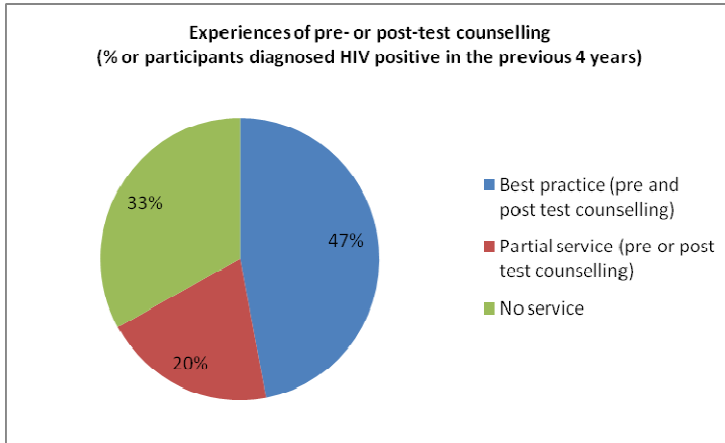
**Table 23: Knowledge of types of organisations offering support to overcome HIV-related stigma**

#### PEOPLE LIVING WITH HIV SUPPORTING EACH OTHER

Almost all participants (n=133, 82%) being part of a people living with HIV support group or network and ninety percent (n=146) having supported another person living with HIV, which may be biased by the research design as indicated above. Support included emotional (n=144, 88%) and physical support (n=50, 31%) as well as supporting the referral to other services (n=79, 48%). Fifty percent (n=81) of the respondents volunteered or are employed for HIV projects and hence the high numbers of mutual support may reflect the caring nature of their work and the increased contact that these individuals have with the wider community of people living with HIV.

## COUNSELLING

It is important to note that the questions relating to counselling in the questionnaire refer to at time of diagnosis, which may have occurred outside of Scotland and for most will not reflect changes in policy and practice in recent years.



A third (n=55, 34%) of Scottish participants reported that they received no counselling when they were tested, and seventeen percent (n=27) reported that they received only post-test HIV counselling. Forty-four percent (n=72) of participants reported that they had received the full counselling services at time of diagnosis. Of those diagnosed in the last four years (total n= 54, 33% of the sample) large variations were observed in the counselling received; Pre- and Post-test (n=25, 47%), Pre-test only (n=3, 6%), Post-test only (n=8, 15%) and no counselling (n=18, 33%).

**Graph 4: Experiences of pre- or post- test counselling**

Eighteen participants (33% of those diagnosed in the previous 4 years) reported that they had received no pre- or post-test counselling; and twenty-six (43%) had received at least some counselling.

## 4) RIGHTS

In the UK there are several legislative frameworks that affect the human rights of people living with HIV. Three key ones were specifically included in this research:

- 1) 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.
- 2) The Disability Discrimination Act (DDA) (UK, 1995, 2005)—An act that provides the potential access to benefits for people living with HIV.
- 3) The Offences Against the Person Act (OAPA) (UK, 1861) or the common law offence in Scotland of ‘Culpable and Reckless Conduct’—provisions that potentially criminalize HIV transmission or exposure.

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

Scotland has its own legal traditions, its own body of common law and statute law, its own system of courts, its own legal profession and its own Parliament. The DDA does apply in Scotland, with minor adaptations, and Scotland is included within the reporting and target setting relating to the UK commitment to the UNGASS Declaration of Commitment on HIV. The law in Scotland concerning HIV transmission or exposure is a common law offence and as such no specific definition is given of ‘Culpable and Reckless Conduct’, which may also be called ‘Causing Real Injury’ (James, 2009). However, in the draft Scottish Legal Code further particulars are given, referring to section 42 about “causing unlawful injury”: “a person who intentionally or recklessly causes injury to another person, without that person’s consent, is guilty of the offence of causing unlawful injury” (Clive et al, 2003). There is also an offence of “causing an unlawful risk of injury” (section 43).<sup>14</sup>

Overall, the results indicate a need for more and better information about rights and legal services, and more support for people living with HIV to translate notions of human rights and about shared responsibility into practice. More effort is needed to strengthen legal mechanisms—and the knowledge and accessibility of legal services—to protect the rights of people living with HIV. Knowledge of key national statutes is low, with just over half of people living with HIV (56%, n=92) having heard of the DDA and even fewer (40%, n=65) having heard of the UNGASS Declaration of Commitment—two national legal mechanisms to protect and promote the human rights of people living with HIV.

Even though twenty-six percent (n=42) reported being physically harassed threatened or assaulted in the last 12 months, of whom fourteen percent of all participants (n=14%) said this was at least in part related to their HIV status, only four percent (n=7 participants) sought legal redress.

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### RIGHTS – ABUSED

In the whole UK, almost half (n=167, 46%) of the participants reported that their rights had been abused or were ‘not sure’ if these had been abused (n=233, 27%) in the last 12 months. In Scotland, forty-four percent of respondents (n=71) identified that their rights had been abused (n=29, 18%) or were not sure if these had been abused (n=42, 26%) in the last 12 months as summarised in the table below.

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<sup>14</sup> Many thanks to James Chalmers of Edinburgh University for useful insights about the draft Scottish legal code. Although the code was published by the Scottish Law Commission, it was an unofficial project and there are no signs of it being taken forward in the foreseeable future.

Have any of your rights as a Person living with HIV been abused in the last 12 months?	n	% of N
Yes	29	18%
No	91	56%
Not sure	42	26%
Non-response	1	0%
<b>Total</b>	<b>163</b>	<b>100%</b>

**Table 24: Recognised human rights abuse in last 12 months**

Ten individuals (6%) reported that in the last twelve months they had lost their job or other source of income because of their HIV status. However unemployment amongst the participants was high at sixty percent (n=98) and of those who lost their job or source of income, seven were unemployed at the time of the survey. In terms of education, ten individuals (6%) reported that they had been prevented, suspended or dismissed from education in the previous twelve months. Of the seventy-five individuals who reported that they had children, two said that their children had been suspended, dismissed or prevented from education because of parental HIV status.

## LAWS – KNOWLEDGE

Forty percent (n=65) had heard of the UNGASS Declaration, but only 17% had ever read or discussed its content. The findings were higher for the DDA, with 56% reporting having heard of the Act and 34% reporting having read or discussed its content. These findings are summarised in the tables below.

Heard of “Declaration of Commitment on HIV/AIDS”	N	% of N	If yes, have you ever read or discussed the content?	N	% of N
Yes	65	40%	Yes	28	17%
No	97	60%	No	62	38%
Non-response	1	0%			
<b>Total</b>	<b>163</b>	<b>100%</b>			

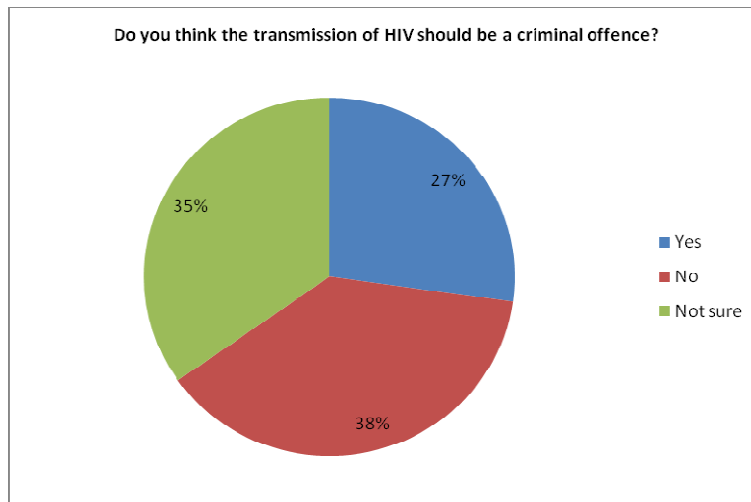
  

Heard of ‘Disability Discrimination Act’	N	% of N	If yes, have you ever read or discussed the content?	N	% of N
Yes	92	56%	Yes	55	34%
No	55	34%	No	79	48%
Non-response	16	10%			
<b>Total</b>	<b>163</b>	<b>100%</b>			

**Table 25: Knowledge of human rights frameworks and UK legislation**

Twenty-six percent (n=42) reported being physically harassed threatened or assaulted in the last 12 months, of whom fourteen percent of all participants (n=14%) said this was at least in part related to their HIV status, only four percent (n=7 participants) had sought legal redress.

Ninety-two percent of participants (n=150) felt that when sexually active, both partners, regardless of HIV status, share equal responsibility for preventing HIV transmission. However in response to a question about whether the transmission of HIV should be a criminal offence, the responses were split with the majority of individuals (n=60, 38%) believing that it should not be a criminal offense. Of those believing that the transmission of HIV should be criminal offense, twenty-seven identified themselves as gay men and this comprised fifty-two percent of all gay men in the sample.



**Graph 5: Attitudes towards the criminalisation of HIV transmission**

The results show almost unanimous agreement (92%) that both partners, regardless of HIV status, share equal responsibility for preventing HIV transmission. However in response to a question about whether the transmission of HIV should be a criminal offence, the responses were split in thirds between no (the majority, 38%), yes (27%) and not sure (35%). Of those believing that the transmission of HIV should be a criminal offense, twenty-seven identified themselves as gay men and this comprised fifty-two percent of all gay men in the sample.

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*“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”*

–Stigma Index Researcher, London Researchers Training Workshop, May 2009

## 5) EFFECTING CHANGE

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 stigmatise or discriminate.

The questionnaire also sought to measure the actions, aspirations and challenges people living with HIV face in confronting and effecting change to address stigma and discrimination in the UK.

Forty-four percent of participants (n=71) of people living with HIV in Scotland have confronted, challenged or educated someone who was stigmatizing or discriminating against them in the last 12 months. Forty-nine percent of women (n=29) compared to forty percent of men (n=42) confronted, challenged or educated someone and fifty percent of all refugees or asylum seekers (n=16 of 32) and prisoners (n=7 of 14) compared to thirty-three percent of men who have sex with men (n=20 of 60).

Sixty percent of participants (n=97) 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 in Scotland. The breakdown of types of influence is described in the table below:

<b>Do you feel that you have the Power to influence any of the following?</b>	<b>N</b>	<b>% of N</b>
Legal/rights matters affecting people living with HIV	53	33%
Local government policies affecting people living with HIV	45	28%
Local projects intended to benefit people living with HIV	79	48%
National government policies affecting people living with HIV	45	28%
National programmes /projects intended to benefit people living with HIV	38	23%
International agreements/treaties	14	9%

*\*n.b. participants could identify more than one response*

**Table 25: Perceived power to influence change**

Of the 60% of people who reported that they feel power to effect change, fewer men felt empowered to effect change. Forty-six percent of men (n=48) felt that they did not have influence over these projects and policies, compared to twenty-nine percent of women (n=14). Refugees and asylum seekers felt that they had influence to effect change with only twenty-five percent (n=8) reporting that they felt they could not influence projects and policies.

When asked to choose one action for the future, the top three priorities identified by the 163 participants in Scotland were the same as the priorities identified across the UK:

- 1) Raise public knowledge and awareness about AIDS (29%)
- 2) Advocate for the rights of people living with HIV (22%)
- 3) Provide support to people living with HIV by providing emotional, physical and referral support (20%)

The findings illustrate that stigma and discrimination remain a challenge in Scotland. Scottish participants reported being denied access to services, experiencing verbal abuse and physical harassment relating to their HIV status. The results also indicate that many of the participants internalised these experiences and stigmatised themselves, affecting their self-esteem, quality of life, participation in social events and approaches or expectations regarding intimacy.

The results from the Index answer as well as ask many questions about the state of stigma and discrimination relating to HIV in Scotland in 2009.

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

The results identified by *The People Living with HIV Stigma Index* and outlined in this report have consolidated participants' experiences of living with HIV in Scotland in 2009. The findings indicate that stigma remains a significant challenge in Scotland.

Recommendations:

- 1) **Implement the HIV Action Plan in partnership with and informed by people living with HIV.** The Plan acknowledges that people living with HIV were consulted in the development of the actions described, yet the actions do not explicitly refer to the empowerment or involvement of people living with HIV.
- 2) **Develop a rights-based information campaign for the general public about HIV.** The priorities identified by the participants in the Index echo the findings of the NAT public attitudes survey in 2007 and identify that a key trigger of stigma relating to HIV is lack of information about routes of transmission and highlight the need for a more effective multi-media public awareness campaign.
- 3) **Develop a rights-based information campaign for specific key groups of people living with HIV.** Not enough people living with HIV are familiar with their rights or with legal mechanisms and other support services that can help them claim their rights. Even though specific actions outlined in the HIV Action Plan specify social marketing materials and guidance targeting key populations including MSM, people living with HIV and people originating from countries with a high HIV prevalence (actions 8 and 9), this is framed in terms of 'preventing onward transmission' and should more broadly promote human rights to effectively address underlying issues relating to vulnerability to HIV and other social determinants of health, marginalisation and inequality.
- 4) **Build on the key issues identified in follow-up and in-depth research** with under-represented communities of people living with HIV and on key issues (outlined in detail below).

*"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"*

--Stigma Index Participant, Glasgow, September 2009

*The People Living with HIV Stigma Index* is fairly unique in its ambition to engage individuals within the context of their own lives and realities to shape the reflection, action and vision for change—an approach crucial for addressing stigma, which straddles deeply personal feelings and wider social attitudes. For lasting change, the kind of momentum and ideas generated through community action needs to be supported and reinforced by wider institutional, policy, social and legislative frameworks. The results discussed in this report provide both an opportunity to better inform and support policies and practices to address stigma related to HIV, as well as a challenge to translate this evidence into action that generates change.

## AREAS IDENTIFIED FOR FURTHER RESEARCH AND EXPLORATION

Globally stigma and discrimination continue to create barriers to holistic and effective healthcare, to full social and civic participation, and to self-confidence and a happy life. More in-depth follow-up research is needed to explore layers of stigma that can disentangle the experiences of different groups and individuals living with HIV, and to ensure that the services provided are updated and adapted to meet the breadth of needs in 2009.

Further focus group discussions and regional roundtable events will build on this analysis to consult more widely with the community research team and the wider community of people living with HIV in Scotland about the results. The results and discussions will provide a space for the community to collectively develop recommendations for supporting and improving the implementation of the HIV Action Plan, building on the actions identified as well as exploring further areas for consideration in the future.

Some of the key areas identified by the team—from the results from the quantitative and qualitative results from the Index, their own reflections, and the anecdotes shared in the interview sessions—for further analysis directly correspond with some areas identified in the HIV Action Plan, and include:

- Mental health – especially related to self-esteem and time since diagnosis, since the results indicate a link between living longer with HIV and low self esteem.
- Intensity and incidence of experiences of stigma and discrimination in accessing or within specific sub-sections of the health sector such as with dentists, general practitioners, receptionists, and other non-specialist HIV consultants.
- Dimensions of quality of the conversations people living with HIV are having with healthcare providers about emotional well-being, sexual and reproductive rights and other health needs. Further research could also deepen analysis and data collection relating to experiences of pregnancy, knowledge and realisation of reproductive choices, support to realise reproductive choices, and the prevention of mother-to-child transmission.
- ‘Positive prevention’ that addresses the sexual health and reproductive rights and needs of people living with HIV that is concerned with their health and well-being and not only framed in terms of preventing onward transmission<sup>15</sup>—further research about prevention messages and practices that focus on the needs of people living with HIV to protect themselves, as well as possible research into the links between prevention approaches and overcoming internalised stigma.
- Trends linking stigma and sexual activity, and other aspects of life and identity, the extent to which this interrelates with other aspects such as drug use, alcohol, self-esteem, experiences of disclosure, perceptions of criminalisation and other issues. It would be interesting to consider the reasons why forty-two percent of the sample reported that they were not sexually active. There could be a number of hypotheses proposed, such as circumstances, related to self-stigma, linked to mental health, a naturally occurring rate in wider population, age related, or HIV status specific.
- Aging and living with HIV. Further research could explore the experiences of stigma for older people living with HIV (50+ currently comprise about a fifth of all people living with HIV in the UK). Similarly, another important group are young people who were born positive and have now been living with HIV for 20+ years. Special issues may emerge such as long term employability, fears regarding drug side-effects, long term healthy-living style and sustained safer sex practises and disclosure.

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<sup>15</sup> See for example INP+, IPPF, FPAI (2010) for further information.

- Attitudes towards shared responsibility and the criminalisation of HIV transmission and exposure. The findings relating to human rights and to the criminalisation of HIV are also very timely. The results from the Index indicated that stigma and discrimination were identified as a potentially significant barrier for testing and the threat of legal action was identified as a deterrent to testing. Given that promoting HIV testing and reducing delayed presentation for testing are identified for priorities by the DH (UNGASS 2008), and HIV Action Plan in Scotland, efforts need to focus on reducing stigma and possible 'fear' associated with prosecution for HIV transmission or exposure in Scotland and in the UK. Even though previous research has not found conclusive evidence linking the criminalisation of HIV transmission to deterrence for testing, the possibility remains that individuals who believe that they are at a high risk of testing HIV positive may be deterred from testing (Chalmers, 2008, p151). The criminalisation of exposure for the first time may provide more conclusive insights in this area.<sup>16</sup>

The diverse team of people involved in *The People Living with HIV Stigma Index* in Scotland and in the UK are committed and passionate to work alongside partners to support and collectively enhance the effectiveness of our collective efforts to address and overcome HIV related stigma and discrimination.

In many ways, this report builds on and colours-in some of the priorities already identified by the Scottish Government in the HIV Action Plan (2009) as well as the Strategy and Action Plan for Improving Sexual Health (2005).

'Give Stigma the Index Finger' provides both an opportunity to better inform and support policies and practices to address stigma related to HIV by listening to the voices and real life experiences reported by people living with HIV, as well as amplifying the ongoing challenge to transform good policies into better practice that generates a demonstrable benefit for the lives of all people living with HIV in Scotland.

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<sup>16</sup> The recent case of Mark Devereaux (Edinburgh High Court, January 2010), as the first man in the UK to be charged and convicted for the risk of HIV transmission, highlights the need for a clearer statement or guidelines about Scottish prosecution policy relating to HIV. Further research should explore both the public health and human rights implications of the Court's Decision. Mark Devereaux, a 41 year-old man who now lives in Dundee and was diagnosed with HIV in 1994, pleaded guilty to four charges of culpable and reckless conduct after being accused of not disclosing his HIV status to four women between 2003 and 2008, only one of whom became HIV-positive. Although there have been almost 20 convictions for reckless HIV transmission in the UK since 2001 (of which only two were in Scotland), this is the first time that a conviction for HIV exposure following non-disclosure has been successfully prosecuted in the United Kingdom, although Scottish law has always allowed for this possibility (Bernard, 2010).

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## ANNEX 1 – RESEARCH DESIGN AND SAMPLING FRAMEWORK

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 in a large part of the UK, including Aberdeen, Birmingham, Belfast, Brighton, Cardiff, Edinburgh, Glasgow, Leeds, London, Manchester, and Wolverhampton. This is the report from total Scottish sample; regional variation will be analysed within the UK research report to be published in 2010.

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 UK research. This model was then extended for the Scottish sample.

### Characteristics of the UK population of people living with HIV

	SOPHID	SOPHID Percentages	Stigma Index	Percentage (Variation)	Scotland*	Scotland percentages	Stigma Index (Scotland)	Stigma Index (Scotland)
<b>EXPOSURE CATEGORY</b>	<b>(N = 56,556)</b>		<b>(N = 867)</b>			<b>(N = 5459)</b>		
Men who have Sex with Men	23,990	42.4%	284	33% (-9%)	1,923	35%	60	37% (+2%)
People who use drugs (IV)	1,466	2.6%	53	6% (+3%)	1,270	23%	20	12% (-11%)
<b>SEX</b>	<b>(N = 56,556)</b>							
Male	37,256	65.9%	518	60% (-6%)	3,899	71%	104	64% (-7%)
Female	19,300	34.1%	348	40% (+6%)	1,560	29%	59	36% (+7%)
<b>UK Breakdown</b>	<b>(N = 56,556)</b>							
London	25,126	44.4%	367	42% (-2%)				
Rest of England	27,012	47.8%	260	30% (-18%)				
Scotland	2,736	4.8%	163	19% (+14%)				
Wales	1,015	1.8%	42	5% (+3%)				
Northern Ireland	378	0.7%	35	4% (+3%)				
British Isles Other	24	0.0%	-	-				
<b>AGE (Excluding &lt;15)*</b>	<b>(N = 55,584)</b>							
15-24	2,321	4.2%	21	2% (-2%)	1,154	21%	6	4% (-15%)
25-29	5,039	9.1%	58	7% (-2%)	1,079	20%	11	7% (-13%)
30-39	20,348	36.7%	255	29% (-7%)	1,894	35%	46	28% (-7%)
40-49	19,154	34.5%	359	42% (+7%)	812	15%	71	44% (+29%)
50+	8,722	15.7%	172	20% (+4%)	348	6%	29	18% (+12%)

In the SOPHID data 972 (1.7%) of individuals diagnosed with HIV in the UK receiving care are younger than 15. As this is a specialist group requiring additional ethical and methodological considerations this group will be excluded from the sample for the HIV Stigma Index. The percentages calculated exclude the 972 individuals under 15. The principle change in new diagnosis is the increase in the African population (20% of those in 2008 - HPA data released 29<sup>th</sup> March 09, compared to a 12.4% representation in the total population in contact with care services). During sampling additional participants were recruited to represent this change.

## ANNEX 2 — ABOUT IPPF

### WHO WE ARE:

IPPF is a global service provider and a leading advocate of sexual and reproductive health and rights for all. We are a worldwide movement of national organizations working with and for communities and individuals.

IPPF works towards a world where women, men and young people everywhere have control over their own bodies, and therefore their destinies. A world where they are free to choose parenthood or not; free to decide how many children they will have and when; free to pursue healthy sexual lives without fear of unwanted pregnancies and sexually transmitted infections, including HIV. A world where gender or sexuality are no longer a source of inequality or stigma. We will not retreat from doing everything we can to safeguard these important choices and rights for current and future generations.

### OUR VISION:

IPPF envisages a world in which all women, men and young people have access to the information and services they need; a world in which sexuality is recognized both as a natural and precious aspect of life and as a fundamental human right; a world in which choices are fully respected and where stigma and discrimination have no place.

### OUR MISSION:

IPPF aims to improve the quality of life of individuals by campaigning for sexual and reproductive health and rights through advocacy and services, especially for poor and vulnerable people.

We defend the right of all young people to enjoy their sexual lives free from ill health, unwanted pregnancy, violence and discrimination. We support a woman's right to choose to terminate her pregnancy legally and safely. We strive to eliminate sexually transmitted infections (STIs) and reduce the spread and impact of HIV/AIDS.

### OUR CORE VALUES

IPPF believes that sexual and reproductive rights should be guaranteed for everyone because they are internationally recognized basic human rights. We are committed to gender equality, and to eliminating the discrimination which threatens individual well being and leads to the widespread violation of health and human rights, particularly those of young women. We value diversity and especially emphasize the participation of young people and people living with HIV/AIDS in our governance and in our programmes. We consider the spirit of volunteerism to be central to achieving our mandate and advancing our cause. We are committed to working in partnership with communities, governments, other organizations and donors.



[www.ippf.org](http://www.ippf.org)