



THE PEOPLE LIVING WITH HIV STIGMA INDEX QUALITATIVE DATA:

**FINDINGS OF THE QUALITATIVE WORK UNDERTAKEN TO COMPLEMENT
THE PEOPLE LIVING WITH HIV STIGMA INDEX**

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EXECUTIVE SUMMARY

In 2009 the People Living with HIV (PLHIV) Stigma Index was undertaken in the United Kingdom (UK). This ongoing project aims to empower the community of PLHIV to overcome challenges and play an active role in effecting change. Training was provided to allow individuals living with HIV to undertake fieldwork, data entry, transcription and to foster opportunities to present research findings. By effective collaboration with voluntary sector partners across the UK a diverse range of 867 participants were engaged. The PLHIV Stigma Index is an international project with research teams operating in a range of countries to monitor and address issues relating to stigma and discrimination.

This qualitative work was initially completed to complement the quantitative data extracted from the PLHIV Stigma Index United Kingdom. The numbers within the document (e.g. 3B.6) relate to the question numbers within the Stigma Index. This linkage allows some topics to be supported by additional quantitative findings. Stakeholders supporting the ongoing work of the Stigma Index team highlighted the value of such a resource to the wider community and were keen to ensure it is shared widely.

The current document has been created as resource for individuals, associates, stakeholders and health professionals in, or working to empower, the community of people living with HIV. This community as a whole has ownership of this document. It is hoped that each reader will extract and utilise the information that is valuable for them. Quotes or summaries can be incorporated into leaflets, presentations, press releases and reports to offer context to the issues being addressed. As a standalone report this document holds limited value. By contextualising the contents and targeting an audience this resource has potential to be a powerful tool.

Our plea is that you optimally utilise this resource and offer feedback on how it has been helpful and how it could be improved. The final section of this document outlines a number of hypothesis offered by participants. These have been included to support funding bids for further research or investigation as these can be identified as requests made by the community. Over 2010-2011 further resources will be created using the PLHIV Stigma Index quantitative and qualitative outcomes. These will be shared with stakeholders as they are completed.

To create this document focus groups were undertaken across the UK collecting the ideas and opinion of sixty-one individuals living with HIV in 2010. Six sessions focused on health, self and disclosure. And a further six explored rights, support, and effecting change. These were themes extracted from the Stigma Index that were considered would benefit from further exploration.

Literally hundreds of insights, explanations and considerations from PLHIV are offered in this document, too many to do them justice in an executive summary. Disclosure decisions, experiences of isolation, management strategies, opinions about criminalisation, compromises on sexual practices, combating discrimination in a range of environments, and reactions encountered within health care settings are some of the topics covered in the discussions. Each topic is presented under a heading (see contents page) with a summary of the reports from participants followed by a selection of quotes relating to the topic. A number of interesting quotes from a range of topic areas are listed below to offer an indication of the richness and value available.

"I haven't told my family. ... I know a number of people who haven't told family members and the reason ... isn't necessarily because of stigma and discrimination but because they don't want them to worry about them." Focus Group (FG) 3.

"Some people are wicked. Instead of telling the partner, the person just continues and lets the person get it [HIV] so when the partner tests positive they will not know who to blame." FG 6.

"I know there are ... rights to treatment, rights to a decent quality of life. Other than that ... with regards to working ... no idea." FG 10.

"[having] HIV and suppressing it, it's a bit like holding a football underneath the water in a swimming pool, it takes a lot of energy. And I thought, there [are] better things I could be doing with that energy.... So when I was diagnosed ... I was able to stand up and say, 'I'm shitting myself'." FG 12.

"I told a friend who told others without my consent ... I feel strongly if I am going to disclose my status I am the one, it's my choice, but ... you have to be forgiving when people tell." FG 6.

"When I go to my GP now, he doesn't ask me so many questions, he'll just say, 'you are not breastfeeding'. He won't say 'because you are HIV'." FG 9.

"I used to get my dental care from my HIV specialist dentist until they got rid of that and I don't disclose to my dentist now at all." FG 8.

"[As] positive people, we can't carry this baggage of telling people that we are HIV positive, people should be responsible for their [own] sexual life." FG 10.

QUALITATIVE METHOD

Between April and August 2010, twelve focus groups were undertaken across the United Kingdom (UK) with people living with HIV. The locations of these groups included Glasgow, Edinburgh, London, Manchester, Leicester, Cardiff, Belfast, and Leeds. The sessions were organised through partner organisations that had supported the data collection phase of the PLHIV Stigma Index. The groups involved between 3 and 7 participants. A total of 61 participants were involved. Participants completed a short questionnaire that monitored participant demographics in line with the SOPHID database, which collates information about all individuals diagnosed with HIV and accessing NHS care.

Two or three facilitators executed the sessions. Two focus groups were completed with the researchers recruited initially to undertake the PLHIV Stigma Index. The researchers were briefed in qualitative methods in 2009 during training to recruit and undertake the Stigma Index. On completion of the two researcher focus groups, a top-up qualitative training session was undertaken on the facilitation of focus groups. This enabled the researchers to contribute to the running of the other ten focus groups.

Two sessions themes were developed. Half the groups explored: health, self and disclosure. The other groups focused on: rights, support, disclosure and effecting change. These themes were identified as areas of interest or areas requiring additional context when analysing the quantitative data from the PLHIV Stigma Index

The interview schedule was presented using PowerPoint slides to facilitate discussion, this ensured consistency across sessions. Presenting themed index findings highlighted discussion points. In addition areas that are difficult to interpret or which the index did not explore in sufficient detail were identified and discussed.

The information extracted from the qualitative groups was used in a number of ways. Principally, observations relating to the thematic topics were grouped into subsections allowing information to be extracted and presented in relation to topic area. In addition, hypotheses were generated for current data exploration and future studies. This process fed into the development of a template for the data presentation for distribution and to contribute to the UK PLHIV Stigma Index Report. Hypotheses that required additional data collection were collated to ensure that those within the HIV community in the UK had an opportunity to influence future studies. Concerns specifically related to the asylum seeking and MSM populations were outlined to contribute to specialised reports to be shared with partner agencies.

The participants' perspectives on the key themes have been summarized with related quotes from participants linked to these observations. This presentation style allows members of the HIV community to support data reports with qualitative explanations from PLHIV.

FG	Date	Location	Location	Health	Rights	Researcher Training	No.
1	27/4/10	Glasgow	Scotland	✓		✓	7
2	27/4/10	Glasgow	Scotland		✓		3
3	28/4/10	Edinburgh	Scotland		✓	✓	4
4	18/6/10	Belfast	Ireland	✓		✓	5
5	22/6/10	London	London		✓	✓	5
6	5/8/10	London	London	✓		✓	5
7	4/8/10	Wales	Wales		✓	✓	5
8	11/8/10	London THT	London	✓		✓	5
9	18/8/10	Manchester	NW	✓		✓	4
10	19/8/10	Leeds	Yorkshire		✓	✓	6
11	20/8/10	Manchester	NW		✓	✓	6
12	30/8/10	Leicester	NW	✓		✓	6

Characteristics of the UK population of people with HIV accessing care with guidance on recruiting a proportionally representative sample

	SOPHID Percentages (N = 56,556)	Stigma Index Percentages (N = 61)
EXPOSURE CATEGORY		
MSM	42.4%	39.3% (n=24)
Sex: M & F (Male)	18.3%	13.1% (n=8)
Sex M & F (Female)	31.4%	52.5% (n=32)
IDU	2.6%	8.2% (n=5)
Blood to blood products recipient	0.9%	1.6% (n=1)
Mother-to-child transmission	2.2%	3.3% (n=2)
Other / not reported	2.2%	0%
ETHNICITY		
White	51.7%	54.1% (n=33)
Black-African	12.4% (20.0%)	42.6% (n=26)
Black Caribbean	2.9%	3.3% (n=2)
Black – Other	1.6%	0%
Indian / Pakistani / Bangladeshi	1.2%	0%
Other Asian	1.5%	0%
Other Mixed	3.5%	0%
Not reported	1.1%	0%
SEX		
Male	65.9%	45.9% (n=28)
Female	34.1%	52.5% (n=32)
Transgender	N/A	1.6% (n=1)
UK Breakdown		
London	44.4%	24.6% (n=15)
Rest of England	47.8%	37.7% (n=23)
Scotland	4.8%	19.7% (n=12)
Wales	1.8%	8.2% (n=5)
Northern Ireland	0.7%	9.8% (n=6)
British Isles Other	0.0%	0
AGE (Excluding <15)*		
15-24	4.2%	0% (n=0)
25-29	9.1%	11.5% (n=7)
30-39	36.7%	23.0% (n=14)
40-49	34.5%	57.4% (n=35)
50+	15.7%	8.2% (n=5)

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 the 2008, compared to a 12.4% representation in the total population in contact with care services). Additional participants were included in this group in an attempt to represent this change.

OBSERVATIONS AND COMMENTS: UNRELATED TO SPECIFIC GROUPS

Frequently when discussing disclosure experiences, people's reaction to disclosure and experiences of discrimination, participants talked in general terms rather than linking them to specific groups of people and locations. This section outlines these general discussions. Additional experiences that relate to identified groups or environments are contained within these sections.

3B.1 Disclosure: They don't know my status

A number of participants offered insight into decision they had made not to disclose their HIV status to family and friends. Some participants explained that they generally opted not to disclose. A number of participants explained that they had initially been very open about their HIV status but more recently had only disclosed when essential. Some indicated that they simply didn't want people to know and others felt it would be too difficult and complicated to disclose. A fear of rejection was cited as another reason. A couple of people from the African community explained that people in the community were extremely reluctant to engage with people living with HIV. Careful selection of those to disclose to was another approach outlined. One participant explained that she, and several people she knew, had opted not to disclose their status to their families to avoid them worrying. They did not believe their families would react negatively but instead that they wanted to avoid stress being imposed on them. Some people opted not to disclose their status to anyone, deciding simply to undertake medical treatment and cope independently. Another participant explained that disclosing his HIV status would be too much hassle in some circumstances. He felt it would be a challenge to ensure that some people still saw him as a person and didn't just focus on his HIV status. A gay man explained that his partner was HIV negative and that he believed people would make the assumption his partner was also HIV positive if he were to disclose. One participant who had not disclosed their HIV status to one group of friends had observed their reactions to HIV and reported being aware of considerable stigma making her reluctant to be judged by disclosing her status. Other people also explained that they were aware of people making assumptions and judgements relating to HIV transmission. One man explained that he had opted not to disclose his status to anyone in his personal life. He had a physiotherapist who he saw regularly and who he knew from childhood. He confided in this man and felt his reaction had aided his coming to terms with his status. There was discussion about a person living with HIV's right to get a tattoo. One individual explained that having disclosed his HIV status on a questionnaire in a number of tattoo parlours he was advised that local council policy meant he could not receive a tattoo. As a result he went to a parlour outside the area and did not disclose his HIV status. He explained that he felt guilty about having to be dishonest but that he resented being discriminated against. He highlighted that lots of people will have tattoos without knowing they are HIV positive and that the equipment should be sterilized sufficiently to avoid risk to any other customers. Another person in the group reinforced his point by explaining that she had had her tattoo done before she was aware of her HIV status.

"I can't see ... disclosing to someone unless you are one of those individuals who really has made up his mind that he is going to stand up and is going to be counted and he doesn't give a damn. There are people like that and good on them and you know, but most people can't do that." FG 6.

"I don't really like people knowing." FG 6.

"A lot of people don't understand the risks associated with disclosure... We are all afraid of rejection. The moment you tell someone that you are HIV positive they might just run a mile and never look back." FG 10.

"You are basically creating more complexities to your life within the relationship [with the person you disclose to]." FG 6.

"I would love to think there would come a day when we could all be open. It won't be in my lifetime, but if we could be [as] open about it as we can be ... with any other illness or virus ... but it will be a long time coming... People just don't understand it. They just put you in a box... If you've got HIV then you've been very promiscuous, you have been a drug user... Whereas people like C.....and I who were married and leading a normal life and we still end up ... in the same boat. I have got a gay son and the first thing he said was, if anybody in our family was going to come home with this virus mum it was me, as a gay man. But it's not, it's you mother." FG 11.

"I think as human beings we don't want to be rejected ... I want to be liked, I want somebody to want me whether it's sexually or as a friend and so the thought that ... some fact about me that is going possibly to put somebody off ... that had deterred me from [disclosing]... Once you have got to the point where you recognise that actually, ... what I have is not something to be ashamed of and if somebody has problems with that then actually that's not about me, that's about their lack of information or their wilful ignorance on the subject." FG 8.

"Some people when they hear that's someone's HIV positive, ... especially us Africans ... they'll be seeing someone who's dying, someone who is not supposed to touch anyone." FG 7.

"...We Africans ... run completely away from [PLHIV], you don't even want to know them... They think when you touch them ... you can catch HIV... I just heard some people saying, 'if I know someone who is HIV I would never, ever talk to the person again, I will never go to that person's house, I will never do anything with the person'." FG 7.

"I have been very measured for a very long time in my lifetime with HIV about who I've chosen to tell." FG 8.

"We have so many people who come to us who have not told anybody about their HIV and cannot ask anybody about things that they should know about their HIV, so I do think this is where the organisations should be coming in. HIV organisations should be providing a lot of these services." FG 10.

"The first thing you think about [is] disclosure. Am I going to tell them?.. What are the risks if I don't tell them?.. Do I need to disclose and if I don't disclose what happens?" FG 9.

"I am not excluded from family activities and I don't think I would be, but then I haven't told my family. ... I know a number of people who haven't told family members and the reason ... isn't necessarily because of stigma and discrimination but because they don't want them to worry about them. It's almost kind of an altruistic reason and it's like 'I am doing fine, there's no need to worry.' I know about half a dozen people ... who haven't told their families so I don't know how they'd answer [the Stigma Index question about exclusion]. They'd probably say they haven't been excluded because it hasn't been an issue." FG 3.

"To come on to the educational thing ... my partners mother ... she would probably be one of the last people I would tell because it think it would be such a wide discussion ... it's just so much hassle. ... There are very few people who you can actually say 'look, this is me, this is what I am living with, it isn't all, HIV isn't all me but it's something I'm dealing with' ... It's not that people want sympathy necessarily, they want people to understand." FG 3.

"People make assumptions that they can't necessarily prove and they often make the wrong assumptions and in my case it's very difficult because I am living with a partner who is negative and has been for the past 10 years and was recently been tested again and thankfully is still negative. ... people could assume that for instance that my partner was HIV positive, which he is not." FG 3.

"I don't turn around and tell them that I am [HIV positive] because I know what their reaction would be. ... I hear the way they speak about it. The people that I swim with [ask] 'You couldn't catch it could you if they are swimming in the same pool as us?' Even taxi drivers, like 'How could you work with someone like that, why would you want to work in a place like that?'" FG 2.

"I said, 'by the way I am HIV positive'... They were surprised I think in the first place and then they were quiet for some time... I think they think people who have HIV ... look different... Afterwards I asked them, 'how do you feel now that I have told you?'. They didn't say sorry, they said, 'thank you for sharing with us, now we understand' and ... they were listening to me more than the trainer... They wanted to know more about me, about HIV. It was like I was an expert [not] the trainer." FG 9.

"[We were] fundraising... there were a guy there and he said, 'oh what are you collecting for?'... And when we told him it was for people living with HIV, this is a gay man, and his response was, 'oh, well anybody who catches that deserves it'." FG 10.

"Sometimes I just want to be myself without HIV. Before I was open but nowadays I'm closing ... because I think I've been associated with HIV for a long and I want to have a life, so I'm closing my doors and windows." FG 9.

"I go to physio and I have known this guy, ... all my life ... I told him and he never batted an eyelid and I had to tell somebody and I felt that I could trust him... Nobody else knows. Now I have a few close friends, I have known them for years and I wouldn't dare tell them because of their reaction. The only person apart from the doctor and the dentist is this physio guy, nobody else knows." FG 4.

"I couldn't. I am not close enough to anyone to tell them that." FG 4.

"I tried to get a tattoo in Glasgow and I couldn't get one ... because they ask you on the form 'Are you HIV positive?' I ticked the one for HIV. He turns around and says 'We can't take you'. He says it wasn't to do with changing the needles, it was to do with the cleaning equipment. I went to ... a few different tattoo parlours. They wouldn't do. They say it's the way Glasgow City Council says. Yeah but the shops were busy. I felt ... really small and I was really, really upset." FG 2.

"I myself got a tattoo when I didn't even know I was HIV positive so ... how can you justify that." FG 2.

3B.6 Disclosure empowering

The experience of disclosing was reported to be liberating. It was suggested that being open about HIV minimised opportunities for others to gossip. Telling people face-to-face was considered to help ensure people respected confidentiality. Participants suggested that over time disclosure became increasingly empowering as their confidence grew. The role and value of disclosure varied between participants. Some found overcoming the dissonance caused by compartmentalizing their life, into those who were aware of their status and those who weren't, an empowering experience. Some didn't consider disclosure to be of any particular interest, it was solely a means of communicating information about themselves. The decision relating to disclosure when children were involved was described as the most challenging. Decisions not to disclose to children were generally related to ensuring the children were protected from potential discrimination. It was proposed that disclosing yourself rather than asking someone else to do it was the most effective means of disclosing and gaining understanding.

"I think disclosure ... may liberate, free a person." FG 6.

"The more people I told, the easier it was and ... once everybody knew, well what's there to gossip about ... I talk openly ... so gossip isn't possible... That's how I am able to be happy and not have to worry about it at all." FG 8.

"Overall listening to people and my experiences overall, disclosure is a positive thing, it is an empowering thing." FG 8.

"As long as there is a way of disclosure, [it's] best be able to disclose for yourself than to get somebody else to do it ... [it's] about personal responsibility." FG 8.

"Ultimately [disclosing] was empowering because ... I was able to go back to the individual who was gossiping and kind of put them in their place." FG 8.

"[Disclosing is] a process and an ongoing thing, the first time might feel really scary and disempowering, but ... it actually was an empowering process ... I believe personally that if it's a crap experience, it's probably because I was choosing to tell the wrong person. They had no real need to know." FG 8.

"I disclose where I feel I am safe." FG 9.

"...From my experience of disclosing, it depends on how confident you are... [When I was first diagnosed], I wouldn't sleep with a person without using a condom ... because even if I was on treatment, I didn't know how to protect them apart from [by using] a condom. But as I learnt about HIV and I went to support groups ... I have [the] confidence to tell a person... It was through organisations, through peer support that I gained the confidence." FG 10.

"I am very, very careful who I tell. My friends I know would not tell anybody else." FG 11.

"When you tell people [face to face], they feel like they are responsible for keeping that information... You have ... trusted them and you have told them so they don't gossip, like if they heard from another person." FG 11.

"I've been very careful as to who I tell. I don't think I have been discriminated against or stigmatised in any way, but I think that's because of who I've chosen to tell." FG 11.

"[Disclosing] does become more and more empowering as time goes on." FG 8.

"I find it's a very empowering process really because once you disclose the dissonance in your life just stops because you are one person... In the last maybe eighteen months I was working for the council and each time I was going for this three monthly medical, ... I had to say I am going to the doctors to see my consultant I had to come up with some story and for me that was the most difficult thing because I was leading double lives... So for me disclosure, it's really good, it's very empowering because it stops this confusion." FG 1.

"[Disclosing] does empower you. You feel like you're in control... Nobody's going to gossip about you ... you can show them that you have HIV but still you're okay. So I found it really, really empowering in most cases when I have done it." FG 9.

"I didn't feel empowered by [disclosing] it but most of the time it's, you know, one of the things you mention about yourself." FG 1.

"For me disclosure is about protecting people, you know, for example I disclosed when my children were old because I knew then they can defend themselves. But if my children were younger ... I think I wouldn't have because then you know children can talk, 'oh my mum is HIV' ... and then what does it do to them, you know. So ... I have got mixed feelings about empowerment." FG 1.

"What I discovered with all the people that I talked [to] with HIV, was that women with kids find it [disclosure] the most difficult of all because they want to protect the kids from getting bullied in school, from other kids and stuff like that. There should be more support there." FG 1.

"I emotionally dumped on a lot of my friends initially ... and then I realised I didn't need to tell every one... It was very important to help me cope and prove to me that my friends were all good." FG 4.

"Being HIV positive made me a better person I think. I felt empowered ... you realise that you can do this and I have very good friends who have had it for 20 odd years." FG 4.

"I don't feel empowered by telling people about it because it is still a bit of a shameful thing to [have]. So it's is not something that I am proud of... I would have kept it to myself given the chance." FG 12.

"If I sat up in front of a group and disclosed my status, that's empowering, but not in other circumstances." FG 12.

"Empowering [is] about affecting change, it's about challenging individuals, groups and society... To be able to affect other people's thoughts, is a very powerful thing to do ... whether you do that by disclosing your status [or] disclosing your sexuality ... it's alright... We [do] a lot of outreach work to schools ... The kids are absolutely fantastic. This is where we have got to start. We have to educate all the way through, but ... we have to start with 14 and 15 year olds, who are already sexually active, who are already putting themselves at risk." FG 12.

"[Disclosure] has been a good thing ... it has been an empowering process because now I am free, I don't have to think about it." FG 12.

"[Disclosure has] been an empowering process because it opens up ... support in other places... In other places it has opened up ... rejection, but that's when you get to know who ... your real friends [are]." FG 12.

"As a gay man, I learnt very early on [about] coming out and ... I was really clear that if I was going to live with HIV for the next 40 or 50 years, I was going to make damn sure I was friends with it. And I thought,... [having] HIV and suppressing it, it's a bit like holding a football underneath the water in a swimming pool, it takes a lot of energy. And I thought, there's better things I could be doing with that energy than trying to hold this in. So when I was diagnosed ... I was able to stand up and say, 'I'm shitting myself'." FG 12.

"This project has been ... key for me ... I was able to disclose safely and I felt supported, [which] was hugely comforting. The idea of going home with that medication on my own ... would have been a completely different experience." FG 12.

"When you want to disclose, it is empowering, because there is a difference ... we are free... I put my medication wherever I want to put it, I am not hiding ... we talk about anything... When I walk into the clinic, ... I know that half of them who come there are in the same situation, so ... now I just walk in with a smile, sit down and do my thing and come back and that's it." FG 12.

3B.6 Disclosure not empowering

It was reported that, irrespective of the person's reaction, the actual process of disclosing was generally draining. Participants found it particularly difficult to disclose when they had received a negative reaction from people during previous disclosure experiences. One individual admitted that, despite being reluctant to disclose, on occasion they did to challenge people who were making judgements about people living with HIV. One challenge people who were open about their HIV status faced was others disclosing their status on the assumption that it was acceptable. Participants were keen to clarify that it was unacceptable for their status to be shared by anyone else. One participant suggested that the individual's approach to disclosing could impact on the reaction they receive, therefore if someone indicated that it was a particularly bad piece of news then people would react to it in that way. Finally, one participant believed that the collection of her medication from the pharmacy risked disclosure as the bulky packaging resulted in her having to collect 15 bags of medication at each visit.

"I wish that I had been told more about disclosure when I was just diagnosed." FG 6.

"Every single time it's difficult [to disclose] ... it's a pain and it's really draining to do it. Even if I know that you're going to be great about it..." FG 8.

"This ... person said to me, 'I haven't known anybody with HIV before' and I said, 'how do you know?'. It's not something that's hung up on our forehead." FG 8.

"I have told people ... and not had the response that I would have liked ... and it became quite hard work." FG 8.

"Shutting my mouth also is a problem. I end up disclosing even when I say I'm not going to do it... When people irritate me I say, 'by the way I'm one of those people you're talking about'." FG 9.

"I'm open about my HIV, but I don't want anybody to disclose for me and I think sometimes people get it wrong... It has happened to me because I'm open and people think they can tell other people. It's not okay at all. I want to do it myself... You have to create a way of letting those people know that you don't want people to keep talking about it, because they'll take it for granted that since you are open, then they can talk about it." FG 9.

"Disclosure is a very ... personal thing... Some of us are fortunate enough to be in a position where disclosure, we use it as a tool. We use it as something quite powerful and we are able to be completely open and upfront with

family friends, society, even in the work place. I personally have got no experience of my HIV status having been shared without my knowledge. To be perfectly honest if anybody does then, that is just completely unacceptable, because everybody has the right to that privacy and that security. Disclosure is a very personal private thing and you choose to disclose as and when you feel it is necessary and appropriate for you.” FG 12.

“If I was telling somebody, I would like to do it myself.” FG 12.

“I haven't given anybody ... permission [to disclose my status] apart from health... If it's doctors and they need my consent ... I would do that. But in terms of friends, family, people, it's just not their place.” FG 12.

“[If you] say ‘oh I've got something really awful to tell you, I've got HIV’, well you'll get a crap reaction ... maybe it's time to take a look at ... how I'm communicating this or if indeed I needed to communicate it at all.” FG 8.

“I make sure I shake everybody's hand in the room before I tell them [my status]. They blush and turn a funny colour.” FG 10.

“Stigma starts with the health settings ... for example the pharmacy, you go there to collect your monthly or six monthly life support, you have fifteen bags full of carton boxes which have very small bottles. So one, packaging is wrong, it discloses who you are and what you have.” FG 1.

“I do think there should be a duty at the point of diagnosis to make it clear that there are these very real social stigmas and that ... it's not just ‘you've got it and go home’.” FG 6.

2A Discrimination

Participants considered stigma and discrimination to be considerable issues in the UK. However, some stated that they had not experienced any discrimination. Others highlighted that the threat of potential discrimination was the principal issue. Variations in types of discrimination were identified. Some considered stigma experiences to go unnoticed because they occurred discreetly. A number of factors were identified that influenced people's experiences. Of particular importance was the environment people inhabited. Support offered by friends and family was considered to be of particular importance. HIV related discrimination was observed to be secondary to other sources of stigma such as homosexuality, immigration or drug abuse. One participant explained that the improvements in medication meant that people were less judgemental and less avoidant of people living with HIV.

“It's obvious that stigma and discrimination haven't gone away and unfortunately it's still a huge obstacle to people living with HIV in this country.” FG 7.

“The likelihood of experiences [of stigma and discrimination] obviously depends on a number of areas, such as whether you live in the city or in rural areas, or if you are in a certain type of employment ... or your circle of friends or people's understanding, or where your friends are at, particularly in a social context. All of those would impact on whether you actually experience it or not.” FG 7.

“I think there's potential for me to have been discriminated against and to have not noticed because it's not been that in your face, it has been very subtle, if it has happened. But it may be that I have not experienced any.” FG 7.

“I've been lucky enough never to experience anything like that [discrimination].” FG 10.

“I think it's people telling me I am going to be stigmatised not the actual stigma that I've come across.” FG 10.

“I do know a lady who is an ex-drug user and she has accounted to me on a number of occasions that ...she feels that she gets stigmatised more because she was a drug user.” FG 6.

“There’s been a change over the past few years with regard to how people view HIV and AIDS ... acceptance of HIV being in the community ... because of improvement of the medication ... it’s not much of a death sentence. So [if] you know someone who is positive you are not going to be staying away from them now.” FG 10.

2A.4a Awareness of being gossiped about

Some participants indicated that they were aware of people talking about HIV within the wider community and recognised that on some occasions their status may be discussed.

“I have been fortunate in that I haven’t been excluded ... maybe people have gossiped about me but I haven’t been aware ... And I [am] very openly out with my sexuality and my status ... It’s not something I’ve kept secret.” FG 7.

“I have heard people talking ... not to me, but about things that they have seen on the television or read in the paper about these people with HIV ... and you think, ‘you’ve got no idea’.” FG 11.

PERSONAL EXPERIENCES, FEELING, CONCERNS AND BEHAVIOURS

2C.1 Internal Stigma: challenging and overcoming negative feelings

Some participants explained that they had initially felt negatively about their diagnosis but come to terms with it. Others explained that they had not experienced severe negative feelings in relation to their HIV status. One participant explained that in coming to terms with her diagnosis she realised that if she processed her HIV as similar to cancer, it made it easier to develop a routine and engage with life. Some members of the group recognised self-stigma in their own beliefs, these have been presented in themes below.

“You go through all those things once you are diagnosed with HIV... It’s like a transition... You go through all these things, you blame yourself, you feel you are useless... I am not ashamed, I don’t blame myself, I don’t have low self esteem, I don’t feel suicidal. People can talk if they want to talk, I know what I am. I don’t care.” FG 9.

“When you are being told of your status, you go through those stages of feeling ... anger, you blame yourself, you feel ashamed... But as you go along ... to these meetings, meeting people with the same condition, you build up your confidence.” FG 9.

“I have probably felt all of them at some point in my life. But now ... every now and then I would be fearful of being gossiped about.” FG 12.

“I have never felt guilty, I have never felt ashamed, I have never blamed myself, never had low self esteem and I have never felt suicidal in all the years I have been diagnosed.” FG 8.

“It’s just another part of me. It’s not something I am either proud of or ashamed of... It’s just something else... I look upon it I as I would with a my broken leg: I broke my leg, I told people about that.” FG 12.

“I am proud to be HIV and I am proud that I am living with people who just accept me. It’s all about love.” FG 9.

“I’ve been fortunate enough have a medication regime where I can lead a normal life and ... I suppose I compare my life also with somebody who has cancer or somebody who has Leukemia and it’s pretty much the same thing it’s learning to deal with that situation and accepting that this is what my life is and making changes accordingly so I suppose empowerment is key.” FG 5.

“I have a friend who used to call it ‘the cat flu’. He would go for his cat flu check up and take his cat flu pills. He sometimes had his cat flu shits, sometimes he had cat flu stomach or cat flu headache. That’s how he dealt with it. ‘The cat flu’.” FG 12.

2C.1 I feel ashamed

Some participants indicated that they felt shame as a result of their HIV status. A couple of individual explained that they felt unclean because of their status.

“I feel guilty, I feel ashamed and I blame myself.” FG 6.

“I never felt like killing myself to be honest but I have felt low, I blamed myself, I felt ashamed, I felt guilty but now I am so confident, I am not ashamed anymore.” FG 9.

“I really felt ashamed of myself ... a woman being HIV positive ... not clean at all.” FG 12.

“When I was first diagnosed I felt like putting a placard round my neck and ringing a bell shouting out loud ‘I am unclean’.” FG 12.

2C.1 I feel guilty

Guilt was a feeling a number of participants recognised in themselves. One woman explained that because society found her status unacceptable she felt guilty and had to keep her status a secret. This resulted in her living two conflicting lifestyles. In addition she felt angry with herself for not being aware of the risks she faced

prior to contracting HIV. Another woman explained that her partner constantly blamed her for introducing HIV to their relationship and as a result had come to feel guilt. Some people explained that the guilt they felt was because they had been careless and unaware of the risks they faced. Another individual had lost a child to AIDS and her other child was HIV positive and this troubled her greatly. Other people stated that they did not feel guilty and that they considered HIV to be similar to any other illness.

"I don't know why I feel guilty, probably because the society doesn't accept it, so I am guilty. I feel ashamed because I can't even openly talk about it, so I'm still living another life. I blame myself probably for not being well enough educated to know what this HIV was all about." FG 1.

"I was constantly made to feel I actually brought this HIV in this relationship. So in a certain way I can relate to feeling guilty and also feeling that I should be punished but also it was a lot to do with the company I kept so to speak, you are constantly being reminded, 'oh well, if it wasn't for you then we wouldn't be in this situation, you know it's your fault.' When you hear it over and over again, you start to feel that actually it might be my fault and for a long time I did feel that way." FG 5.

"I feel guilty all the time because of my daughter, because essentially my daughter is positive and it's through vertical transmission... She doesn't usually throw it in my face, but occasionally she will... I also feel guilty that I had a baby that died of AIDS ... because he died because ... I didn't choose to have an HIV test... Because I'd had negative test, I thought naively that I would be negative forever... I do feel guilty, not so much about my HIV status, ... but more about the fact that my status has meant that two other people have been infected." FG 7.

"I feel guilty particularly in relation to myself. I feel as though I let him down ... and I suppose feeling ashamed comes into that ... blaming myself." FG 6.

"I don't feel guilty because I feel I have not infected anybody." FG 6.

"I [am in] a new relationship where I don't actually feel guilty [about my status], but I'm conscious of the guilt I would experience were my partner to become accidentally infected... I had no feelings of guilt while I was abstinent ... but the minute I went into a relationship where I was intimate with someone then those thoughts of potential guilt rose to the surface." FG 7.

"I never felt guilty. I don't think I deserve any punishment, I didn't blame others for it. It's just like any other illness." FG 5.

"[When] I meet that person, I will insist on having condoms because I don't know him, he doesn't know me, but I know myself that I am positive. The good thing is not to pass it on because I feel guilty ... that what I am doing is wrong. I know what I am and that person doesn't know... You just want to be safe. And I cannot say ... I am not going to have sex, I am still sexually active and but I have to practice safe sex." FG 9.

"[If you tell yourself] the HIV status now proves that I am not a good person, ... that I'm not going to be happy and that I'm not going to be confident ... then it's a self fulfilling prophecy." FG 8.

2C.1 I blame myself

Linked in with feelings of guilt was individuals' tendency to blame themselves. One woman had moved to the UK from Zimbabwe. She explained that she had engaged in a relationship where she had put herself at risk of HIV infection. She had understood that the man she had entered into the relationship with could help her bring her family to the UK. This had not happened and as a result of engaging in unprotected sex she had become infected with HIV and blamed herself for being naive. Similarly, other participants explained that they felt they were to blame for not protecting themselves.

"I blame myself, like I said, if only the bells were ringing that day... When I came to this part of this world [from Zimbabwe] I was so eager to just get my family over here, which I couldn't then, and all I did was work and sleep. And then you find this guy who lives in the same block of flats as you, who is very single, who drives a very nice car, who is really, really very nice and you think 'Who says life is not good?'... He told me, 'I used to have an

African girl, I really wanted to marry that girl but then she refused and went back to Africa.' If only someone were to slap me, that very moment I could have saved myself." FG 4.

"My main feeling when I first found out that I had HIV, was why me?... I blamed myself for getting it ... for not being careful ... but eventually I realised that it wasn't my fault, it was just some selfish person who decided not to tell me that they were HIV positive." FG 10.

"I've got a friend who's slandering the person who gave it to him... My argument has always been you were there too... You are responsible for yourself. Surely you've got to take some of the blame as well." FG 10.

"I blamed myself for being careless that's all." FG 5.

2C.1 I blame others

One individual explained that although she had not experienced guilt she had felt a lot of anger towards God for her HIV infection. Another individual stated that she held her husband responsible for infecting her because he was unfaithful.

"I didn't feel guilty but ... for a long time, I blamed God. I thought how did he let this happen and it was unexplainable... How could he let something like this happen to people ... sometimes to children, sometimes to a person who is just innocent... It took a while and then I started to forgive him." FG 5.

"I blame others... It was my husband that infected me so I blame him. It should never have happened... It's his fault. He should have lived [as] a faithful and loving husband ... and he didn't. So I blame him. I still blame him." FG 11.

2C.1 I feel suicidal

A couple of participants indicated that their initial reaction to diagnosis was suicidal thoughts. One had overcome these thoughts by thinking of the child that would be left, another resulted in the individual being admitted to a psychiatric ward for support. One gay man explained that he had cheated on his current partner with an ex-partner who was HIV positive. As a result he felt extremely guilty about his HIV status and suffered greatly from depression and suicidal thoughts.

"I have felt suicidal on many occasions and it was my first plan to kill myself. That was my first thought, it's not difficult, just kill myself. But then of course, I thought of my son and I couldn't." FG 6.

"[When I was diagnosed] I felt very unclean. I felt guilty that I was alive and my partner was dead. I blamed myself even though we didn't know who had infected who or whether we were both infected before we were met. There was no way of knowing. I know there is now but there wasn't then. I have actually had serious mental health problems ... not only did I feel suicidal, I was suicidal and I was admitted and sectioned. That was ... more to do with the feeling of guilt, of losing someone ... did I infect him? Would he still be alive today?" FG 12.

"[I feel] Guilty. Because I shouldn't have slept with that other guy. I was in a relationship and I feel a lot of guilt for that. He was an ex partner and he knew he was HIV but he didn't tell me... So I have a lot of guilt for my partner. I am worried. I told him I was HIV and he stood by me. I've only known over about a year... I am suicidal all the time, they've got me seeing a psychiatrist. Very low self esteem. I can't even go out and buy myself clothes or I can't go on holiday. It's just a job to eat... The word 'HIV' is enough to drive me cuckoo. I can't talk about it. I can't read about it." FG 4.

2C.3 Fear of being gossiped about

Some participants indicated that people gossiping about their status and health was a concern for them. One participant suggested that this was a particular problem for those in Black and Asian communities.

"I am fearful of being gossiped about." FG 6.

"I have that fear that if I tell anybody, they will gossip about me." FG 6.

"The threat is just gossip. Because what more can they do, it's just gossip!" FG 12.

"This is quite a cultural thing... With the Asian and Black communities. They really are worried about people talking about them and it getting out within their communities." FG 12.

2C.2 I have chosen not to attend social gathering(s)

People indicated that they opt to exclude themselves from situations to avoid queries they would prefer not to answer. For example where there is overlap between people who are unaware of their HIV status along with people they know through the HIV community, thus raising questions about how people know each other. Or situations where people are likely to enquire about their HIV related health.

"... people who exclude themselves because "I don't want to go to that because I know that everybody is going to be asking me about my HIV" or "there'll be lots of other HIV positive people there and I don't want to explain to the to the other members [who are not HIV positive] how I know them." FG 3.

"I've disclosed to guys upfront ... and they've ... said 'oh yeah I know because so and so told me' ... It's a barrier to my disclosure to people. It's a barrier to me going out and engaging with my community to hanging out with people..." FG 8.

PERSONAL RELATIONSHIPS: PARTNERS

2A.9 Psychological pressure from a partner

Psychological pressure from partners was something many of the participants could relate to. Some participants found that disclosure to a partner was initially an empowering experience but later, faced with disputes, it made them feel incredibly vulnerable. One individual suggested that husbands of HIV positive women might lie about their own positive status to allow them additional power over their partner.

"I have actually had a 6 year relationship with a negative man and thank God it's over now! It was an absolute nightmare. Every three months we used to go for a three monthly check, waiting to see had something happened. And then towards the end ... we actually had our first accident with a condom ... but he is okay... But ... I couldn't have the quality relationship that I felt I deserved, because I was always frightened... I have already had one partner who died... He never rejected me, but yes there was psychological pressure there, there was manipulation there, because I was always seen as the weaker link because of my status. And as much as I fought against that ... we could never move away from that totally." FG 12.

"When everything is going good your HIV status is not an issue and you come into your full sense of security where you are actually thinking this is so accepted by this person [partner] and then the first argument, ... it's the biggest, lowest blow they can give you and it sets you back they have no idea how much this sets you back. ... Getting called 'AIDS bastard.' ... The impact that has on your health and mental status is massive." FG 1.

"Husband and partners, when ... you have a falling out, they always threaten to ... tell your work place." FG 12.

"The woman goes home, tells the husband that she is HIV positive... He tests, he discovers he is positive, he goes home and says that he is negative, then that gives him power and control over her and that is not uncommon at all." FG 6.

"Some people are wicked. Instead of telling the partner, the person just continues and lets the person get it so when the partner tests positive they will not know who to blame." FG 6.

2C.2 I have decided not to have sex

Some participants indicated that they had opted to avoid relationships and sex to avoid issues being raised relating to their HIV. One man described meeting a female and being reluctant to become involved in a sexual relationship. When they did have sex he had not disclosed his HIV status and he reflected that he should have used a condom. He confessed this to the female and described her fury with him. He explained that despite her testing negative she had continued to make his life difficult and he had opted to avoid any future sexual relationships. One female explained that she felt lonely at times but couldn't face the process of disclosure to a partner so opted to remain single. Another individual indicated that initially they opted out of sexual relationships but did not feel this was a long term solution.

"Being HIV psychologically, it's just affecting us. You can't just be bothered to start being involved in a relationship. The fact that you are positive and then of course you need to disclose... You'd rather stay and enjoy your life and enjoy yourself... I've just given up and I just take care of myself." FG 9.

"About 4 years [ago] ... I think I felt as if I had leprosy, they referred to it here as the plague and I swore I would never, ever have a relationship with anybody again. And then I met this girl ... and we started going out and I am sure she must have thought something was wrong with me because I wasn't trying [to have sex with her]... Eventually we ended up having sex and I realised I should have to used a condom... I had never used condoms and it was just because I hadn't many sexual relationships... I realised if I told this girl that would be the relationship over... Eventually I got the opportunity to tell her and well, Jesus it was a nightmare, she was going to have me... They had promised me at the hospital that if I would ring them up, they would test her right away and let her know... I says three months have passed here and when you go in and get tested they would be able to say you haven't got it, end of story... We got up to the hospital and she was not very pleasant to anybody ... they phoned her up later that day to tell that she was all clear. For about the next three years, up until nearly six months ago, she has nearly put me round the bend with that 'I have ruined her life', 'I am the worst thing that

ever happened', 'she can't have another relationship'... I know my life's been affected by time here because I've got this thing... It got so bad about 3 months ago, I had to turn around and make it impossible for her to contact me... So I haven't had sex since this " FG 4

"[I decided not to have sex or relationships] because I can't bear.... If it was possible I would be happy if I were to find someone who is HIV positive then I don't have the idea of explaining... At least you ... don't have this whole idea of, should I, should I not, do I tell him... I think it's the best for me at the moment [not to be in a sexual relationship]. I am happy the way things are." FG 4.

"There are times when I really feel so low but that is as a result of a lot of other reasons, one is not being able to having sex actually. Not having a relationship sometimes, ... it can be very lonely... As I said HIV is just part of the jigsaw... There are times when you just sit and think 'I can't be bothered, that guy is asking me out and I can't be bothered to go and disclose' so it goes on like that." FG 1.

"Because of my HIV status, I have decided not to have sex ... eventually, there will be a desire to have contact ... on a personal level with someone... It's an awful thing because it cuts through right to the very soul ... the very core of your existence, the very fundamental act that human beings do without even thinking, we get rejected for." FG 6.

"[Abstinence was] where I was for the first six months or so but in the end libido took over for me." FG 8.

"It's easier [to not have sex], it's less complicated. I don't have to think about anybody else apart from myself." FG 12.

2C.3 Fear that someone would not want to be sexually intimate with you

2A.10 Sexual rejection

Concern about sexual rejection as a result of disclosing their status to a partner was highlighted by a number of participants; others explained that they had experienced this rejection. Some took this personally, where others considered it rational for their partner to implement strategies to avoid HIV infection. HIV was considered to impact on confidence during intimacy. Some participants discussed their preference to find a sexual partner who was HIV positive to minimise the challenges of disclosing. Others said they were unsure if they would want an HIV positive partner because it may force them to observe and address health outcomes associated with HIV that they were not ready to cope with. Another challenge identified as a result of limiting sexual partners to others living with HIV is that sometimes the relationship was secondary and sex became the focus. One man explained that not having a sexual relationship was detrimental to his confidence and that he was tempted to use a sex worker to address this need as then a condom would be used automatically and he would not be obliged to disclose.

"I had to accept that somebody not wanting to have sex with me is one of their HIV prevention strategies." FG 8.

"I feel if you [disclose], especially to women, they seem to want to run a mile ... I said, 'do you want to look it up on the internet and come back to me and let me know what you think?' She did, but she still didn't want to have sex." FG 8.

"It became clear that he felt that if he kissed me he was going to get it." FG 6.

"My ex-partner ... died, so I am scared since then about a new relationship." FG 6.

"Being a gay man and meeting another gay man who is available is difficult enough and then to add on HIV positive, Jesus, it's quite a narrow sort of gauge for people to meet... I don't know if I'd want to meet somebody with HIV. Possibly because of the other health needs ... they [may] have been diagnosed for a lot longer, maybe it's impacting on their health and seeing that, maybe that's a reminder of that possibly that's something for me further along." FG 4.

"I thought to myself to somebody like me [who is HIV positive], because ... I see girls that I like and ... I wonder if I asked them out and maybe it started getting serious, how do you turn around and ... tell them and you don't know what the results are going to be and they might say... So it's easier, truthfully, it's easier not to bother... I had even actually considered ... escorts ... I have considered phoning up... Obviously I wouldn't go in there and say, 'by the way I am HIV' because I would assume that you would go there and they would insist you would wear a condom... I thought maybe if I go there, professional, I might ... discover I can still have sex; it might ... give me wee bit more confidence." FG 4.

"The fear around sexual rejection, I can absolutely understand that but as I became more confident around my HIV status, I was then much more able to talk about it... I think that for many people having an HIV diagnosis is a real shock ... as big as a bereavement and it just takes time for us to get everything back to normal." FG 8.

"Not that I am having sex on a regular basis, but I would like to have sex... Obviously I have limited myself to ... looking for partners who are HIV positive and I find myself going to websites to look for partners who are in the same situation ... so that I don't have to think about ... explaining my status to anybody... But ... I find the men so sexual starved that even they remove the relationship part of it. And ... they just want to pounce on you, without even getting to know you." FG 12.

3B.1 Disclosure to your husband / wife / partner

One participant explained that disclosure to her partner had been important for her and allowed her to live without guilt. The reasons that some people do not disclose their status to partners were discussed. It was suggested that the principal rationale for this was fear of the reaction. Some participants were shocked that people did not tell their long-term partners about their status. Participants also debated the responsibility of sexual partners to keep themselves safe from sexually transmitted infections (see criminalisation section for additional discussion). One woman explained that she would be reluctant to disclose her status to a new partner, as her past experiences had been so difficult. Some participants had not been informed of their partner's positive status until they themselves disclosed their status.

"I was very, very happy because I disclosed to him [partner], no secret between me and him until his death...[if I hadn't told] I would be feeling guilty that he didn't know his status before he died." FG 6.

"Husbands and partners ... don't know about their HIV status. I think that's shocking. I think it goes back to the whole stigma thing, people are afraid. It's the fear of telling someone because they don't know what to expect." FG 1.

"I can't see a reason why someone should be living with someone without being free and open to the person." FG 6.

"If you don't tell your husband how do you have sex?" FG 6.

"Even when I meet men, like nights out and you're sat and talking to them and they ask 'Where do you work?' [tell them support worker for Hepatitis and HIV]. 'Oh seriously, God, why would you want to work in a place like that'. Turn around in a couple of months and say to that man, 'Do you know what I don't just work with them, I have actually got the virus as well' and you see the reaction as soon as you tell them. And it 's not just one, its every single guy that I meet." FG 2.

"In my case the guy who infected me told me he was okay. It was only ... after I tested positive that he turned around and said, "oh actually, I am positive"." FG 10.

3B.5 Reactions from your husband / wife / partner to disclosure

The focus of discussions relating to disclosure to partners was on negative experiences. In the stigma index 48% of participants reported neutral or positive experiences when disclosing to a husband / wife / partner but this proportion was not reflected in the qualitative discussions. One individual indicated that having an HIV positive partner was useful for support. One woman described how her neighbours had been informed of her status by her partner and also that her home and car had been vandalized with graffiti. Other participants reported that

their partners had laid the blame for infection on them, despite being unsure if this assumption was accurate, or they had failed to disclose their status to them. One individual explained that when it was established that her partner was not HIV positive, the relationship broke down. One participant explained that people sometimes remained together to minimise difficulties in other areas of their lives. One female explained that she was furious with her partner because he did not disclose initially and as a result she became infected with HIV.

"I have ... a partner [who] is HIV positive, so we do talk about it at times." FG 12.

"The last two partners I told [about HIV status] and I had to leave my house, twice I had to leave my house because they kept ... spraying my car, and my door and telling my neighbours to do stuff to me and I thought why should I have to put myself through that again. They're [people pressuring people to disclose their HIV status] gonna put us underground again." FG 2

"Especially [with] black African men ... I will ... say, 'if I was HIV how are you going to take care of me?' They say 'I'll run away, I'll kill you'." FG 9.

"I am pregnant and I didn't know my status and ... when you are pregnant, they take your blood ... then [you] find out that you are positive. You ... approach your partner [and] ... say I'm HIV positive ... but men, they tend to put ... back the blame... He'll ask you, 'where did you get it from?', yet he has not yet been tested." FG 9.

"When I was diagnosed I told my partner. He went [to be tested] ... he was negative ... and it's just destroyed the relationship." FG 6.

"I know that if I tell my partner that I am HIV positive that is the end of the relationship. So to me I'd rather live [with the knowledge] on my own." FG 6.

"I did disclose to my partner ... and found out in time afterwards that he hadn't disclosed to me." FG 8.

"People stay together for many reasons. It could be economic factors... It could be a relatively new migrant so there could be legal problems and children... Some people who stay together even have separate bedrooms." FG 6.

"Me and my ex ... were together for 8 months. And all the while he told me he had cancer... And on a night out he just came out with it and said, 'oh, I am HIV positive'... I was ... so angry that he didn't disclose his status to me at the beginning... I would have loved him ... no matter what. He should have just told me. He should have given me a choice ... but he didn't. He was just too afraid of being rejected... Now there's like one more extra person living with HIV." FG 10.

2A.12 Discrimination directed at your partner / person living in your home

One gay man explained that his long-term partner (HIV negative) is obliged to attend the clinic and undergo a battery of sexually transmitted infection tests every six months. Despite being in a stable, monogamous relationship, a single HIV test is not facilitated.

"I am in a stable relationship for the past 8 years and my partner's negative. We found out [about the HIV status] half way through the relationship which is quite hard. [He] get [s] hassled off the health professionals to get an HIV test at least twice a year even though I am undetectable and using a condom. It's putting a strain on our relationship because it's going back to day one again constantly. ... My partner went to Sandyford to get an HIV test and they were adamant that he also got STI's tested. ... this is about the 4th or 5th time he's been so they knew the situation and he actually came to me crying, ... they made him feel like a tramp ... they made him get him STI test as well even though he says 'I've not done anything, I have to get an HIV test purely because ... my partner has got HIV. ... They made him get it [all the STI tests] which I think is wrong." FG 2.

PERSONAL RELATIONSHIPS: OTHER ADULT FAMILY MEMBERS

3B.1 Disclosure to other adult family members

Some people described using their family as a means of support when diagnosed. Others said that they waited until they had come to terms with their diagnoses before confiding in their family. Some had been selective about who they shared the information with within their family. Others opted not to inform their family of their diagnosis, either in a bid to protect them from the knowledge or because they were concerned about the reaction they would receive.

"I told my family. The first thing I did I just told my sisters." FG 4.

"The person I would never, ever tell in my life is my mum... She will die. You know back home, they are highly ignorant of HIV. They don't even believe that there is a way you can manage your life and live longer. Once they hear that someone is HIV positive, the ... thing that comes into their head is death... I wouldn't want her to know about it. She might die thinking about it". FG 6.

"I only told my mum but [she] was ... thinking I'm dying because ... I lost three sisters [and] was the only child ... she has got now. She was crying. But I told her ... I was getting better because I was ... very, very sick [before]... If my mum was in Africa, and I was here, I couldn't say anything because she would think ... I will ... die. Because she is here and she is seeing I'm getting better ... I ... told." FG 11.

"My immediate family, mum and dad, brother and sisters, they all know. But we decided as a family unit that it would be right and appropriate for my mum and dad to choose who else within the family [to tell]... Because I am physically very distant from my family they all live in Scotland [and] I've lived over in England for the last 20 years. So ... it really doesn't make that much difference to me for extended family to know. It was, however, very important that my immediate family did know. And I don't know who they have told and haven't told. But again that's my health, it's never been an issue so far and it's not been necessary for anybody to know." FG 12.

"My family doesn't know ... because I just can't get to say it." FG 12.

"Not all of my adult family members know, because we are not close and there is no point telling them" FG 12.

"None of my friends or family know." FG 12.

"I've never disclosed my status to other family members... When my husband passed away ... my dad came to me and said, 'I dreamt about you, you were stick thin and I didn't imagine my daughter dying from HIV.' ... And my uncle then suffered HIV and he was divorced and the house was sold and they took care of him until you know... I could imagine my dad used to put a cup there for him, 'please don't touch any cups, only use this cup'... I confronted my dad, I said, 'no, this is not right what you're doing, what if tomorrow it's me?' He said, 'not in my house. You will not die in my house with HIV'. So how do I ... tell my dad... Until and unless he practices and knows love for HIV people he ... won't know... But I don't want to die before he ... knows. I have to tell him." FG 9.

"My brother passed away in 2007 in America... Once he knew he was HIV positive, he just refused to take medication... So my mum went through a stage of actually pulling him back to health, and he would pull himself down ... it was a tough time. And I think because we are far away from each other, [if I told them my status] they [would] need to see me and to see that I am doing well... The time will come when I will go home ... then I will tell them. I will say, '...look at me! I am still doing alright'." FG 12.

3B.1 Reaction of other adult family members to disclosure

There was discussion about the family reactions data with some people highlighting that their parents were dead and this may bias responses. In addition, the reactions from different generations within the family were not consistent. A number of participants highlighted the importance of being able to approach those close to them for support. The need for family members to be able to access support was also considered important.

"It could be that different generations could have different attitudes to it as well." FG 3.

"I told friends, all my friends and my parents, many years down the line. Partner, ... I told him three or four weeks after and that was a good experience." FG 4.

"If I am upset, the only way I can get relief is telling someone that is very close to me." FG 6.

"When it came to [disclosing] my HIV status [to my parents], I ... thought well, they need support ... I need to encourage them to go to [the local support agency] and get some support. They wouldn't do it however, but eventually started to talk to close friends." FG 8.

3B.1 Disclosure to other adult family members without consent

One individual described the challenges they faced after members of their family shared their disclosure without consent with a wider group of people.

"My family members told about 20-25 people, the majority of whom I didn't know, without my consent about 2 or 3 years after I had been diagnosed and that was really difficult for me at that time because I thought only seven people knew... [I felt] really angry, really furious. I felt like dying back then." FG 8.

PERSONAL RELATIONSHIPS: CHILDREN

3B.1 Disclosure to children

There was considerable discussion relating to disclosure to children within the family. Many participants had opted not to disclose their status to their children, some saying they didn't trust the information not to be circulated; some expressed a desire to protect their child; others explaining that they believed it would be too traumatic; and others saying they were too young. Age and maturity were considered important when deciding about disclosing to children.

"I suppose it depends on the age of the children [whether or not to tell them]." FG 8.

"Women have a great deal more to lose and especially if there's children and certain ethnicities, certain religions involved." FG 8.

"I never show my face on photographs ... in different groups, I never allow my real name to be used because that would kill my son [if status disclosed]." FG 6.

"My children, they don't know anything. And my friends. I don't tell anybody. I just ... keep it to myself because if I tell anybody ... they might tell somebody, so I just learn to ... not to trust anybody. Unless somebody meets me here, ... then they know that I am positive." FG 11.

"My daughter is very young, she doesn't know, she even sees me taking my pills and she say, 'mum your medicine' but she obviously she doesn't know." FG 12.

"I have got a daughter and a son... I haven't told them about it, but my daughter just gives me tablets, but I haven't said anything to her. She is nineteen." FG 12.

"My children: one knows [and] one doesn't." FG 12.

3B.5 Reaction of children to disclosure

One parent who had disclosed to their child reported their child's reaction was concern that their parent was going to die.

"I have ... a son [15] and a daughter [17] and I told ... them straight away and first thing my daughter said to me is, 'are you going to die Dad?' And I [said], '... no there's medication out there'. I educate them ... but it should be more in schools... Somebody like us going around to schools to talk about HIV." FG 11.

3B.1 Disclosure to children without consent

One individual's son had been informed without her consent by a friend's child.

"My child was told without my consent... My friend in Leeds, [her] children knew her status so ... they were talking to my son saying 'you know what your mum and my mum are like' ... so that's when my son got [to] know. But ... I wanted him to be ready, not that I don't want to disclose... I said, 'you know this disease is not the one I'm suffering from... [It's] heart failure, so if you worry me, I'll die so what you must do just take care of me until the right time comes...' That's how he stopped asking me about it. He said, 'they were lying, they were telling me my mum is HIV and you know my mummy will die so I didn't want you to die'. So ... now he doesn't ask me, because I've explained it..." FG 9.

PERSONAL RELATIONSHIPS: FRIENDS AND NEIGHBOURS

3B.1 Disclosure to friends and neighbours

Discussion occurred about decisions relating to the information shared with friends about HIV status. Some participants described the compartmentalisation of friends into those who have been disclosed to and those who have not been. One participant explained that she is selective about the friends with whom she maintains close relationships. Another explained that over time she had become less and less open about her status. The reason offered was that disclosure had made her vulnerable. Some of the difficulties with the compartmentalisation of status disclosure were outlined. One participant described socialising with friends who were HIV positive and negative. Not all of the individuals who were HIV positive had disclosed their status. This made explaining associations challenging in order to avoid disclosure without consent. Others explained that being overt about their status made their life less complicated. This allowed 'friends' to make decisions about the contact they maintained with the individual, therefore making it clear to the participants who the friends they should value and trust were. A number of participants highlighted the importance of their friends in supporting them with their HIV. One participant explained it was unlikely that she would disclose to her neighbours, explaining that it would be inappropriate given the limited relationships she had with the people living in the surrounding accommodation. Others explained that they would be concerned about their neighbours' reactions if their status was disclosed. Another individual reported that an elderly neighbour had been one of her greatest supports. Some participants reported difficulties when friends disclosed their status to other people. Generally participants indicated that the decision to disclose should always lie with them.

"I tend to find myself from the time I was diagnosed until now being less open, a lot less open. I don't talk to anyone about all these things anymore. Because ... it made me really vulnerable." FG 1.

"I was at a party last Saturday and there was about ten of us, five of us we knew each other because we were HIV positive. And we kept being asked how we knew each other... But you can't say 'oh we know each other because we go to the HIV positive women [group]'. I could have said it but obviously I couldn't disclose other women. So, I mean that's how difficult it is, it's an obvious question for people to ask. I kept on diverting the conversation." FG 1.

"The reason why I disclosed to some friends is because, at the time I was very sick and the friends were nurses so they knew what the problem was." FG 9.

"I find it easier to disclose because half the time I forget who I have told and I don't want to have these two lives you know where I have these people who do know and those who don't know... And if people choose to fall away, they fall away and if people choose to stay that's when you can see who your true friends are and who your true family are. And my partner knows my status - it was very hard to disclose to him. He said 'were you afraid to tell me?' I said 'yes' and he said 'why was that?' For the simple reason 'the stigma in you, I think it was going through it in your own head, you'll think what? Will you think less of me? Will you love me less because of this? Have I put you risk?'. He went and got tested and he is negative... I said to him that if you want to disclose to your friends you can because you need support." FG 1.

"I am very open about my HIV status. My family know, my employers know, my neighbours know, my doctor knows, my dentist knows... They have needed to know, but I have also felt confident to be able to tell them because I expected the response I had from them. And I think that's because I live in Cardiff because of the work I do and because most of my friends work in the same type of field so therefore are ... more knowledgeable than your average [person]." FG 7.

"I was forced to explain myself to somebody because they heard it from somebody else ... so I felt that I had to explain to that person when I wasn't ready for it... So she understood, because we are close friends... It's the other person [who told] her that I am not friends with ... because it wasn't her place for her to [tell]." FG 12.

"How can you tell your neighbour you know? 'Oh Good morning, I'm the lady in Flat 2, I am HIV positive. Have a nice day.' You can't." FG 4.

"I don't like telling my neighbours about my status." FG 12.

"I wouldn't want my neighbours to find out because ... I wouldn't know what sort of retaliation they would take." FG 12.

"I self disclosed in every area except neighbours, for the simple reason, [I live in] a predominately white area of the city. And it would be a problem... Threats of violence, intimidation... I am perfectly open about my sexuality and I am very, very aware of them watching me very closely, and that's in no way, shape or form paranoia on my part. I am very aware of that white working class community, watching me coming, going, who comes and goes, when they come and go. They make no bones about it and to be perfectly honest my HIV status is not necessary for them to know. It's none of their business. That's the culture that I have to live in, I don't choose to live, I have to live there." FG 12.

"I sometimes feel guilty that I am not more open about my status and I would like to be a lot more open... Sometimes I think am I pre-judging people where I live but I am not prepared to take the risk, because once that information is out there you can't take it back..." FG 7.

"A neighbour in their 70's ... she knew something had happened so over the weeks I was telling her these elaborate lies and in the end I just told and she has been one of the most supportive people." FG 6.

3B.1 Disclosure without consent by friends and neighbours

A number of situations were outlined where a friend without their consent had disclosed a participant's status. This was considered unacceptable as it had an impact on the individual's life which they were not in a position to control. One participant did indicate that he accepted that friends should be able to discuss with their partners if he had disclosed.

"All my friends I ever told, I just made the assumption, ... [they] will tell their partner... All of them told bar one of my friends, whose husband is like proper conservative and I have a bad relationship with him. So he was just the only one that wasn't told but I just made that presumption they were going to tell them." FG 4.

"[A] close friend ... went and told other people, which has affected my life considerably to the point where I no longer go to the place I used to go to because I think the people would know and it's one of the reasons I want to leave the town I live in... But it's very difficult ... because of housing problems. It's impossible to get housing because ... you have to have points and ... I would get vulnerability points but I'll lose it all because I've already got good housing." FG 6.

"My friend actually met somebody on the internet and I was on the same website and then I met them together. But then ... my friend realised that ... she didn't want him and then she [disclosed to him] she is ... HIV positive. So this man sent me an e-mail, [saying] 'it's okay I know your status and it doesn't bother me'. And I said, ... 'how do you know my status? What status are you talking about?', because it wasn't a HIV website... So I forwarded that e-mail to my friend and she said, 'I'm sorry actually I told him that you are also HIV positive'." FG 9.

"I told a friend who told others without my consent ... I feel strongly if I am going to disclose my status I am the one, it's my choice, but ... you have to be forgiving when people tell. Maybe the burden of that knowledge is too much for them to bear on their own and they need to tell someone else." FG 6.

3B.5 Reactions of friends and neighbours to disclosure

Participants did not elaborate greatly on the reactions of friends and neighbours to their disclosure. Some indicated that it was important to decide carefully who to disclose to; others indicated that friend could offer support that was appreciated; and others indicated that their friends were unsure how to address the topic following disclosure. One individual explained that a close friend's husband had suggested that they cease contact following disclosure.

"It's good to disclose if you trust the person you are disclosing to ... because you get some advice from the person and commitment that will keep you going." FG 6.

"You have to choose your friends. Actually, I can count on my one hand ... how many people I can rely on. And that's really sad. I have got hundreds of people I can talk and have a laugh with but there are only so many that I can actually go back speak with. I do feel like an alien living here. I do feel like I am from another planet I am an imposter." FG 1.

"I have ... a close friend [who] comes to the hospital with me when she is not working." FG 12.

"I haven't had many negative reactions when I told people, but there was one... It was my best friend at university... It's her husband ... he said 'oh, maybe it's best if you don't come and visit us'." FG 7.

"I've got a couple of friends that know and I know they won't say anything to anybody else... They do ask me questions about why I am so thin, this always crops up and I just say, 'I've always been thin, it's just the way I am'." FG 11.

WIDER COMMUNITY: OTHER PEOPLE LIVING WITH HIV (PLHIV)

2A.11 Discrimination by other PLHIV

One participant explained that they were open about their status and, as a result, some people from their support group were reluctant to be seen publicly with them because it increased the likelihood of them being linked with an HIV diagnosis.

“Sometimes ... if we are coming from a support group and we are [at the bus stop], some women would go and get a bus from another stop, because if I am standing with them, some people might suspect them of having HIV, because I am open about my status. So as much as we talk about positive speaking it has its repercussions also, because I don’t want people to run away from me.” FG 11.

3B.1 Disclosure to other PLHIV

Participants explained that attending HIV clinics had allowed them to meet and disclose to other people living with HIV. Some felt they could trust people in a similar situation and gain support from them. One participant explained that she had opted not to disclose to people outside her family, but when a friend disclosed her status she reciprocated. She felt this had helped her and strengthened their friendship. Another member of the group indicated that he felt this was a positive situation as he felt isolated because no-one he knew from his everyday life was HIV positive. He did say he recognised people at the HIV clinic but that nobody was comfortable with engaging in that environment.

“[I have told] friends, the ones that are also HIV positive... The others I separate it, I just ... feel, if it doesn't concern you I am not going to tell you about it.” FG 12.

“I personally don’t want to tell anyone apart from people that are living with HIV. I am very happy to tell people I feel I trust are living with HIV. I think it’s okay to tell them.” FG 6.

“I have people who ... know my status because we have met in the clinic... We call ourselves members, it’s a members club.” FG 12.

“[Other PLHIV] know because we are meeting in the same place.” FG 12.

“I’ve got only one friend who knows about my HIV status because she told me about hers. She ... said, ‘there’s something I need to tell you. If anything happens to me I am HIV positive... I should tell you where all my deeds are and everything.’ ... I said ‘why are you telling me all this?’ ... She has got one daughter who is 18, her daughter always says if she ever finds out that she is HIV positive she will kill herself... I said ‘you know what, you are not alone because I am too.’ So it’s gone better because of that... If she hadn’t told me, I wouldn’t have told her... My children know just in case anything happens to me.” FG 4.

“[You are lucky] to have a friend that is HIV because I never really known nobody. A few faces, I recognise in the clinic, a few faces I grew up with, you know. And they’re afraid to look at you.” FG 4.

Reactions from other PLHIV to disclosure

Some participants considered others living with HIV to offer the most support. Another participant indicated that they found it suspicious when someone attempted to deny their HIV status.

“[Talking to other PLHIV is] where I probably get most of my support and ... it’s what I encourage other people to do.” FG 8.

“As ... positive people ... when you know that somebody actually is positive and is trying to cover it, there’s no trust with that person.” FG 9.

WIDER COMMUNITY: RELIGIOUS ENVIRONMENTS

3B.1 Disclosure in religious environments

Some participants indicated that they would be reluctant to disclose overtly within their religious community. Although they felt it unlikely that they would receive a negative reaction they continued to be concerned. One individual did indicate that they had disclosed within their religious community and were comfortable with the reaction they received.

"I think we are all still a little bit frightened of disclosing into larger groups, say the church for instance. I have recently started going back to church and the priest from the church, he knows but he's not said anything to anybody, not even his wife." FG 11.

"I think they wouldn't exclude me [from religious gatherings] if they knew. I am not taking the risk... Like anywhere else, some people would be alright with it but a lot of people wouldn't." FG 11.

"My church ... knows that I am HIV positive and it's not an issue and they don't talk about it. And when I meet them I am not worried that they are going to talk about my status." FG 11.

3B.5 Reactions within religious environments to disclosure

Participants perceived that people with religious beliefs made judgments about them in relation to their sexuality and HIV status. One man explained that he understood that protestant people believed that HIV was God's punishment for him being gay. Another described his conversation with a member of his church congregation who indicated that he could only be sympathetic to people who contracted HIV vertically from their mother.

"One of the things I have found out, ... Christian orientated people ... if you told them that you had this illness they just treat you like a plague. The first thing the Christian ones would want to put you down like a dog because most of them are so anti-gay." FG 4.

"I have found out that protestant people ... don't have a lot of tolerance for people that are [HIV positive or gay] they seem to look down their noses on you as if you are a bad person and if you seem to be gay they look down and that's [HIV is] God's punishment." FG 4.

"Recently when we did walk for life, it came on a Sunday where we normally go to church and we made known that there was some event ... and we would not be at church... Different members of the congregation asked what was. 'It was the walk for life, we were raising funds for people living with HIV.' Well for some of them it ended at that but for one particular individual ... [said] 'I can understand some of the people get it because it is passed from mother to child... I think for those I could have a sympathetic view towards but to those who just get it out of their own, you know.' ... you could sense that there is still ignorance and stigma within even the community that would normally accept you at your face value." FG 5.

2a.1 Exclusion from Religious activities

One man described how he consciously excludes himself from religious rituals because of memories of a humiliating experience in the past. The man was a catholic who attended confession to discuss his HIV diagnosis with the priest. In response the priest pulled back the privacy curtain and argued with him. The next time the man attended mass, the priest publicly withheld communion. A participant whose friend had been excluded by the faith leader within the last year after disclosing her status outlined a similar story. Someone suggested that other lifestyle choices may also cause them to be excluded because they were considered sinners.

"I know for a fact that my faith [Catholic] would just disown me, not just from my HIV. A few years ago the homosexuality itself was enough. I went to confession; I thought I've been diagnosed [HIV positive] maybe its time to speak to the Big One [God]. I went in spoke to the priest and he pulled the curtain back and everything on me. Gave me verbal. 'Why are you living your life like this? It's against the Bible. ... Where is your conscience?' The Sunday I goes to mass, ... [the priest] gives my dad communion, looks at me and just went like that [shake's head] ... and gives it [to the person next to me]. ... He wouldn't give me communion. That was years

ago I still go to mass today but I do not go down to get communion anymore. Why did he have to do that? Right past me. He shook his head so that everyone could see.” FG 2.

“In days gone by [you] were told that if you were HIV positive you weren’t welcome in the church any longer. I have met several people who have reported that as an absolute fact. ... Well because they’d obviously sinned. ... Within the last year someone I know in Edinburgh who told her very supportive clergyman that she thought of as her friend, she told him in confidence and after that he stopped her taking the communion ... because the communal chalice or whatever ... he was worried about it. ... And he also suggested that she shouldn’t touch something else. ... I am not religious so I don’t get all the technical bits of it. ... In a community where she felt she had been accepted and she felt absolutely dreadful that something that mattered to her spiritually became an issue for her because of her HIV. ... It’s a huge issue for people that have a religious faith – the conflict that HIV must create.” FG 3.

“They could also be excluded [from religious activities] for other reasons as well not just the HIV of course, ... it could that kind of sinning aspect again.” FG 3.

3B.1 Disclosure without consent in religious communities

It was reported that religious leaders were recommending communal prayer for individuals that had disclosed to them their HIV status. This meant that others in the congregation were being informed of the individual’s status without their permission.

“But without her consent, because she has consented for a prayer, but they will say it [and] she didn’t want it to be said out [loud].” FG 9.

People with religious beliefs withholding information about safe sex from their children

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

“I think certain religions don’t educate them young enough in their heart of hearts and their minds they [their children] don’t have relationships until they’ve got rings on their fingers and signed on a dotted line.” FG 2.

Termination of treatment recommended by religious leaders

Religious leaders demonstrated ill-informed beliefs. Participants reported that their pastor had advised them that praying would eliminate HIV, clearing them of the infection. These recommendations risk individuals’ health because they are encouraged to halt their medication regime.

“I was actually told by a pastor ... ‘This HIV that you said you have, it’s a demon. Come we’ll pray for you and it will go away.’ I said ‘okay’ ... I was born from a Christian family, my father was a priest so I said ‘the day I was born, my head hit the bible so I know a lot about this bible better than you because you just got to be a pastor recently so I think my God is protecting me.’ I am healthy, it’s just a virus that is in me but for her it’s a demon.” FG 5.

“Why is it that the pastors tend to tell people to stop taking medication? ... I mean people end up dying.” FG 5.

“I think the issue [is] that they regard it as a demon which can be exorcised and once it has been exorcised you are free of HIV which is a fallacy. It shows lack of understanding of how the HIV virus operates so they will need a lot of education so that they will not detract people from taking medication on the belief that the demon has been exorcised and they are now clear.” FG 5.

“I have raised a few concerns about a few people that I have met with that have stopped taking their medication because of the pastors from the churches but what should we do, some of these churches don’t want to listen to any information on treatment.” FG 5.

"We have [an African] church... Men come here, they are positive and then they marry these girls who are ... looking for papers and then they infect them... So we are insisting that they bring a certificate to prove that they are negative... [But the] doctor wouldn't give anybody a certificate ... after testing ... when you can actually be infected tomorrow anyway." FG 9.

"I go to [an] African church... If I disclose it to [the] Pastor, [he] will tell some people... He'll [say] to the elder, 'let's pray for [her] ... she's HIV we want that HIV to go'." FG 9.

"Pastor Chris ... said, 'they must not take medication'. I said, 'that's not true, I'm continuing with my medication and I'm praying'. Prayer is just to relax your mind keep your life going." FG 9.

"It started in South Africa. [My friend] confronted me when my mother was in hospital. She said, "do you know that I'm positive? ... I've stopped medication, Pastor Chris said I must stop medication, I'm healed." ... So what I'm saying is mostly don't listen to these churches, your medication is your life... I stopped for 2 weeks when she told me, but I was having all these rashes and I went to a doctor he said when did you last take your medication your CD4 count has gone down ... so I was confused... As soon as I started my [medication again], my CD4 count went up." FG 9.

"There's a lot going on in African community churches ... and when you talk about these African churches, nobody wants to, it's like they jump... I don't know if it's because they don't want to confront them... One time ... somebody in Manchester said the Pastor mentioned we have to pray for [someone] to chase away this curse of HIV." FG 9.

EMPLOYMENT

Pre-Employment Experiences

2.C.2 I decided not to apply for a job / work or for a promotion

Accessing employment when diagnosed with HIV was considered challenging. Overcoming the pre-employment health check, then the screening process and then the difficulties related to attending medical appointments were some of the difficulties. Participants from African communities suggested that they still considered racism an issue over and above their HIV status. Immigration laws also prohibited some people from working, despite their desire to gain employment. It was hypothesised that these barriers may make it unlikely for individuals who received a diagnosis a long time ago to attempt to gain employment.

"From an African background there are also other types of barriers in terms of immigration status for example, that's quite a big barrier if you are not allowed to work to start with." FG 5.

"I cannot work because I am not allowed to, but I have tried to get through my MP to engage with the UK Border Agency and I have had in writing responses that I am in entitled to work and should make an application to my case worker and now it's six months down the line, I have not had nor the courtesy of a response... [I have been living in the UK for] 10 years now... It is a long time. It is very frustrating." FG 5.

"Those are barriers in themselves. You spend all your time trying to get on to the right footing of actually being allowed to look after yourself [by working] and even that, you are not given the opportunity." FG 5.

"Barriers crop up when people attempt to go back to work, in the application, the screening process which we have discussed and mentioned before and once one is at work and they ask for time off work to get medical attention and things like, people will start questioning, they want to find out why and once they know that's the reason, they will either be forced out of that job by you know, subtle ways that will make people feel unwanted. Yes. And that will deter a person like that and it will knock you self confidence and you will not relive that experience again because it is so humiliating." FG 5.

"Sometimes it's the uncertainty of if I go back to work, suppose I fall ill again, what will happen to me... They were on benefits and then they go back to work and then when they fall ill they have got to start that process again which is such a rigmarole. So they would rather not even start." FG 5.

2B.2 Refused employment or a work opportunity

Employment was an issue that participants were passionate about. Many highlighted the merits of working; one was excited to be returning to work on the following Monday after two years out of employment. Participants hypothesised that many of the people who were not working would be keen to work but have been excluded as a result of systems that are in place. Others explained that maintaining full-time employment was challenging on occasion due to poor health and that this could result in difficulties in reducing contract hours without disclosing. One person explained that they felt too old to work now and did not intend to pursue future employment. Medication was cited as a reason that PLHIV did not work. The side effects of medication that prevented people from working in the past had been addressed, but other side effects were identified which still caused difficulties. One participant explained that she had faced difficulties because she had not disclosed her HIV status to her employer and therefore travel restrictions necessary as a result of her status were not considered when her projects were allocated.

"'Good employment is good for people', we all know that and yet here we are giving people medication that helps them put their lives back on track ... and yet people then go on to the scrap heap." FG 3.

"Of those 62% who are not working I would be interested to know how many of those people want to work and are capable of working full time and equally of people who are on meds who are doing very well who are trying to get back into work?" FG 3.

"Even the 17% of part time, is it part time out of choice or not? And I think that the way HIV is going, really a lot of people are going to be hoping to be working." FG 3.

“He had to do a physical job and couldn’t continue doing late nights ... and 10 hour days and he wanted to do less hours and they wanted to know why. And he was off work for nearly a year with the stress of having to tell them.” FG 10.

“I am just too old to work. Nobody would employ me anyway. But I don’t want to, I’ve done my share.” FG 11.

“I have been out of work for two years since being on medication ... but I start work on Monday.” FG 11.

“I am probably one of them [people who are unemployed] because of medication. ... Where could you work when you’re constantly running to the toilet for three months with diarrhea or you’re constantly sick or sometimes your hair used to fall out. ... It’s not that we didn’t want to work, you just couldn’t because sometimes you couldn’t get out of bed it was that bad with the medication. It’s come on a bit but there’s still the side effects, there’s still the lipodystrophy. I still suffer from that. I had that way back 7 or 8 years ago and my muscles are not the same, my knee joints keep coming out every so often if its too cold or if its too hot. And they say the medication that people are on now isn’t as bad or severe but it still causes it. I mean I still get the stomach swelling up.” FG 2.

“Or they might send you to countries that you wouldn’t be allowed to go to. That’s one of the things that I had to consider... when I did VSO. I had to be extremely careful because even a lot of countries where you can go, you can visit but you won’t get a work permit if you’ve got HIV. So the countries that required and HIV test, I couldn’t say I wanted to go. So I ended up in Cambodia. ... I mean that was 10 years ago and it was at that stage VSO did not have a very good policy and if VSO had known my HIV status they would have refused to allow me to become a volunteer and I would have missed out on the best job that I ever had. But I had to keep it a secret.” FG 3

Employment Experiences

2B.2 Job description or nature of work changed

Once in employment, participants were concerned about its stability should they disclose their status or become ill. One individual who worked in the field of HIV explained that this was a recent development for a person diagnosed with HIV to be an employee within such an organisation.

“There is discrimination over their status or some of the people belong to the African communities, I think there is discrimination in the work force as a result of colour... I think in terms of health, maintaining their health or [they] might have mental health issues around their HIV, it makes them harder to apply, in terms of lacking in experience, it’s a very, very competitive job market out there... You almost don’t want to try because you feel like there is no opportunity.” FG 5.

“I was the first person that ever worked in [my local] AIDS Support services that was HIV positive and I’ve been there less than a year and it’s 21 years old... How can they help people with HIV if they don’t know what it’s like living with HIV?” FG 10.

3B.1 Disclosure to co-workers and employers

One participant had disclosed to human resources because they intended to leave their employment, despite being anxious about disclosing, they found the reaction to be supportive. There was limited discussion about the process of disclosing to work colleagues. One person had requested that their boss disclose on their behalf and found this to be a positive experience. Another individual found that a number of colleagues were also positive and found this a useful support. Participants considered it inappropriate to be obliged to disclose their HIV status or medication regime during the application and interview phase of employment. Participants wanted to feel assured their employment resulted from their skills base rather than the decision being related to their health status. Some participants confessed that they had made the decision to lie about their HIV status prior to employment to ensure it did not influence the employer’s decisions. One participant had witnessed members of a Human Resources department discussing the appropriateness of promoting an individual with diabetes due the impact their health could have on their performance. He felt that if this was the treatment of an individual with diabetes there was little hope for PLHIV if they disclosed their status in similar circumstances.

One participant explained that he believed people distinguished HIV from other chronic disorders and empathised differently. The principal difference he identified is that people believe that HIV is something you bring upon yourself as a result of your lifestyle. Participants reported finding it a challenge to avoid disclosing to work colleagues and employers. When attending frequent medical appointments, they felt it necessary to deceive other employees to avoid needing to disclose. Several participants explained that they did not want to be judged for the quality of their performance at work or for co-workers to believe they were taking periods of time away from work because of their HIV. Similarly, there was an assumption that some people would not be able to see the person anymore and would focus primarily on the HIV status. One individual suggested that their type of job helped them to decide to disclose: they suggested that if it was within the field of healthcare then people should disclose. Others felt that, provided their health professionals were aware of their status, it was unnecessary for anyone else to be informed.

"It took a lot of courage to actually tell occupational health, but that's obviously because you have to tell the truth as to why you want to finish. But I never had any problems from it. But I didn't tell the people that I worked with what was the matter." FG 11.

"I don't have to [disclose to colleagues] when my boss can do that and so ... I handed over disclosure to somebody else and it was fantastic actually." FG 8.

"Two or three [people I have worked with] ... are also HIV positive so we ... discuss ... it." FG 12

"I don't want to be employed as an HIV positive person, I want to be employed because of my skills and abilities." FG 3.

"I have had to fill in a form to say that I have a medical condition. ... A pre-employment health questionnaire. ... I didn't include [HIV], but when I had to go for the occupational health examination that's what I had to disclose." FG 3.

"Very often on [employment] forms they will not ask directly about HIV but they will ask questions that can enable them to come to a conclusion... Whether you have a chronic medical condition or whether you are on regular medication or something that might stop you performing certain duties, things like that." FG 5.

"[Employment forms asking] about some other inoculations, knowing very well that people living with HIV are not supposed to get some of the inoculations. You will have to say why you are not having these inoculations." FG 5.

"In my line of work recently we've had what we call workshops around getting people back into education and employment... One of the main barriers was the fact that you get application forms that ask you your HIV status and because they're not quite sure how to handle that situation many of them just don't apply or many of them don't go and look for work " FG 5.

"I think being HIV positive has possibly affected my decision not to look for other jobs. Although now ... the law changed [so] they can't ask about your medical history prior to the interview, so that might make me slightly more inclined to apply for another job." FG 7.

"I recently had an experience ... to fill out a pre-employment health questionnaire in which HIV wasn't asked specifically but your medication was asked. What drugs are you on? It was an NHS organisation. ... [It] had to be filled in before I went for the interview. It made me almost think about withdrawing from the interview although it also made me think do I tell the truth or do I lie? I lied. I wasn't happy about it ... I think as a gay man I have come out of one closet I am being forced into another closet, ... having to lie about a health issue because you feel that it might mean that you go on to a reject pile. ... It wasn't given to an occupational health person it was to go back to HR, the same people who were responsible for the interviews." FG 3

“Who else really has a right to know about these things? Unless ... in an employment ... there is a level of professionalism, there is a level of confidentiality rather than ... giving out information about yourself and you haven’t even got the damn job.” FG 3.

“I don’t see why we should feel that you’re forced to tell employers.” FG 11.

“I think I would think very carefully about whether I was going to disclose this to an employer what my HIV status is. I mean I know that a lot of employers such as NHS organisation they have tick boxes for equal opportunities and they want you to say ‘we are really positive about disability.’ You present them with the fact that you are HIV positive and they will find other reason to say that you are not [suitable for the job]. ... I was working for in a temporary job through an agency ... last year. ... I was walking along the corridor one day and there were two HR people talking, very badly, very unprofessionally. They were actually talking about an interview that they had just had for a promotion. It wasn’t HIV, it was someone who was going for a promotion who had diabetes and basically, it was like ‘oh we can’t really... there could be a health problem’. ... How would they feel if they knew that they had me, even as an agent’s member of staff who had HIV? It just made you think, you’ve got to hide it.” FG 3.

“If someone is in the working environment or in a social environment where with their colleagues they feel they can’t be open and honest – this is the problem. If you’ve got cancer, if you’ve got diabetes, you can talk about it much more. You can’t talk about HIV. ... Because of the fact that you brought it on yourself, it’s oh you’re gay or you’re a drug user or whatever.” FG 3.

“You go to one appointment and you are told you need to come back after two weeks because this particular bloods that we’ve drawn are not at the same level, ... and you think but I’ve said already that I’ve got a school meeting... What else shall I come up with, and it gets quite awkward actually.” FG 5.

“... I think it is down to that I am working part-time, not full-time because that way I will never be accused of being somebody who, because of their status, doesn’t pull their weight. ... You do not want anybody to start saying ‘oh, HIV, well you can’t expect them to do that, you know they’re always off sick or they’re always going out for appointments. And I don’t want that sort of gossip about me’.” FG 3.

“I don’t disclose in my work environment because even though I actually think it might help the cause to talk about HIV positive people doing fulfilling jobs. ... I don’t trust them not to think that I am not as good a teacher because I am positive. I don’t trust them to be broad minded enough to forget the HIV.” FG 3.

“You just don’t know what to expect from telling ... your employers that you are positive... As long as my doctor and family know, that’s fine. My job and my ability to do the work is not related to HIV at all and I don’t think ... employers should ask people to disclose their status.” FG 10.

“It depends on the job that you are going for. If it’s anything to do with the health profession ... well then yes. But if you have got a job as a mechanic or something like that, you should know you don’t need to. You shouldn’t have to disclose your status.” FG 10.

“I have been off of work for 2 years since I caught it. One of my main worries is do I tell them or not. I’ve got an interview coming next week. Don’t know whether to tell them or not.” FG 11.

3B.5 Reactions from co-workers and employers to disclosure

Some participants described their experiences of disclosing their status to work colleagues. One was a support worker and had confided in two colleagues. They recommended not disclosing to others in the workplace, firstly to avoid gossip and secondly, to prevent rejection by clients. Another participant had been open about their status and believed that any gossip within the workplace was because they were empowered to address discrimination rather than because of their status. Another participant described their positive experience of disclosing in the workplace, with people being very understanding. One participant explained that they believed employers felt an obligation to share a person’s HIV status across the workplace in an attempt to protect other employees. Reasons offered for discrimination within the workplace included lack of knowledge in colleagues

about HIV transmission and also legal barriers, which mean that some professions are obliged to disclose on the premise that the role may cause risk to others.

“Although two of my colleagues know about my status, they have both said to me ... not to tell anybody else at work... It’s not because of the organisation, but because of the fear of being gossiped about... Because I am a support worker, I would worry that people ... would say ‘I am happy to receive support but I don’t want support from the one with AIDS’... So I don’t have any fear about my rights at work because I know that ... the organisation is quite aware of how they have to ... behave.” FG 7.

“Being gossiped about in the office, obviously I get that but whether it’s because of my HIV status I would say no, it’s just about that I stand up for my rights because of my status, not because of my status.” FG 10

“I think I am fortunate that I work and I have always worked in the social care setting... Although there’s ignorance everywhere, there’s a greater level of understanding, both from my colleagues who accept why certain things happen in certain ways ... but also from my employers who have responded ... positively.” FG 7.

“A lot of the people ... said, ... if somebody told me they were HIV positive, if somebody told me as their manager ... they would immediately feel they had to tell everyone to protect everyone ... they felt it was their duty, because they have a duty of care to other employees.” FG 7.

“I had a session with Unison ... [and] we gave them a scenario of somebody who was working in the canteen as a cleaner and he was HIV positive [and asked] if he should have told the manager... It was ... a focus group of 60 women and most of them [said] yes, this person should have told the manager that he was HIV positive. We said, ‘why?’, and they said, ‘because he touches cups’. FG 11.

“Sometimes what we read in the newspapers can put you off from looking for employment. There was an article around four months ago about a doctor from Germany who was diagnosed in Germany but he didn’t declare his status in the UK... And he worked for 12 years in York and somehow they found out that he was HIV positive and they had to alert whoever he had operated on and he had operated 2700 people since he came here... I think it did say ... that ... within the NHS ... if you operate or if you are a surgeon ... you are supposed notify them of your status.” FG 11.

Experiences of ending employment

2B.2 Lost a job or other source of income

Some participants believed they had been denied promotion or employment because of their HIV status. Others believed they had been let go from employment as a result of disclosing their HIV status. Generally there was a consensus that employers would cover up discrimination related to HIV by using other excuses to explain their decisions. One woman described her experience of being sacked following her disclosure to employers. As a result she had decided not to disclose her status to her new employer. She suspected that if her status was disclosed then the quality of her work may be judged. Another participant explained that since her husband disclosed his status to his employers, he has been pressured to leave employment. He had been sacked two years later because he had misspelt a word, English was his second language and she believed the route of his termination of employment was his HIV status. One man explained that he had opted not to disclose his HIV status when claiming Jobseekers Allowance. This decision was made because he had confidentially enquired about how his HIV status would impact on his employability and found very little support was offered. He explained that the focus had been on managing a physical disability rather than considering other aspects of employment such as stress levels or fatigue that may impact on performance. He was enthusiastic about gaining employment but recognised that his capacity could vary and was keen to ensure he could offer optimal work performance.

“I was denied promotion, which I believe was due to my HIV status even though I can’t prove it. ... I was well qualified for the job. I was the only person internal to get an interview. ... The person that got the job, fair enough she was downgrading because she was made redundant. But I told them before obviously I had it [HIV] because I had to go and book appointments and stuff. ... When I had a follow up interview ... a senior director had turned around and says I ‘wasn’t going to get it anyway’.” FG 2.

"The refused work certainly that has been my experience. ... I stupidly thought somebody might be more sympathetic by telling them [I was HIV positive]. It was about 7 years ago. What happened was they said 'oh you were on a 3-month trial and it hasn't worked out'. And I got told to leave. And I fought it, I took it up to the senior management level and ... they gave me a further 6 months to try out because I [was] totally convinced it was my HIV status and I still am. Of course they said it wasn't and it was a horrible 6 months and at the end of the 6 months I had passed my probation and I was offered the job but it was so awful that as soon as I passed it I left. ... It also left the stigma that I will never tell anybody in my work place." FG 3.

"They're not telling you that they're sacking you because you're HIV, they're telling you that because of your time keeping or late or whatever, ... even though probably the biggest majority of the times it is because of your HIV. You can't prove it. How can you prove it?" FG 2.

"At one point I thought actually I was denied a job because of [my status] and now I am trying to change my application... If you read my application, you might think this woman is HIV positive... So I am thinking ... that I need to tone it down a bit." FG 10.

"I would say the vast majority of people don't disclose to people they work with and for very good reasons... I disclosed to my employers five years ago and they sacked me. ... Even though I am now five years into a different job ... I don't disclose. I just don't want ... anybody if they did find out to say 'oh well she was always taking time off' ... I don't want anybody to think that I am finding an excuse for doing a less good job than everybody else and I don't want people to sort of sneer about 'oh HIV positive people don't pull their weight in this place.'" FG 1.

"My husband ... has just been fired for misspelling a word, two years after telling them he was HIV positive... They have tried everything possible to get rid of [him]. And he misspelled a word and they just fired him. And English is his second language." FG 10.

"I am currently unemployed ... I am just getting jobseekers allowance right now. I don't discuss anything about health problems because at the moment I am fairly fit, I should be able to work for a while. ["You would be £20 better off if you push the disability thing."]. ... The thing is I had a word informally with a sort of adviser on the phone, didn't say my name, said what my current situation was, disclosed my HIV status and they were hopeless. ... They had no idea really how to deal with someone with HIV. They saw it very much in terms of simple black and white. The way in which they measured the disability, it was very much of the physical kind, the kind of checks that they do. ... You know there's all that emotional side as well, ... they have no understanding of what it can feel like, the fact that you're living in a state of hopeful uncertainty. That you don't know how the future is going to be ... what you do know is that you might want to pace yourself a bit more. You might want to think about certain jobs, ... that you might have done a few years ago, because they're too demanding, ... because of the working hours or the work pressures. So you are wanting to sort of try and find a fit." FG 3.

2C.2 I took the decision to stop working

Some participants had opted to stop working as a result of their HIV status. Immigration made accessing work too difficult for some, others stopped because they had children, others as a result of ill health and some cited avoiding disclosure as a reason for stopping work.

"I stopped working ... when I found out that I was HIV positive and I was pregnant as well. So when my son [was] born, I didn't go back to work... I ... also [had] problems with immigration, so I had no right to work... Then I started college... But now I've tried to apply for work, I can't get any. They just say, 'fill the for'", but most of them are asking if you are positive or not, but I just leave it, I don't put anything." FG 11.

"I have been retired because of ill health for a long time, but ... the reason that I finished work was because I didn't want people to find out and especially patients and relatives, because I didn't want them to ... think that I could have given somebody something." FG 11.

"People who have been HIV for a long time had that experience of stopping work and probably finding it very difficult now to get into the workforce." FG 5.

HEALTHCARE

2B.7 Denied health service

Participants discussed experiences relating to poor health service provision. It was widely believed that people should receive the same standards of care irrespective of their HIV status. Denial of health services as a result of the HIV status was a concern for participants, although no participants offered any specific examples of being denied a health service. It was felt that PLHIV should be protected by legal rights to access care. However, participants reported that these laws were not being respected by health professionals or utilised in support of PLHIV. Lack of awareness of legal rights was considered to prevent people challenging any discrimination faced. Accessing specialist services such as clinical psychology was highlighted as challenging for the whole population in some locations. One participant commented that perhaps people over-emphasise discrimination relating to HIV in health settings to justify their avoidance of hospital environments.

“The fact that people have been denied health services... after they have disclosed. That frightens me... Regardless of whether you are positive or negative. It shouldn’t come into the equation. You shouldn’t be denied health service, full stop.” FG 1.

“Discussion: 1) The law should be against them [health professionals] for denying access to family planning. 2) The law is against them, that’s the thing, it’s not being implemented properly.” FG 1.

“I have never been denied health services but I have certainly not been able to access them because they were not in existence ... for example, I live in a city outside London and we have a population of approximately 350,000 people and we only have one psychologist ... I’ve definitely not been able to access [health services] because they haven’t been in existence.” FG 6.

“If people understood their rights with HIV that might help ... to empower them ... to be able to challenge [decisions to deny services].” FG 8.

“...but sometimes people hang their coat on their HIV status when actually it’s not necessarily ... the [reason they were denied a service]... avoiding going to a local hospital when they need to, that’s ... a choice.” FG 8.

2B.7 Denied dental care

Participants reported varying experiences when disclosing to dental services. One participant believed their treatment had been effected because they had disclosed their status and staff were reluctant to support them. Another criticism was that dental practices leave HIV positive patients to sit in the waiting area until the final appointment. It was suggested that this was to reduce the inconvenience of sterilizing equipment. One participant explained that she had experienced infections on a number of occasions following visits to the dentist, which she believed were a result of the dentist not changing their gloves before treating her. One person had been asked to leave their dental practice following disclosure. A number explained that other people’s negative experiences had made them anxious about disclosing. One explained that following withdrawal of HIV specialist dental services they opted not to disclose. Participants’ suspected that their dentist would make judgements about their lifestyle, request that they leave the practice, or that they would insist that they booked the final appointment of the day. However, the disclosure experiences described were generally satisfactory. In contrast, one man described being pressurised to disclose to his dentist by the HIV clinic. He was reluctant because of the anticipated response and his concerns were realised. The dentist reacted in a negative manner and the participant suspected that the dentist shared his status with other staff within the dental practice.

“Even the dental hospital, you go up there ... and the minute they find out you’re HIV positive, you’re sat for three hours, and you have to be the last person because they don’t want to clean everything. ... Sometimes they don’t even change their gloves. I don’t know the amount of times I’ve ... come out with infections. ... Every single person I’ve spoken to that’s HIV positive will go up there and will sit for hours and hours and hours and they’ll be the very last patient be it the dental hospital or dental surgery, they give them the last appointment.” FG 2.

"I know that was one of the big things I thought, how was I going to tell? So I told my dentist, I didn't have an issue with my dentist and I haven't had, but I know people anecdotally who have said there have been problems with dentists." FG 4.

"My dentist is a woman and I have known her for a long, long time and I found it difficult to tell her because I thought ... she would have turned around and looked at me as if ... 'he's been rolling about with bad people' ... you know, I thought she would have thought less of me and then eventually ... I just says, 'look I've got something that I have to tell you' and she never batted an eyelid. She says 'well, how are you doing?'" FG 4.

"The dentist I am paying privately so there was a possibility he could say, 'well look I'm referring you to a different dentist' but he didn't. He just asked a few general questions. He did put in on my records... I think the next time I went I was a little bit self-conscious because I knew it was on my medical records... For me the way I cope with it is, 'you are professionals here, you have to treat me and you should be working in the best practice way anyway.'" FG 4.

"I've heard time and time again has been about the dentist, people are being left, are being made to wait to the last appointment of the day." FG 4.

"I needed a lot of work done on my teeth and ... I was thinking, 'why do I have to tell?' 'I can't tell.' I've known him all my life and it was hard to get another dentist. I tried everywhere, even to go private and I ended up having to tell and the look on his face. He said, when he opened up his business, my father was his first customer. You know, just things like that and....I knew he had told everyone in that dentist, you know? That I was HIV... I couldn't prove it. But why were they all looking at me oddly? You know? I didn't imagine it. I found it really, really difficult to tell him and I couldn't wait for the work to be done so that I would never have to go back there again... And I was pressurised into telling them... [by] the clinic and the doctor in the clinic, the social worker." FG 4.

"I have avoided going to the dentist for fear of my status. I don't know, should I disclose or not disclose, ... and I am afraid to go because of perceived stigma or possible stigma because I have experienced stigma in the past from a professional and that has made me much more cautious about health service." FG 6.

"I have been denied, or was told I would be denied dental health [care] because of my HIV status and I moved my care elsewhere." FG 8.

"...dentists are the most erratic rather than GPs." FG 8.

"maybe we focus a lot of work on GPs and making sure they are up to speed ... maybe there's room for more working directly with the governing body of dentists or working with colleges that train dentists or doing some work locally with dentists." FG 8.

"I used to get my dental care from my HIV specialist dentist until they got rid of that and I don't disclose to my dentist now at all." FG 8.

"For a long time, I didn't have a dentist, not because ... they refused me, I just didn't want to face discrimination I avoided confrontation... Finally, I went to see a dentist... They said, 'when was the last time you [saw a dentist]?' I said, 'about 5 years ago', they said, 'why?' I said, 'because you discriminate [against] us'... So they took me on and we talked about it and I told them there are so many people who are positive and they just can't access services. Not that they have been denied, but they can't face it. You don't just want to go into confrontation with dentists." FG 9.

"I've had tooth extractions and I know that normally there is an assistant ... but then, I don't know whether it was because I just being paranoid, there was this dentist, alone, extracting my tooth. My mouth was full of secretions and he kept saying, keep on swallowing, swallowing the blood which was in my mouth... And I could hear nurses talking in the corridor... By the time I had finished I was really angry and I was in pain and that made me not [want] to go to the dentist again." FG 9.

"[It's] like they [dentists] are not ready to treat people, but they have no choice... But you just feel bad that ... they know you are positive, [but] they have no choice other than treating you. But you don't get the care you'd get if you were negative." FG 9.

"I have actually been denied dental care ... it was a number of years ago and it's not a very nice position to be in." FG 12.

3B.3 & 3B.4 Disclosure without consent and confidentiality of medical records

Some participants indicated that they were unaware of their status being shared without their consent. However, a number of participants reported occasions in recent years when they were aware that this had occurred. The majority indicated that they were happy for health professionals caring for them to be aware of their status. One participant explained that they felt it was courteous to inform their health professional of their status but requested that it not be recorded on their notes to minimise the risk of the information being shared. One participant explained that they opted not to tell their dentist because their practitioner followed safety recommendations anyway. A number of people were concerned that other staff within the GP's surgery would then be aware of their status and did not trust them not to share this information. An occasion was described where a dentist was referring to another professional and included the person's HIV status in the referral letter. The individual was comfortable with this occurring as the dentist had advised of his intentions and also copied the person into the correspondence. A number of participants highlighted that attending the HIV clinic in the hospital meant that they were disclosed to everyone in the waiting area, one individual indicated that they opted not to attend their appointment to avoid this. Numerous participants outlined situations within the last five years where they had been given a copy of someone else's medical notes by mistake. This was because the other individual's notes had been attached to their file or a health professional had written up another person's notes along side theirs. Generally the attitudes about information sharing were inconsistent, some considered that health professionals should share information freely to ensure continuity of care whilst others believed the priority should be for only the HIV specialists to know. Two of the participant's discussed a recent experience they had had with two health professionals facilitating peer support at an NHS Blood Borne Virus Centre. During this meeting they had been advised by two members of the nursing team that they would disclose the participant's status to their sexual partners if they did not disclose themselves.

"I don't have a problem with all the appropriate health people who are involved in the provision of your health care sharing information." FG 12.

"I have not experienced any situation where my [status] has been exposed to another person or somebody without my authorisation." FG 6.

"As a matter of courtesy, wanting to tell their doctor or dentist but not wanting them to record it on the notes, because of fears of the temp who is going to be on reception and people who maybe aren't clued up with confidentiality and might come across information." FG 4

"Recently the dentist had to refer me to a consultant and he disclosed my HIV status but he emailed me and copied me the letter beforehand and told me he was going to be doing it and I didn't have an issue with it. But I suppose ... everybody knows there's no such thing as true confidentiality because human beings are human beings and we are nosey." FG 4.

"My friend ... was once taken ... to Romford Hospital... The mistake came when the ... doctor ... said, 'oh could you go home and bring all her HIV medication?' ... to her ... friend ... sitting by her bedside. And this person [didn't know her status]... And [the doctor] said, 'sorry, sorry, I think I made a mistake'... And later on she apologised to my friend and said, 'it won't happen again'." FG 12.

"I don't even tell my dentist... He wears gloves and a mask anyway, he always has done, so I don't see any point in telling him." FG 11.

"It's probably that fear I would be refused treatment." [Dentist]. FG 8.

"My GP gave ... an open letter to the receptionist clipped on to my prescription which had my HIV letter from my consultant ... the receptionist would have seen it and I felt that was ... a lack of care and responsibility towards ... respecting my wish not to disclose my status... I did disclose it to my GP ... on the advice of the [NHS]." FG 6.

"I was assured by my GP that in actual fact all employees at the surgery are subject to the same code of conduct as doctors are and that if it ever came that someone had divulged information about a patient they would immediately be dismissed. The thing is, I don't want anyone to divulge anything." FG 6.

"Living in a small, relatively rural town I feel quite vulnerable about ... disclosing my status to anyone ... my doctor knows but I am concerned that people who work in the GP surgery might know and they might then know my family." FG 7.

"I still feel apprehensive and not fully convinced that my medical records are completely confidential... I have been in a room where someone else's file was right next to me." FG 6.

"At the beginning they told me it's private, no one has to know... I say okay, I don't want nobody to know, I don't want my GP to know ... but I was very surprised, everybody knows, even ... my baby's health visitor ... I feel like it's not private anymore." FG 7.

"My GP disclosed my status when I was just going for a check up and the consultant was horrified to see that it was actually on my records ... he was just going to have a look ... [at] my knee ... [no] giving blood or anything like that. I think it depends on what GP practice you are in ... how professional they are at keeping things confidential." FG 8.

"I know that medical records aren't kept completely confidential. Because I received somebody else's blood records, with their name and address, in my medical file... just 6 weeks ago. They [the hospital] said that wasn't in the medical file. I says 'well, I've got it at home'. So they apologised." FG 1.

"My husband died five years ago... I got access to the medical records through my solicitor. In amongst my husband's medical records was somebody else's file. Their name, their address, their situation, everything about this person. So how can they say that everything is confidential? ... I would hate to think that my file ended up in somebody else's hands." FG 1.

"I requested my medical files from the [hospital] and I got them and whilst flicking through them I discovered somebody else's blood results with their surname, first name, initials that, their address, his full address and postcode so I know for a fact they're not being kept, not all the files are being kept completely confidential." FG 4.

"I read my file at the [hospital] one day and in my file there was somebody else's notes had been written in my file. It was just the guy's first name and I just had to bring it to their attention and say, those aren't my notes... This was actually their viral load, their CD4 count, bloods." FG 4.

"Apparently we are supposed to be allowed to access our own medical records and I did actually say that I wanted copies of all communications regarding my own health and apparently the doctor said she had never, ever heard of anybody asking for that before. But in actual fact our local general hospital is filled with leaflets telling people that they have access to their own data." FG 6.

"I am not sure about my medical records being confidential." FG 6.

"Is [the] hospital supposed to know all my business?" FG 6.

"They [hospital staff] all have a duty to each other ... if there are bloods they would have to [tell]." FG 6.

"I think when they log on to your data or your date of birth and name, I think everything comes up there." FG 6.

"With the hospitals where we ... pick up our medication ... we might be like mixed with people going to some other divisions, but then ... there are those charts where it's written all ... about HIV... Sometimes you feel insecure because ... I feel as if people are talking, maybe when they call your number you go in and then you have to come out and wait for ... medication, you'll be feeling as if people are talking [about you]." FG 7.

"[In the hospital], there are two rooms, ... off a central waiting area and if you go through that door, then you go to the HIV clinic, if you go to that door, you go for any ... or test. So there are people that are waiting that are ... not HIV positive, but are also are aware of the difference [between] those two doors." FG 7.

"How you can be sure that your medical records are being kept confidential?" FG 8.

"I had to get my HIV doctor to write to somebody about my health and ... [they wrote] 'P attends the clinic regularly with his partner who is also HIV positive'. I'm not talking about my partner, I just wanted [them] to [write] about me." FG 8.

"If it's about something medical, even if it isn't HIV related, the fact that I'm on various medications, the fact that I've got HIV, is possibly and probably going to be relevant to ... any treatment ... I need... It's always better that people know than they don't." FG 8.

"What is confidentiality anyway?.. Because to me, as long as you are in the hospital ... if they pass it [your information] over to another person, they wouldn't tell her, 'don't read what is in there'... They might not tell a stranger outside the hospital but I don't understand what confidentiality is all about in the hospital." FG 9.

"Health professionals are supposed to keep confidentiality, the code of ethics... I know some people who don't like their GP to know their status, but I also ... think it's not right, because I want my GP to know what I am suffering from, because if my GP doesn't know, how is he going to help me?.. I was admitted in NMGH. When I was discharged, I think my consultant sent some report to my GP ... but I didn't see that was a problem because it is a continuation of care." FG 9.

"If I go ... to another hospital for anything, I do always tell ... [but there] is patient confidentiality..." FG 11.

"[A nurse leading an NHS peer support meeting] says that if we had a partner and we were with them for say a couple of months we would have to tell them that we were HIV positive and if we didn't they would go above our heads and tell them. And I says, well we're not putting anyone at risk. I've been positive for 20 years and have never put anybody at risk. I'm going to tell the hospital that I've not got a partner because I'm not having them telling the partner. I'll tell them when I'm ready to tell them. I don't see why the hospital should." FG 2.

3B.5 Reactions from health professionals to disclosure: Negative

Many of the participants contributed to discussions about negative experiences with health professionals relating to their HIV. Participants described being very aware when their doctor was uncomfortable with their HIV. One woman explained that a doctor was assessing her swollen leg. During the examination she made the doctor aware that she was HIV positive. Following disclosure, he opted to wear medical gloves before continuing the examination. A situation was described which occurred in the last couple of years where a patient with HIV was undergoing clinical investigation as a result of bowel problems. The medic in charge warned the nurse not to go near the arm with the needle feeding the drip, informing the nurse that the needle was 'live'. When questioned by the patient about his terminology he stated that because she was HIV positive and not taking medication the needle was 'live'. Another participant said he believed the doctor would be willing to prescribe him just about anything because he was so anxious for him to leave his surgery. A recent situation was described where someone had sought advice from a nurse about risk behaviours related to HIV. The nurse recommended that no kissing should occur to avoid transmission. Concern was raised about health professionals familiar with patients enquiring regularly about their sexual practices. One participant explained that he felt the doctor didn't trust him to be truthful and got frustrated by the constant questioning. Another explained that some people assumed she was a 'slapper' based on her being HIV positive. A number of personal

experiences with health professionals demonstrating inappropriate consultancy methods were outlined. The tendency for some health professionals to jump to conclusions about transmission modes had alienated people from medical environments. One participant explained that a doctor had concluded without referring to her medical notes that she was an injecting drug user and that is how she had contracted HIV. She found his offer of Valium or Methadone offensive and as a result is extremely particular about the health professionals she engages with. Another example was outlined where a junior doctor quizzed a woman about her HIV contraction whilst treating her broken arm.

"I remember when I went in with a swollen leg and this doctor was looking at me, this was like two years ago. 'You are on medication?', I said 'yes'; 'What medication?'; 'HIV medication.' Before he was holding my leg without gloves, he went back, got gloves on because I could pass on HIV to him... You really need that to change because he is a doctor, he should know better, he should understand how HIV is passed on." FG 1.

"I went to get my bowels investigated ... the drip thing was sticking out of my arm ... The doctor says [to the nurse] ... don't go near that side, there's a live needle there. I says 'What do you mean live?' and he says 'Are you on medication?' I says 'No' because at the time I wasn't, so he says 'So you're live then.' It weren't that long.[ago], last year, the year before." FG 2.

"My own doctor, if I asked him for heroin he would give it to me just to get me in and out. You know, one of them can't even bear to look at me... He can't the prescriptions wrote out quick enough for me... Because [of] his upbringing, he's stuck up. His father was a doctor, you know. Just think very anti-gay, but what can you do about it? ... I think he is afraid of my HIV. You know, I might sneeze on him." FG 4.

"Last time I was in hospital, I felt stigmatised ... It wasn't by the nurses and it wasn't by the consultant in the clinic but ... when I was in A & E, doctors in there. But even the junior doctor was alright, it was ... some higher doctor ... just his whole attitude" FG 6.

"Every time ... I go to the GP, even if I am not going for HIV, ... they always talk to me about that ... making me feel very embarrassed." FG 7.

"My daughter ... didn't like going [to the paediatric HIV clinic] because it reminded her that she was HIV positive... when the nurses took her blood they always put on two pairs of gloves and ... those dreadful yellow tape stickers ... danger of contamination ... high risk and that just reinforced the stigma she felt and how she felt at the time about her own HIV status." FG 7.

"First of all I was admitted at NMGH. The treatment I got there was really perfect. And the next time I got sick I was admitted at WH, but the treatment I got that time, it was different... I think because it is not a speciality with HIV... Nurses ... couldn't even handle me... Even the doctors didn't know what to do about CD4 count... I realised that if I stay on in this hospital, I'm not going to get the treatment I need ... so I requested ... I be referred to NMGH, because NMGH have my records and they know me better and my consultant is [there]. And actually they transferred me to NMGH." FG 9.

"Some nurses they don't have the knowledge and when it comes to handling HIV it is a mess. But you don't blame them because they don't know. They think just touching somebody you can get it." FG 9.

"[I had an operation] to remove my gall bladder... They put me in a ward which ... had nothing to do with HIV... The following day I wanted to go home. They just said 'no'... Nobody wants to touch me. Not even breakfast. They put ... oxygen on me. I had to throw it away the following day because nobody came. Even the drip ran out, nobody came to touch it. Late in the night a woman came and said, 'have you taken your medication?' I said, 'which ones? You haven't given me any medication... She didn't want to face it, that I have HIV ... to make sure that I have taken my tablets, nobody asked me... And they didn't even ask me, 'what time do you take your tablets?'... Even breakfast, they will come and read then they would look at me.... Why are you looking at me?.. Maybe they are scared ... to understand a person with HIV." FG 9.

"I think people have less anxiety in the HIV clinics than they do in primary care or with dental." FG 8.

"I had a client who phoned in the other day and she had started a new relationship and in this relationship she disclosed to her partner that she was HIV positive and then this partner phoned some nurse from some clinic and he was told that he could actually contract HIV from kissing. And so that meant that relationship was coming to an end completely. And this is a health professional telling this guy that you can contract HIV from kissing." FG 1.

"Every time I go and see my doctor for instance, I have told him every time that I am still with the same person but he will still ask, 'Have you had unprotected sex?' 'How many sexual partners have you had?' Every time I go. I went 'Do you not trust me, do you think I go sleeping about or something?' And he says 'No, no, no ... I've just got to ask you in case your status has changed'." FG 2.

"They [health professionals] ask you all the time. ... 'Have you met someone?' and 'how many people you've slept with?'. They'll be counting and I'm like 'I've never done that in my life. Why would I start that now that I am HIV positive?' ... They [health professionals] automatically think you're a slapper because you're HIV positive and that was how I got it. I can pin point exactly how I got it, I went with one person, ... it was that person that was cheating on me and he gave me it and now I'm getting the stigma about how much I am a tart... And it was my first sexual experience and I was 22 when I got it". FG 2.

"Knowledge about HIV transmission is very low among the public and the worst culprits are GPs and those who do specialist services like dental services. A lot of them don't have that much knowledge, so to me this shows that there is a big gap. People [living with HIV] missing out in the system, they go first time [for medical services], they never come back." FG 1.

"People say that they actually feel the most discriminated against, the most stigma, when they are dealing with health people... not necessarily the HIV clinic where the people are sort of a bit more up... but it's ordinary places... You go to casualty with a broken arm and they say, (Student doctor): 'Are you on any medication?'; (Participant): 'Yes I am HIV positive'; (Student doctor): 'Oh how did you get that?'; (Participant): 'Er, sorry?' I mean luckily the doctor who was there said 'I don't think you need to know that'... That happened.... I broke my arm in November eighteen months ago.... Because you're asked what medication are you taking, then you don't want to go... Like, when I got my eyes tested 'Are you on any medication?' I just said 'no; this time because I just didn't want to say 'yes, I am on HIV medication'. I don't see how that's going to affect how you can test my eyes." FG 1.

"I had a horrendous experience...there was a replacement doctor in and I walked in... he didn't even look up from his desk, he didn't even look at who I was, nothing. I sat down and he went, 'well er, what are you on Methadone or Valium?' I could feel the pouted lip coming on, you know that point where you feel really emotional and I went 'I beg your pardon' and he went, 'what are you on Valium, Methadone?' I said 'you haven't even looked at my notes. You don't even know who I am. I don't take Methadone and I don't take Valium' and I got up from my seat and by this time the tears were streaming down my face... So if you're feeling judged by the people who you're meant to trust, I am not surprised... It has made a difference to me because I have had to actually hand pick my doctors to... by them looking at me in my face when they're talking to me, not looking at the floor or looking at the window or checking their watch... I still hear horror stories to the day from people." FG 1.

3B.5 Reactions from health professionals to disclosure: Positive

Concerns were raised relating to health professionals reacting negatively when an individual discloses their HIV status. However, this was not the case for many participants. One man outlined his anxiety about disclosing to the family doctor who he considered to have a much more privileged lifestyle than himself. However, when he did disclose his status he considered the response to be appropriate and non-judgemental. One participant explained that she had recommended a health professional wear gloves while taking her blood and disclosed her status. She felt the response was very supportive and reflected on the nurses gratitude for her honesty. Other participants commented on how fortunate they were to have such a high level of care, although one explained that their experience of General Practitioners had not always been positive.

"I needed to get my blood test done. There was a nurse who came in and ... I said 'oh you better protect yourself' ... she said, 'thank you'. ... I said 'you better put your gloves on, just to be careful.' And she said 'you know what, thank you very much, not many people would just say'... She was very kind to me." FG 4.

"I very reluctantly told my doctor [GP] ... there is a big generation gap. He was never brought up the way, he wouldn't know what the word 'working class' would be... He wouldn't have had an idea what it was like when we grew up and I can't really relate to him... So when I told this doctor [GP], he was quite all right, just right." FG 4.

"We have ... excellent HIV services ... some of the best in the country, but ... health care amongst GP's is very, very patchy... And they do actually discriminate." FG 12.

"We [went] to a conference and ... we thought, my God aren't we lucky here in Leicester because we can access services so easily and readily?" FG 12.

3D.3 Has a healthcare professional advised you not to have children?

One participant was aware of a person living with HIV who had been advised that their status meant they would be unable to have fertility treatment.

"[PLHIV seeking] fertility treatment ... [have] been to hospital or a service where they've been told, well we can't do that for you with HIV, you can't be having children." FG 8.

3D.7 & 3D.7 Experiences relating to pregnancy, childbirth and infancy

Those participants who described experiences during the ante- and postnatal period generally described negative occurrences. Doctors had been reluctant to engage with them and avoided direct contact with their infants. One participant described a recent experience where a woman was dismissed by health professionals from an antenatal clinic and told to go and seek out HIV specific services. Another participant appreciated her GP not focusing on HIV and rather focusing on care provision.

"When I was pregnant ... there was this doctor ... when I opened up and told him my status ... he wasn't even looking at my face. He was talking to me as if nothing. I was annoyed, I wasn't happy about it although I didn't show him I wasn't happy, but the way he treated me I was thinking maybe it's because I am HIV positive... the way he was talking to me. He wasn't allowing me to say anything... he didn't even touch me as a doctor should." FG 6.

"I have been discriminated ... when I had my son and ... they wrote on the front [of his medical book] that he was taking HIV medication... They told me this is private, they don't have to write it if I don't approve. They don't have to tell my GP if I don't approve. So I went to the GP, for him to just check the baby he wore two gloves and my baby was only 3 weeks old." FG 7.

"[At the] check up when my baby was 12 weeks old, ... [the GP] wore two gloves and he made me feel bad, my baby is not HIV positive... I didn't even want to go to the doctor anymore with him." FG 7.

"A client called in to say she was stigmatised just because she was HIV and pregnant... She was told something like 'you are HIV and why are you pregnant? We don't treat people who are HIV. You have to find your own clinic.' ... They were laughing at her... The clinic in London... Saying ... Find a clinic where you can go where they'll treat you." FG 5.

"When I go to my GP now, he doesn't ask me so many questions, he'll just say, "you are not breastfeeding". He won't say "because you are HIV"." FG 9.

2C.2 I avoided going to a local clinic or hospital when I needed to

Some participants reported that they were reluctant to attend hospital appointments or A&E either because of risk of being disclosed or obligation to disclose. Some individuals explained that they went to larger clinics further from home to receive optimal care and increase their anonymity.

"I am very fearful about attending [hospital] appointments. I happened to cut my foot and it was a real trauma for me to go there [A&E] although it's near my home I was just so keyed up about the fact that it was a cut and should I say or should I not say and then you think of the legal ramifications and you hear these ... stories of 'well she should have told me' and ... people taking people to court even though they haven't contracted HIV from you, but because of the stress you may have caused them by not having told them ... and it does make you apprehensive about going to do things that ... people not living with HIV would find easy to do." FG 6.

"We are trying to get more black men to access our services here ... apparently a lot of them go down to the clinic under the cover of darkness, in the night ... in the evening." FG 12.

"When I saw two people I know in the clinic, ... I knew everybody who went through that door is HIV positive ... so I thought if I go in they will know I am HIV positive, so ... I didn't go in. I pretended I didn't understand the number." FG 7.

"Some people avoid their clinics for a while because they don't want to go on to meds and they avoid their local clinic for fear of someone seeing them because they don't want to disclose their status... When I first went to my clinic I ... did actually say ... don't you have like a back door or something, can I not find another way in and out? And it was a real trial going down to my clinic because it was such an open area of our local general hospital and it was quite a task to walk through the car park to walk into the building And I used to look around thinking maybe somebody ... [will] think, oh, what's she doing... So it's always a fear ... not everyone wants to come out into the open with their status for many reasons and ... many of those things can be quite stressful." FG 6.

"A lot of people do come into London to go to rather than go to any local hospital for fear of people recognising them ... a lot of [people] go to the Royal Free and they travel quite a distance." FG 8.

"[For some PLHIV], the reason that they [travel to a clinic] is because it's a fantastic service, it's close to their work, it's close to where they socialise, it's in the city centre, they don't have to take time away from their work so much..." FG 8.

"I [travel to a clinic because I] know the quality of service is fantastic, I know they can really, really deal with my needs." FG 8.

"I moved to Leicester two years ago, and I have chosen to keep my ... Consultant in London. I go there every four months. I have just chosen to do that because I can't just bear to go into another GU clinic and introduce myself and start seeing another person... And my GP doesn't know, my GP has never known, I have always kept it separate... I just don't feel comfortable." FG 12.

Aging and HIV

Participants raised concern about future if they required additional support as they aged in a care home or from home helps. One participant described a conversation she had heard between home helps who believed that they should be offered a 'warning' if one of their clients were HIV positive. It was suggested that additional awareness training would be necessary to address these challenges.

"Home helps made this comment in my presence ... 'I don't think we should have to go into people's houses when they don't know if they are HIV positive or not... that they should have that warning.' And I didn't make any comment because it wasn't appropriate at that time but I definitely think that shows that care workers are probably going to have less training, less knowledge so once you are in their hands you could end up finding that they were sort of horrified to have to deal with you." FG 1.

EFFECTING CHANGE

2E.10 Raising awareness and knowledge of the public about HIV & AIDS

One participant described getting frustrated about playing the role of educator as a result of her HIV status. She explained that she generally directed people to information rather than passing it on herself. Another participant felt that he was obliged to educate people in a bid to overcome the current misunderstanding. It was recognized that the general population have little understanding of the differences between being HIV positive and having AIDS. A number of participants believed that unless people knew someone personally who was diagnosed HIV positive it was unlikely they would be able to overcome their stigma. One participant explained that he considered disclosure important as it allowed PLHIV as a community to challenge the stigma individuals' experience. There was a responsibility identified when disclosing to someone to offer them support and education to support this process. One participants observed that his mother had always been sympathetic to gay men in the media reported to be HIV positive but felt that it was their lifestyle that made the diagnosis inevitable. However, when he confided in her about his diagnosis she was able to overcome many of the prejudices she held. One participant explained that by informing one person about her HIV status and her experiences that this would allow that individual to reference her when talking to others about the truth of living with HIV. It was acknowledged by participants that without education people had a tendency to make incorrect assumptions. People need to be better educated about the transmission routes and stereotypes to help overcome the associated stigma. The need for information to be shared regularly with the general population about HIV was highlighted with suggestions that PLHIV should try to access groups of people to communicate correct information. It was suggested that information leaflets should be shared with the whole population rather than being aimed primarily at homosexual men. One participant explained that her local community were running a widely accessible information campaign encouraging people to be tested for HIV. Participants explained that even those who were living with HIV were not fully aware of its implications, for example they were unaware of the availability of the sperm washing procedure. In addition, it was recommended that these campaigns should be constant rather than focused solely in the run up to World Aids Day.

"Just because you are HIV positive people expect you to know everything and kind of become a teacher and people are constantly asking you for information and you end up becoming like a counsellor. For me personally I have kind of stepped back and like 'no, you can go here for that advice or there for that advice' and I just lead them in the right direction... It feels like a chore." FG 1.

"If I don't speak out and educate people it will never change ... You know, my epilepsy causes me more problems than my HIV status... When you say to people 'I have epilepsy' they say 'oh' their head goes on the side 'I am sorry for you'; 'and I have got HIV'; there's this gasp, ... and it opens up the conversation. You can throw it out that way and again it's all about educating people." FG 1.

"My experience has been that a lot of people still have this self stigma and that's the biggest stumbling block for people to overcome that and have the confidence to come out... I personally feel that the only way we can overcome it is to come up and challenge it. If we don't as a community we will never be able to make a breakthrough." FG 5.

"I've seen documents ... using the word 'AIDS' when they mean HIV ... and they just automatically say the word AIDS. The AIDS to me, ... it kind of means final, ... it's too strong a word." FG 2.

"When you say 'HIV', they [non-HIV population] say 'Oh you've got AIDS then'. You say 'No, I've got HIV' but they don't realise it's technically different." FG 2.

"Unless people know somebody who's got it, who's close to them, they won't know, they won't change." FG 2.

"When I told her [my mother] I was HIV positive, she told me she was sorry ... she was really, really heartbroken. ... she [told me that she] didn't class it as a gay disease. ... But before that ... like that guy Mark in Eastenders ... or Fred Mercury ... the usual suspects ... She would go like, 'they got that [HIV] for whatever reason' ... The

minute I told her I've got it [HIV] it's like oh, oh my son oh, I can't believe he's got it and she's just changed." FG 2.

"The people ... I choose to disclose to, I do sort of educate them. ...There's a lot of stuff people don't know." FG 2.

"My experience recently was at university, you know you get to know each other and somebody asked me, 'well what do you do in your free time?' I said I work with an organisation that supports people that are living with HIV and AIDS... She said 'oh I'd like to do that but people with AIDS, ... they are always sick and poorly' ... I gave her the task ... 'Google people with cancer and then tell me if there's any difference.' And she came back and said 'you know what you can't actually tell the difference between people with HIV and people with cancer'... One thing lead to another and I told her my situation that I'm positive, have been for 14 years... It's about challenging and she's changed her opinion and her attitude towards it now because of that extra step I took... It's about developing that and educating one more person because I know in turn she'll educate whoever else she you know she'd use me as a reference 'oh yes I know someone who has it and they live just as normal life as anybody else.'" FG 5.

"For me it's often about my confidence in relation to HIV transmission risks and ... in being able to (a) to discuss my HIV status and (b) to allay somebody's fears that I'm going to be some kind of a risk to their health. For me I prefer to disclose upfront because it makes it easier." FG 8.

"How are we raising awareness in this country to people in the community who are not positive? We are not doing anything." FG 5.

"I've met one guy from Ghana ... he's positive, but he didn't know that he can have children and what to do if he wants to have children, because he thought now he's positive everything is gone. He was so depressed." FG 5.

"My borough, they've got banners now. It's been going on for like four months they've got HIV banners to encourage people to be tested... They've put them somewhere you can see they're everywhere in the parks, ... you know where the traffic lights are... I was impressed by that... If the whole of London could do that it would be wonderful." FG 5.

"Years ago we used to go to universities and colleges and get kids in 5th and 6th years and tell them about HIV. ... There isn't any focus in telling folk anymore, educating. We need to keep still educating people and it shouldn't just be when we are coming up to World HIV day." FG 2.

"Why do they only talk about it when it's coming up to the 1st December? ... Is it only that day you can catch it?" FG 2.

"Perhaps that's what we need to work on is educating people that we've moved on, that you don't have to be promiscuous, you don't have to be all those stereotypes that they put you under to contract HIV and people have to move on from there" FG 5.

"People who don't know [about HIV] are in danger of making assumptions from a lack of education." FG 3.

"Maybe we should be out more ... telling people if they want we can go and speak about HIV." FG 2.

"The only places I've seen them [information leaflets about HIV] everywhere is gay bars. ... Because it's still seen as a gay disease. Because the straights won't catch it. That's the attitude." FG 2.

"Most people don't [have the confidence to disclose upfront] because they don't engage with their HIV ... in terms of information ... they don't do the courses, the trainings, they don't talk to the doctors in as much depth, they do the whole thing of going into the doctors getting the treatment, going off and then trying not to think about it. But that is ... like you're in quicksand, you can't get a grip on anything, you don't have an understanding [of] ... the issues ... the levels of risk." FG 8.

2E.1 Have you confronted, challenged or educated someone to overcome stigma?

One participant observed that it was positive that so many participants had challenged, confronted or educated someone about HIV during the previous year. However, she suspected that although occasionally someone would react in this manner frequently they would avoid confrontation. She explained that in certain company it was easier for her to disclose and educate than in others and hypothesized that this would be similar for others living with HIV. Participants were passionate in their belief that public awareness of the facts relating to HIV and AIDS be increased. It was concluded that the majority of general population were primarily influenced in their beliefs by the advertising campaign launched when HIV and AIDS were first identified. One participant explained that she rarely discloses her HIV status and simply informs people that she works with PLHIV. She observed that generally people were shocked that she worked with PLHIV and surprised that she had not contracted it as a result. Participants proposed that clearer information about the transmission of HIV, the treatment options available and the dramatic reduction of people developing AIDS. The sharing of this information would need to be widespread, focusing on health professionals but also members of the public. In addition, it was recommended that a more personal message be portrayed about the effect stigma and discrimination has on PLHIV.

"You may have challenged once and let it pass 10 times. It doesn't mean that 44% of people are out there all the time fighting the battle. I remember I said I had [when responding to the Stigma Index question] because the week before I had been in a pub and people had been talking about people with HIV and I ... said, 'well ... as an HIV positive person myself...' They were perfectly...I mean I am in the position where most people have to pretend at least to be totally open and non-discriminatory. ... I move in sort of circles where people see themselves as liberal and educated. ... To be fair most people are like that, they do take it on board and realise that they'd had a stereotype that I didn't fit into. But I know that I have also not challenged, confronted or educated as well." FG 3.

"There's still a stigma. ... I say that I work in the HIV field and [people] ... can't believe that I work with people who have HIV and I have still not contracted it. And even if you tell them that its really hard to contract they don't believe you." FG 2.

"HIV is now considered as a chronic illness. Nobody is talking about it.... funds are getting cut concerning HIV because they say people can live well with HIV. But they are not even talking about the underlining issues that we face on regular basis... the stigma and the discrimination and the way people perceive people with HIV, you know it's no longer being raised as an issue." FG 1.

"There's not enough people living with HIV going out and raising awareness publicly; speaking to people in classrooms and going round schools, setting up outreach programmes, going out and talking to the politicians." FG 1.

"It goes back to stigma doesn't it? People don't want to do it [disclose and talk about their HIV publicly] because they are afraid of getting their windows bricked in, not wanting to live in the area anymore because they are talking about them, whispering about them so it's about us basically standing up and going right, I am going to do this and I've done it." FG 1.

"First of all, the frontline staff, the doctors they have to know the right information, they have the pamphlets in the surgeries... How AIDS is transmitted. Why it's important to be tested." FG 1.

"[Pamphlets] basically telling you what you can and can't do, what's safe and what's not safe." FG 1.

"I think there's been a huge campaign on Chlamydia screening in Scotland which I know the Scottish Government has put a lot of money to do this ... the same kind of money blitz can be done ... thirty second adverts about HIV and Aids bringing that kind of awareness ... now getting a lot of young adults coming forward to get tested [for Chlamydia] ... your results will be sent to you anonymously and ... if they need to go for further treatment then they do that." FG 1.

"Twenty years ago we were all scared of it [HIV], everybody remembers that and every person who didn't have the HIV that is all they remember. That is what people are stuck with and that's the reason why we are in the state we were in." FG 1.

"I was with a guy that didn't have HIV, I told him that I had it... He says 'how can you expect people to understand?' He says 'We don't know nothing... It's over 20 year ago ... grave stones were sinking with dirty water... Where 's the information in twenty years, the only reason I know is because you are telling me.'" FG 1.

"I think that we are targeting the wrong people. Don't come and talk to me about HIV treatment and how to be tested because I don't need that information ... we are targeting it to the wrong people... Why don't you target that information to hairdressers, nightclubs where people go, because that information is likely to be picked by people who are also negative? You are not only fighting stigma on people who are positive you are fighting stigma for everybody." FG 1.

"We have to explode the myths and then ... there is that little kind of revolutionary inside you that wants to jump out and scream at the world and say, 'for God's sake let's wake up' ... but on the other hand ... reality checks and you think, 'oh my God, maybe I'll die in this situation'." FG 6.

"...If you raise awareness and knowledge about AIDS, ... [if] people are more informed, [they] are less likely to discriminate." FG 7.

"...Educating people and making people realise that HIV is not something to be afraid of... I think that's probably the key to it [changing attitudes]." FG 10.

"I think it's down to education. People standing up and saying, 'okay I am HIV positive but this is what it means to me'... And through that they get people to come and test. Because they don't actually see it as this horrendous, horrific thing they thought it might be." FG 10.

"My mate is a positive speaker and he goes into schools, universities and ... prisons... He gets nothing but fantastic feedback from the kids, from the teachers... The kids, they admit to him they didn't have a clue and he goes in as an HIV positive person and he says, 'I'm living with HIV, these are the facts, this is what it's like living with HIV, this is what you face when you become HIV positive' and ... he gets fantastic results... It's an opportunity for us to get out there and tell people what the facts really are." FG 10.

"I think we have a long way to in raising awareness." FG 11.

"...When you look at [the] media, when they are talking about ... STI's ... HIV has a very tiny [mention]. There was something recently about sex educating young people ... but HIV was so tiny. It was more to do with Chlamydia." FG 11.

"I went in a couple of schools, a good few years ago now and a lot of the problem was parents, they don't want their children knowing about such things. Pregnancy yes ... they want to keep their daughters safe... It's the parents that needed some education, not just the children... When I was young, sex was never talked about. I knew nothing when I was a young girl whereas today ... they know all sorts of things... And yet it falls down when it comes to ... HIV. As for the adults, I don't know, they just seem to sweep it under the carpet, pretend it doesn't exist." FG 11.

2E.2a Do you know of organisations that help with stigma and discrimination?

Generally participants were aware of how they could access support with an issue of discrimination. This information was generally available in treatment environments although participants highlighted that not everyone would be keen to face the stress of addressing and overcoming stigma. It was suggested that PLHIV in more rural environments could easily access alternative support through internet or telephone support if required. One participant explained that initially she felt guilty and confused by her diagnosis but accessing support helped her overcome this and feel empowered to cope with it.

"Most of the HIV places where you go for treatment will have a sign ... If you are at a gum clinic you would expect them to give some information about the support services. Obviously not everybody needs to seek help over an issue of stigma and discrimination in particular because not everybody experiences stigma and not everybody wants an organisation to sort it out for them. So obviously there is going to be a disparity between those [awareness of support and accessing support]." FG 3.

"[Consideration of the experiences of PLHIV living in rural settings in Scotland]. They might be able to telephone organisations such as Terrance Higgins Trust direct ... we are living in an age where I think more and more people are using the internet and could find organisations online. I look at websites quite a lot both for information, mainly for information actually and research and I think a lot of people do use the internet. So if they've got a particular problem they could then phone the helpline and speak to someone at Terrence Higgins." FG 3.

"At first when I was diagnosed I felt guilty but now after, like being empowered... I feel okay. I just feel alright. I am not guilty of anything... You are feeling low at the beginning when you are diagnosed and then you don't know where to go, ... and then you go to these organisations where they give you support and then they empower you, ... you learn more about HIV." FG 5.

Discussion about use of Red Ribbons

One group of participants discussed the role of red ribbons. One participant stated that she did not use red ribbons; another explained that she kept it constantly on her handbag, while another indicated that she tended to wear hers primarily when attending HIV related events. One individual indicated that she had been asked specifically if she was HIV positive because she was wearing a ribbon. There was some discussion about other people wearing red ribbons and interpretation of this. One participant explained that she used people's red ribbons as an opportunity to open a conversation about why the ribbon was important to that person and to avoid hypothesising on their choice to wear a ribbon. Another outlined an occurrence where a nurse in a health centre had intentionally added a red ribbon to her uniform before inviting her in to take her bloods. She felt that even if it had been done with good intention it was inappropriate.

Do you wear red ribbons? *'No, we don't.'; 'Occasionally, I do.'; 'I do, on my bag it's always there.'; I think you become more aware of it if you are attending an HIV specific kind of event and you tend to make a conscious decision 'oh I'll wear my red ribbon'.*" FG 5

"There are some people who do ask, 'Why are you wearing that? Are you one of them?' ... You know like meaning, 'Are you HIV positive?'" FG 5.

"Perhaps that's an opportunity for us to ... ask the question 'Oh I'm interested in your red ribbon can you tell me what it means?' and strike up a conversation and then establish what they do mean. Rather than go back saying 'I wonder what she meant'. I know sometimes the circumstances aren't always easy ... but if I come across situations like that I've learnt to become empowered enough to actually ask questions or challenge that person." FG 5.

"I remember when I went to have my bloods taken for diabetes at the GP practice the nurse knew I was coming. She was wearing her uniform, she walked past, and when I got in there she had a red ribbon. I didn't know what to say but it could be a positive thing that she's in support but I would rather be treated like anybody else... I thought there was no need to wear a red ribbon. Are you trying to say something to me? Are you feeling sorry for me or it could mean "oh I'm in support with you"... But when you go to a doctor's surgery and nobody's wearing a ribbon and they see you and then you go and come back with a red ribbon... I don't know what it meant but I thought she shouldn't have worn it." FG 5.

CRIMINALISATION

Rights Abuse (2d.3): I was arrested or taken to court on a charge related to HIV

None of the participants involved in the focus groups reported personal experience of criminal charges relating to their HIV status, however, many expressed opinions about the legal situation. The impact of undertaking legal action against the individual who passed on HIV was discussed. The negative portrayal in the media concerned some individuals. One participant described his fury with the person who infected him, but he hadn't followed through with prosecution. He explained that he still had not come to terms with his anger and would attempt to attack the man when he saw him socially. One group of participants explained that at a female peer support group a lawyer had explained that providing a person has an undetectable viral load and used a condom, they could not be prosecuted for passing on HIV. Another participant described the challenges faced by an individual she knew who had successfully prosecuted the man who had infected her. It was suggested that the experience was extremely negative as many personal details were discussed and the media portrayed a biased picture of the events.

"If you are going to bring them to court ... move away because everybody is going to know who you are and what you have... They can't control the media. They want to know who you are and they want to know who the other one is. And I don't think it's right." FG 4.

"When I found out, I knew exactly who it was and I actually told him. It wasn't actually just a casual shag. But it was somebody that I knew... I was the world's greatest about sexual health, I went about every 6 months to get myself tested and preached to my straight friends as well... It's sods law, I get. But, so I actually went to the guy, ... you sort of think, 'Well did he know?' ... I never went down that road because I thought I could drive myself crazy. It's my responsibility. I didn't use a condom that night. I can't blame anybody else except me. I knew the risk and I just thought with a horny head or whatever, 'yeah it's okay we'll take this route'. I've seen that guy a couple of times in the town and I have attacked him every time and there's been the police and all been called... I wanted to kill him. Because he has practically killed me." FG 4.

"The lawyer [a speaker at an NHS peer support group] said that if you are undetectable for so many years, say 5 – 6 years and you kept taking your medication and you used a condom, you couldn't get prosecuted for giving someone HIV". FG 2.

"[I met] someone who decided to prosecute the man who had infected her ... [she] went through the ordeal of having the criminalisation act. ... I felt very sorry for her ... nobody ever tells all the truth to everybody so I wouldn't like to judge it but I think it must have been absolutely hellish to go through ... she won but you know what she went through at the time of being accused ... her sex life being described ... and all sorts of things were not what anybody would want. One of the biggest stigmatising things I think is the way the media presents those criminalisation cases. That the whole issue is turned into innocent victim horror, you know horrid evil character who is going out and doing it." FG 3.

"The really, really frightening thing about criminalization is it's driving people underground... [They are] not disclosing." FG 12.

"...you are regarded as very much a second or third class citizen by ... or authorities or laws." FG 7.

3B.1 Disclosure to and reaction from your husband / wife / partner

Participants also debated the responsibility of sexual partners to keep themselves safe from sexually transmitted infections. Some considered that, irrespective of HIV status and disclosure, both partners should be equally responsible for practicing safe behaviours. Others felt that if someone was aware of their HIV status they had a moral obligation to ensure the risk of their sexual practices was minimised, particularly if they had not disclosed their status to their partner. One individual indicated that their partner had not opted to use condoms because he believed they would be together long-term.

"You must be responsible for your sexual actions ... everybody is responsible, not me because I am HIV positive, and sometimes that really makes me mad because you get the media pushing people with HIV to tell every

partner. I mean if you meet somebody you are not going to disclose the next night 'I am HIV positive.' No! You use condoms. The other person who is not HIV must be also ... say 'you know what, we are not having this unless you wear a condom or whatever.' But you know what it's always the person who is HIV positive ... doing everything no, no, no it's supposed to be everybody." FG 1.

"[As] positive people, we can't carry this baggage of telling people that we are HIV positive, people should be responsible for their [own] sexual life." FG 10.

"There is this wounded healer syndrome that because you are positive you are responsible for everybody's actions." FG 1.

"I don't completely agree with that because I think morally ... because I would have liked the person [who infected me], I think because you know that you are HIV I think it's kind of... for me [a] moral [issue] but that's only me personally speaking." FG 1.

"You also had the responsibility to protect your own self from and it should not always be the positive person ... to take the responsibility. Some people are not responsible that's for sure, it's going to happen, so everybody, regardless of their status, should be responsible about their own sexual action." FG 1.

"Basically about the law, I think people living with HIV don't know what is legal and I think it's important that they should." FG 1.

"Most of us are responsible, most of us are thoughtful. Whether we choose to disclose or whether we choose not, the vast majority of positive people do practice safe sex, because quite frankly they don't want to get anything else apart from what they already got." FG 12.

"It's up to both of you to take precautions. It shouldn't be down to one person." FG 12.

"I insisted that I wanted to use condoms, but he said, 'oh we'll be together for the rest of our lives' because things were going good." FG 11.

"My husband obviously thought it could never happen because he said he only went with 'nice ladies'. Those were his words. Not ... prostitutes, just nice ladies. One of those nice ladies infected him. Consequently he infected me." FG 11.

"Isn't it up to you to say 'you must use protection' or 'we must use protection?'... To look after yourself?" FG 11.

1.6 Are you sexually active at the moment?

The lack of clear guidance about how HIV can be transmitted in intimate relations was a major concern for participants. Many explained that they were not confident about how to keep partners who are HIV negative completely safe. The production of a relevant informative document would ensure that health professionals did not communicate incorrect information.

"Whether or not you are having intimate sex ... there is not enough information on what you can do, what's safe, what's not safe... For people living with HIV and for people that not living with HIV who maybe have a sexual partner who is positive... For example, my partner is not HIV positive ... I chew my gums with nerves and I don't know whether that's safe or not, even when I am kissing, small things like that." FG 1.

"I agree with you there should be more do's and don'ts, ... the risks and the non risks because a lot of people are still stuck with information from twenty years ago. Is there anything bringing this up to the future?" FG 1.

"I discovered a thing that was printed by a Gay men's group in London just recently, ... and it was everything from what you can do and what you can't do, a list from A to Z and it's fantastic." FG 1.

“For me personally I am constantly worried and I know, I practice protected sex and that’s fine, but I’m just...it just worries me.” FG 1.

“I know you can’t kiss in the morning after brushed your teeth, ... because you can have bleeding gums ... there is research, ... to check the amount HIV that comes through the gums ... But people really need to understand... I nearly dated about ten years ago ... we went to this nurse and we were told, the guy was told what to expect and then finally she said ‘don’t kiss her’ ... there is a big gap about training. They know a bit about HIV but there is that gap.” FG 1.

RIGHTS ABUSE

2D.4 Not sure if rights as a person living with HIV have been abused.

Participants explained that they were unclear on their rights as a person living with HIV. There was some awareness that the Disability Discrimination Act (DDA) was a tool for protection but its role was not fully understood. In addition, it was considered inappropriate for a person living with HIV to be automatically considered to be disabled, as the interventions and health status of PLHIV are considerably better than they were when HIV was first discovered.

"I don't think anybody knows what their rights are." FG 2.

"I do know that I'm covered by the DDA, but surprisingly when I am doing peer support a lot of people don't even know that. It's a hidden disability, not a physical disability." FG 2.

"I don't think it should be classed as a disability these days because these days people are more healthier these days. ... It's not like 20 year ago, maybe because I've got facial wasting, somebody will go you're HIV positive. ... So I don't think it should be classified as a disability, it should be classed as something else." FG 2.

"I have no idea what my rights are as a person living with HIV." FG 10.

"There's nobody there to tell you, this is what your rights are or this is what your rights aren't." FG 10.

"I know there are ... rights to treatment, rights to a decent quality of life. Other than that ... with regards to working ... no idea." FG 10.

2D.3 I was forced to submit to a medical or health procedure (including HIV testing)

One participant described being pressurised by medical staff to have her children tested. She explained that she knew her children were not at risk as they had not been exposed and felt that this pressure was unnecessary and as a result this was causing her unnecessary anxiety.

"The problem that really is bothering me at the moment... When I was diagnosed, I told my children. My twins ... are now 16... I went to the clinic, and there was this young doctor... who says, 'oh so have you told your children' and I say '[yes]'... He said 'have you got your children tested' and I said 'no'. And he said 'but you should'. And I said why. And he said, 'oh but you have to be sure' and I said 'Why? I am sure. They don't have to be tested.' It was like 10 minutes as he was talking about children and I said you know what, 'I am just going to go. Can I get my blood test and you just let me go because this is just me... I think I am responsible enough to understand where I am coming from and I know where I am coming from so don't push me saying, have you got your children tested?' ... They went on to tell my GP and I have got like 3 letters now to say, 'you realise that the clinic said you should have your children tested and we are still waiting?' They actually phoned me three times and I said 'I am really getting, you know, I don't want to say any bad words to you and I am sure you are doing your job but I feel like you are actually putting me in a tight corner as if ... I am doing something wrong for my children.' I know that for a fact, and if I for some reason want my children tested, it's going to be me, not anybody else [who encourages it]. But I am quite convinced that my children are not an issue." FG 4.

2D.3 I was denied health insurance or life insurance because of my HIV status

Some concern was raised about the difficulty in getting life insurance if a person is HIV positive. This may make people reluctant to be tested. Another concern raised was availability and cost of travel insurance for PLHIV. Some participants had been denied travel insurance as a result of their HIV status or been informed that they could only go to certain countries. There was an assumption that insurance companies would opt not to compensate for medical costs abroad by using the excuse that any illness was a result of a pre-existing condition.

"When they get tested they cannot in effect get life insurance... I cannot get any other life insurance over £10,000 because I am HIV positive. ... £10,000, that's your maximum." FG 2.

"Being denied health insurance or life insurance for being honest enough to disclose their status ... I haven't personally but I do know people who have..." FG 10.

"I get free [health] insurance through my bank and they cover you if you are HIV positive but only if you take one drug. If you take more than one drug for the condition, then they won't cover you." FG 11.

"It [travel decisions] also depends too on things like health insurance or life insurance. ... It depends whether you are actually honest as well as you reveal your HIV status. I haven't." FG 3.

"I mean the health insurance you basically take the chance for travel if you, ... you pay a lot extra and disclose your status to the insurers and you know that they will claim that everything you've got is a pre-existing condition. So you basically are travelling without health insurance. Effectively, I mean I think of my travel insurance as not covering my health." FG 3.

"Well the first question the [travel] insurers ask you is, 'have you been in hospital in the last 12 months?' 'Yes.' 'What were you in for?' 'I had to have 5 units of blood.' 'Try again in 12 months.' They know your status because I'd declared it before... The bottom line is I didn't go to Australia but I can apply again in 12 months and hopefully be able to go." FG 11.

"I wanted to go to Turkey. They [travel insurance] said, 'we won't cover you for Turkey but you can go to Northern Spain'. So I just didn't go." FG 11.

2D.3 I had to disclose my HIV status to apply for residence or nationality

Individuals applying for residency in the UK found the need to disclose and the monitoring of their HIV-related health frustrating. One individual believed that being HIV positive could help your application for residency, but explained that you were obliged to offer evidence of your status. One woman had been threatened with deportation because it was argued that medication was available in Malawi, however, this was contested and at the time of the focus group, the dispute was not resolved. Another person explained that a doctor's report was required regularly for application of residency and he believed this may be to determine if you should be allowed to stay or not. One woman explained her belief that the Conservative government intended to limit immigration and the rights of immigrants to seek employment, thus obliterating many people's hopes. Generally participants felt strongly that there should be no obligation to submit to testing or to disclose their HIV status. It was argued that the decision to disclose should lie with the individual living with HIV. Another suggestion was that the viral load of the individual offers considerably more information and therefore would be more appropriate to disclose than simply the HIV status.

"Having come to Britain, ... on my application [I had] to disclose my status because I wanted to access medication. That was 2002 ... then I had to make an application the following year... To start with I was denied because they said it [medication] was available in my country... And that's the problem when we are applying ... for renewal of your ... immigration status, they will ask for your doctor's report... They already know that you're HIV positive, why would they want to go and keep on asking the same questions? They are very intrusive when they do that. They always want a medical report ... so that the doctor will write whether you're dying or if you are strong enough to, I don't know." FG 5.

"We had a case recently of a lady who was going to be deported to Malawi on the pretext that they was medication in Malawi but while she was in detention, ... had very high blood pressure so ... because she was really in a bad state, she got reprieve. She wasn't deported but they are at the moment still monitoring." FG 5.

"Apparently the new government have completely refused that [amnesty], that's out and obviously that then, you know it shatters the hopes for lots of people... Well, rumour has it that ... they [the Conservatives] are not willing to consider it at all. So that sort of leaves everybody who had that little bit of hope that they might be able to get stay or be allowed to work here, that possibility is not there anymore. And I am not quite sure they've got in place but it's things like that. As an African, coming from an African background, I am quite aware of

many people who would rather work and they are not particularly interested in being able to get the benefits.” FG 5.

“Being forced into medicals and divulging our status ... is shocking ... where does that leave us? Unless you are putting someone at risk there’s no reason why you should have to disclose your status.” FG 2.

“I don’t think your status should matter, it should be your viral load to your blood counts.” FG 2.

“Nobody else has that right to oversee your decisions.” FG 2.

“If you are HIV positive and you have immigration problems, they are likely to send your HIV status to the Home Office. I think most of asylum seekers go through that... If you tell them that you are HIV positive, they don’t believe it so you have to get a letter from your consultant... They ask you, ‘Where did you get it from?.. How did you get it?.. Did you get it from Africa before you came?’... You don’t have to show it. If you want your application to be considered and maybe not to be taken into detention, ... then you disclose.” FG 10.

Rights Abuse (2d.3): I had to disclose my HIV status in order to enter another country

It was suggested that many people living with HIV made the decision not to travel to certain countries because they would be obliged to disclose their status.

“If 6% had to disclose [their HIV status to gain entry to another country] I suspect 50% made their choices on where to go.” FG 3.

“I think that understates the restrictions on travel that people feel.” FG 3.

“There are still countries that will insist on a HIV test for you to enter the country and I find that is not acceptable.” FG 5.

3B.3 / 3B.1 HIV status disclosed to Housing Association without consent

A number of participants raised concerns about their HIV status being shared with their Housing Association without their permission. Generally there was limited understanding of how this had occurred and why it was necessary. In another circumstance a woman had been denied housing until she disclosed her HIV status to those she was currently residing with.

“I get a lot of people coming here [support centre] complaining because their health information has been shared among agencies... Even housing associations have been given this information... I mean that’s ridiculous; you don’t need a better house because you are HIV positive. You just need somewhere to stay and she just needs to be treated like anybody else.” FG 1.

“We have a service user from the HIV support centre in Belfast and she applied for a house ... and they wouldn’t put her on the housing list until she disclosed to all the people in the house flat she was living in... About sixteen to eighteen months ago.” FG 1.

“I have no problems with my documents being circulated among people that I know are going to take care of me. My problem ... why should the housing association know about my health problems... My doctor has got the responsibility to make sure I am protected from that because sometimes you walk in the housing association and even if people don’t react negatively its the positive support that they give you that tells the whole story... Confidentiality [is] very, very tricky within the health settings so I don’t know I have got mixed feelings with that.” FG 1.

3B.1 Disclosure: Government officials

“When they arrest you on drink and driving or another offence ... they ask you if you are HIV positive... I have heard of somebody ... [the Police went] ... to his house and checked and they found the medication. They said, ‘how come you didn’t tell us?’ He said, ‘because it has nothing to do with drink and driving.’ And they said, ‘what is this medication for?’ He said, ‘I’m not going to tell you because it has nothing to do with drink and driving.’ But it happened.” FG 11.

A NUMBER OF HYPOTHESES PARTICIPANTS OFFERED DURING THE SESSIONS:

- Participants felt that the awareness of transmission pathways within health professionals was poor, in particular GPs and dentists.
- There was interest in the disclosure of individuals living with HIV when they become residents in care homes. It was suggested that aging with HIV would be an appropriate topic to explore further.
- In relation to self-stigma: *"I think what would be very interesting, ... to find out, at the time when people when interviewed how long had it been after they had been diagnosed?"* FG 1.
- Some participants explained that they found the disclosure process neither empowering nor disempowering and suggested that it would be valuable to explore this 'neither' category in more detail.
- It would be very interesting if the stigma index ...extended to discussions with health professionals. *"Maybe they also have something to tell us or to blame us for, as we are blaming them. You know we talked a lot about dental surgeries and you know disclosure and things like that, what do they see? Do they see something, which is wrong, passing someone's information to another person or what are their views about the stigma in general? What is their understanding of stigma? How do they feel when I go in there and I am given my card by so many counsellors and social workers? It's just getting their perspective, what they think about the stigma in general, including clinicians because they are the worst culprits."*
- It was suggested that decisions about destinations for travel were made with consideration of the restrictions of travel for PLHIV. Participants believed that many people in the HIV community would avoid travelling to countries where they would be obliged to disclose their status.
- Participants highlighted the high rates of unemployment in the sample as a concern. It was suggested that further investigation should be undertaken to explore why people are not in work. It was hypothesised that barriers to employment for PLHIV may have an influence.
- Further exploration of the reasons people state that they have been excluded, by people or from an environment, were recommended. It was suggested that some people may chose to opt out of situations because they are reluctant to be obliged to discuss things in particular company. For example, they may not attend events in the HIV community because they do not want to discuss their current HIV related health. Alternatively, they may not want to enter an environment where there is overlap between people they have not disclosed to and people they know through the HIV community, thus raising questions about how people know each other.
- It would be interesting to consider when/ how/ where people received their HIV diagnosis as well as the cultural or societal environment? This would allow consideration of the potential impact of this process as someone starts to live with chronic HIV diagnosis.

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