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List of Abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CD4	Cluster of differentiation 4
DFID	Department for International Development, United Kingdom
GNP+	Global Network of People Living with HIV
HCMC	Ho Chi Minh City
HIV	Human immunodeficiency virus
IBBS	Integrated Behavioural and Biological Surveillance (HIV/STI)
ICW	International Community of Women living with HIV and AIDS
IPPF	International Planned Parenthood Federation
MSM	Men who have sex with men
OPC	Outpatient clinics
PAC	Provincial AIDS centre
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PWID	People who inject drugs
STI	Sexually transmitted infection(s)
FSW	Female sex worker(s)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UN Women	United Nations Entity for Gender Equality and the Empowerment of Women
USD	United States Dollars
VND	Viet Nam Dong
VNP+	Vietnam Network of People Living with HIV
WHO	World Health Organization

Foreword

Since its establishment in 2008, the Viet Nam Network of People living with HIV (VNP+) and its member self-help groups and networks throughout Viet Nam have worked hard towards ensuring that people living with HIV are able to live free of stigma and discrimination, are accorded the rights due to them under the law, and can participate in the HIV response.

We are very proud of our part in the global effort to address the need for hard evidence of stigma and discrimination. We hope that the results of the Stigma Index survey in Viet Nam will influence national policy and programmes and improve the lives of people living with HIV.

The success of the Stigma Index survey in Viet Nam was thanks to the efforts of many. Special appreciation must go to the people living with HIV who served as data collectors in the five provinces where the study was conducted. We would also like to thank the Viet Nam Administration for AIDS Control and the Provincial AIDS Centres in these provinces for their support and collaboration. Our gratitude also goes to the advisers from government, academia and international partners who provided guidance during the planning of the study and during the validation meetings in Can Tho, Dien Bien and Ha Noi.

We would also like to thank the Joint United Nations Programme on HIV/AIDS (UNAIDS) for its financial and technical support. We are also grateful to the World Health Organization in Viet Nam which provided invaluable technical support. Thanks also go to GIZ, the German agency for international cooperation (Deutsche Gesellschaft für Internationale Zusammenarbeit), which provided funding for the project.

Finally, our sincere thanks to Do Thanh Toan and Dinh Thi Mai Huong, who who provided technical assistance for the study design, the training of data collectors and the data analysis.

We look forward to using the Stigma Index survey results and recommendations for the benefit of all people living with HIV in Viet Nam.

Do Dang Dong
Chairperson
Viet Nam Network of People Living with HIV (VNP+) Council
XXX DATE 2012

Executive Summary

The Stigma Index study

HIV-related stigma is recognized both globally and in Viet Nam as a primary barrier to addressing prevention and care issues and ensuring access to essential services. The global Stigma Index study was designed to address the need for a quantitative recording and analysis of the different levels and types of stigma, as well as changes in trends and with time, to inform evidence-based policy and programmes. The process of conducting the Stigma Index is as important as the result: the survey is conducted "by PLHIV, for PLHIV".

In Viet Nam, the HIV epidemic is concentrated among people who inject drugs (PWID), men who have sex with men (MSM) and female sex workers (FSW). The Stigma Index study was conducted in five provinces (Can Tho, Dien Bien, Ha Noi, Hai Phong and Ho Chi Minh City) by the Vietnam Network of People Living with HIV (VNP+), an organization run by and for people living with HIV (PLHIV). To ensure that stigma and discrimination among the three key populations at higher risk was identified, to help distinguish between HIV-related and behaviour-related stigma and discrimination and to identify "double" stigma, both a random sampling of PLHIV attending outpatient clinics (OPC) and a purposive (snowball) sampling of PWID, MSM and FSW were conducted. A total of 1,200 OPC-sampled PLHIV in all 5 provinces, 150 snowball-sampled PWID in Dien Bien, 150 snowball-sampled FSW in Ha Noi and 142 snowball-sampled MSM in Ho Chi Minh City took part in the study.

The Stigma Index results

The Stigma Index survey data clearly show that PLHIV in Viet Nam face considerable stigma and discrimination. More than two-thirds of the snowball-sampled respondents and over half of the OPC-sampled respondents reported that their right to live free of discrimination had been violated.

The data also show that HIV status is not the only challenge for PLHIV. In the context of Viet Nam's concentrated epidemic, stigma is attached both to HIV status and to risky behaviours which are stigmatized in and of themselves, as well as perceived to increase HIV risk – injecting drug use, sex work and homosexual activity. Many survey respondents (but particularly snowball-sampled key populations) reported their perception that their behaviours create more stigma and discrimination than their HIV status, or create 'double stigma' in conjunction with their status. Injecting drug use was the most commonly reported reason for non-HIV related stigma and discrimination.

The survey confirms that the health system has successfully scaled up HIV-related services, with high access to ART and one-third of HIV tests resulting from health care referrals. Stigma and discrimination by health care providers is reportedly low. However, stigma and discrimination is much higher outside health care settings. Many PLHIV struggle to maintain sustainable livelihoods: unemployment among PLHIV is high (up to 24.3% among OPC-sampled men), and many reported losing a job (16.2% of FSW, 10.4% of OPC-sampled respondents and 9.7% of MSM in Ho Chi Minh City) or being forced to change the nature of their job, as well as stigma in the workplace (14.9% of OPC-sampled respondents who lost a job). Others – particularly FSW in Ha Noi and women in the OPC sample – reported having been forced to change residence or unable to rent a home (20% of FSW in Ha Noi and 8% of OPC-sampled women). There is also evidence that up to 3% of PLHIV and up to 4% of the children of PLHIV have been denied access to education.

In addition, many of the most egregious examples of stigma and discrimination seem to occur outside institutional settings, in the family or community, with friends and neighbours the greatest

source. Gossip was the most frequently reported form of stigmatization (52.2% of MSM in Ho Chi Minh City, 49.3% of FSW in Ha Noi, 36.7% of PWID in Dien Bien and 32.5% of OPC-sampled respondents). Verbal insults and physical assault were particularly common among women: 8.9% of OPC-sampled women reported verbal insults and 4.9% reported physical assault, while 31.3% of FSW in Ha Noi reported the former and 20.7% the latter. Perhaps for these reasons, over 94% of MSM in Ho Chi Minh City and nearly 85% of FSW in Ha Noi, 80% of OPC-sampled PLHIV and 60% of PWID in Dien Bien have not revealed their HIV status outside their own family. Over 30% of MSM in Ho Chi Minh City and 1 in 10 OPC-sampled respondents reported that their spouse or sexual partner did not know their status. This stigmatization of HIV and of HIV-related behaviours affects PLHIV in terms of social insecurity and isolation, which can be compounded by self-stigmatization.

The data also identify major areas of concern for PLHIV which will need to be taken into account in future law/policy making, service delivery and law enforcement. Firstly, despite legal protection of the right to confidentiality, the serostatus of PLHIV – and particularly that of PWID -- is being disclosed without their consent: nearly 30% of OPC-sampled respondents, 34% of FSW in Ha Noi and 18% of MSM in Ho Chi Minh City reported non-consensual disclosure to neighbours; over 50% of PWID in Dien Bien reported such disclosure to community leaders. Fear of disclosure without consent may serve as a barrier to people being tested for HIV.

Secondly, 13% of respondents reported coerced testing or testing without prior knowledge – again, this breaches the legal right of individuals to voluntary testing and may dissuade others from undergoing tests. Very few PLHIV have sought legal redress for either of these violations of their rights, or their right to non-discrimination.

Thirdly, there is evidence that some PLHIV are receiving inadequate, inaccurate or coercive reproductive health advice. More than one-quarter of all respondents reported being advised not to have children, while a small proportion of respondents also reported being advised to undergo sterilization, or obliged to use contraception.

Recommendations

The survey data, as well as discussions with survey respondents, VNP+ leaders and stakeholders who participated in the three validation meetings, revealed concrete ways to better combat stigma and discrimination and improve the lives of PLHIV in Viet Nam.

In many cases, protective legislation already exists. However, greater efforts are needed to ensure adherence to the law and the implementation of related policies. This may require further training and education for national and provincial health care and government workers. In these regards, the recent *Decree No. 69/2011/ND-CP* on handling administrative violations in health prevention, the medical environment and HIV/AIDS prevention and control provide welcome support for the enforcement of the Law on HIV. In addition, PLHIV will need greater support in seeking legal redress for violations of their rights, such as being forced out of a job or one's home due to HIV status.

Since much of the stigma and discrimination against PLHIV in Viet Nam appears to originate from within their immediate communities (i.e. family, friends and neighbours), social and community education and mobilization are required. Furthermore, given the incidence of 'double stigma' and behaviour-related stigma and discrimination, efforts are also needed to address these at the community level. For example, education should include knowledge about both HIV and risk behaviours to counter community fears that contribute to stigma. Community and mass organizations should also be further engaged in responding to stigma and discrimination at the local level.

Specific recommendations arising from the survey include:

Confidentiality

- Additional efforts are needed to protect the confidentiality of PLHIV – especially in the delivery of health care and social services.
- Additional efforts are needed to ensure that all HIV tests are taken after obtaining informed consent.
- "Treatment as prevention" efforts (such as the new Treatment 2.0 pilot) must include ways to protect confidentiality during the transition from testing to pre-ART to ART enrolment.

Family, society and community

- The role of self-help groups, including VNP+, needs to be strengthened in order to provide stronger peer support to PLHIV to build their confidence, reduce self-stigma and learn about the law and regulations that protect against stigma and discrimination.
- Additional efforts are required to protect female sex workers and other women living with HIV from verbal and physical abuse.
- PLHIV need additional employment support, focused on building sustainable livelihoods, and ensuring that employers cannot dismiss PLHIV because of their HIV status.

Treatment and health care

- Affordable HIV treatment programmes should be maintained and include:
    - Free or easily affordable CD4 count and viral load tests
    - Earlier initiation of antiretroviral treatment in line with WHO recommendations
    - Free or easily affordable medications to reduce side-effects and opportunistic infections
    - Shorter waiting times and increased numbers of well-trained health care providers
- Health care services provided to PLHIV should include reproductive and family planning services, including options to safely have children.

1. Introduction

HIV-related stigma is recognized both globally and in Viet Nam as a primary barrier to addressing prevention and care issues and ensuring access to essential services. However, although anecdotal experience of stigma has been documented, very few efforts have been dedicated to a quantitative recording and analysis of the different levels and types of stigma (both external and that imposed by people on themselves) faced by people living with HIV (PLHIV), as well as changes in trends and with time. Such research is needed to provide the basis for evidence-informed policy and programmes.

The Stigma Index globally

In response to this need, the Global Network of People Living with HIV (GNP+) and the International Community of Women living with HIV and AIDS (ICW), designed a study to measure the stigma experienced by PLHIV, supported by a two-year grant from DFID, the International Planned Parenthood Federation (IPPF), in partnership with UNAIDS. The ultimate aim of this "PLHIV Stigma Index" is to improve programmes and policies to achieve universal access to prevention, treatment, care and support. The study is a tool that can be used to evaluate efforts to address stigma and collect evidence, which can in turn be used to inform policy and advocacy through a more comprehensive and nuanced understanding and documenting of the nature of stigma experienced by PLHIV. For example, it is too often assumed that stigma is directly related to only the HIV-serostatus of an individual. Also too often it is assumed that individuals from key vulnerable populations (men who have sex with men, people who inject drugs, sex workers) may face 'double stigma' that stems from not only their HIV–positive serostatus but also their behaviour or orientation. The Stigma Index is able to move beyond assumptions and actually measure and quantify some of these different forms of stigma, for example by province, by key population or by gender. As the study is repeated over time, the ongoing results of the work will enable analysis of the changing trends relating to stigma within individual countries.

The objectives of the PLHIV Stigma Index are to:

- Document the various experiences of PLHIV within their communities regarding HIV-related stigma and discrimination;
- Provide an evidence base on HIV-related stigma for policy change and programmatic interventions;
- Measure changes over a period of time as it relates to changing attitudes.[1]

The process of conducting the Stigma Index is as important as the result. The survey is conducted "by PLHIV, for PLHIV": PLHIV are the managers of the study, the data collectors and the data analysts.

The Stigma Index survey in Viet Nam

In Viet Nam in 2011, twenty years after the first case of HIV was reported, there were 197,335 PLHIV on record and an overall prevalence of 0.45%[2]. The epidemic remains concentrated primarily among

[1] The Stigma Index survey is not intended to be a one-off study; Viet Nam has completed the first survey, and the intention is to repeat the survey in the future.

[2] Viet Nam AIDS Response Progress Report 2012. National Committee for AIDS, Drugs and Prostitution Prevention and Control, 2012. http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/progressreports/2012countries/ce_VN_Narrative_Report.pdf. Accessed 17 June 2012.

three populations defined by high levels of HIV-transmission risk behaviours: people who inject drugs (PWID), men who have sex with men (MSM) and female sex workers (FSW). According to 2011 sentinel surveillance,[3] HIV prevalence among men who inject drugs and FSW reached 13.4% and 3% respectively; IBBS 2009 data[4] indicate that prevalence among MSM was 16.7%. PLHIV continue to face stigma and discrimination. Acts of discrimination can include abandonment by a spouse and/or family; social ostracism; loss of employment and/or property; expulsion from school; denial of medical services; a lack of care and support; and even violence. These consequences – or the fear of them – may mean that people are less likely to voluntarily take an HIV test, disclose their HIV status to others, adopt behaviours that protect them from infection, and access treatment, care and support.

The Stigma Index survey was conducted by the Vietnam Network of People Living with HIV (VNP+), an organization run by and for PLHIV. VNP+ was officially established in 2008 and has since expanded to include 128 self-help groups, alliances and networks across the country. VNP+ works to: advocate for the rights of HIV-positive people, including access to treatment, care and support; improve prevention activities; fight stigma and discrimination; and increase the involvement of PLHIV in all aspects of the HIV response. The organization creates and maintains information channels among groups, organizations and individuals, thereby helping to form linkages and facilitate information- and experience-sharing related to HIV activities. VNP+ was supported in conducting the Stigma Index survey by UNAIDS, WHO, the Government of Viet Nam and other partners, and the results will provide important inputs to the Government's efforts to increase uptake of HIV prevention, treatment, care and support services.

2. Methodology

> *"The People Living with HIV Stigma Index is not intended to be an abstract academic exercise that is done "to" our community. It is intended to embrace a participatory spirit for all those involved. People living with HIV will be at the centre of the process as interviewers and interviewees and as drivers of how the information is collected, analysed and used."*
>
> **PLHIV Stigma Index User Guide**

Although the number of recorded PLHIV in Viet Nam in 2011 was 197,335, many are unaware of their serostatus. Only PLHIV whose serostatus has been revealed to others (with or without their consent) can experience status-related stigma and discrimination. The target population of the Stigma Index survey was therefore PLHIV who know their status. A rough estimate of people who knew they were living with HIV was obtained using 2009 figures[5] and subtracting the number of reported deaths due to AIDS-related illness (44,050) from the number of reported HIV cases (160,019). From this total (116,000) children – who were not to be included in the study given the complexities of obtaining informed consent – were subtracted, leaving an estimated total of 113,700 adult PLHIV who knew their status.

It was important for the sample size of the target population be large enough to produce results with a reasonably small confidence interval, particularly if another Stigma Index survey is conducted in future to track trends (if such a future survey produces a point estimate within the confidence bounds of the first study, it will not be clear whether there has been a change for that indicator). Obtaining a random sample of the target population was a particular challenge. One possibility was to recruit from the members of PLHIV self-help groups. However, there were concerns that this

[3] Sentinel Surveillance Survey 2011. Viet Nam Administration of AIDS Control, 2011.
[4] HIV/STI Integrated Behavioural and Biological Surveillance (IBBS) in Viet Nam – Round II 2009. Ministry of Health, 2011.
[5] Report on 2009 HIV/AIDS Epidemic. Viet Nam Administration of AIDS Control, 2010.

population would not include a significant percentage of PLHIV in the country. It was determined that a broader sample of PLHIV could be obtained through the lists of registered patients kept at Provincial AIDS Centres (PACs).

In addition, given the fact that Viet Nam's epidemic remains concentrated among people who inject drugs (PWID), men who have sex with men (MSM) and female sex workers (FSW), it was judged important to estimate with reasonable confidence intervals the levels of stigma and discrimination faced by these sub-populations of PLHIV. The assumption was made that – due to the stigmatization of drug use and sex work (and indeed the administrative detention of drug users and sex workers) and a lack of acceptance of same-sex sexual activity in Vet Nam – PWID, MSM and FSW might not self-identify within a general sample, and it was therefore decided to conduct both a random sampling of PLHIV attending outpatient clinics (OPC) and a purposive sampling of PWID, MSM and FSW. It was also hoped that this would help to distinguish between HIV-related and behaviour-related stigma and discrimination and to identify "double" stigma.

The Stigma Index survey was conducted in five provinces – Can Tho, Dien Bien, Ha Noi, Hai Phong and Ho Chi Minh City (HCMC) – to cover a range of geographical and economic conditions, HIV prevalence and donor presence.[6] These provinces also contain an estimated 48% of Viet Nam's total population of PLHIV.[7] One thousand two hundred PLHIV were interviewed at outpatient clinics (OPC) in the five provinces. They were recruited by randomly sampling the pre-ART/ART registration lists at Provincial AIDS Centres (PACs), with VNP+ study coordinators and their support groups in each province collaborating with PAC staff, who obtained consent from the people randomly selected by VNP+.[8]

In addition, as explained above, members of key populations at higher risk living with HIV in provinces with greater concentrations of such groups were selected by VNP+ study coordinators and their support groups in Dien Bien, Ha Noi and HCMC using snowball sampling. In this process, 10 people were randomly selected by VNP+ from a list of people belonging to the key population at higher risk and interviewed. At the end of the interview, each of the 10 people were asked to introduce the interviewer to two other members of the key population. This process was repeated until the required number of participants was reached. These included 142 self-identified men who have sex with men (MSM), including 14 who self-identified as transgender, in HCMC; 150 women who currently work, or have worked, as female sex workers (FSW) in Ha Noi; and 150 people who inject drugs (PWID), or who have done so, in Dien Bien. In total, data were collected from 1,642 PLHIV. It is important to note that it is not possible to directly compare the data from OPC respondents with the data from the snowball-sampled PWID in Dien Bien, FSW in Ha Noi and MSM in Ho Chi Minh City, in part due to the very different sample sizes. The two sets of data therefore stand alone.

[6] The numbers of participants chosen in each province were not weighted according to their PLHIV populations, as this would have skewed the results in favour of Ho Chi Minh City. An effort to take into account PLHIV populations can be seen in the higher numbers of participants in Ha Noi and Ho Chi Min City, but it was not proportionate.

[7] Preliminary Viet Nam HIV/AIDS Estimates and Projections, 2011. Ministry of Health, National Technical Working Group on HIV Estimates and Projections, 2011.

[8] This group also included members of key populations at higher risk (PWID, MSM and FSW) but they were not selected on this basis.

Table 1: Stigma Index participants by province and sampling method

Province	OPC sampling		Snowball sampling			Total
	Male	Female	PWID	FSW	MSM (including transgender)	
Ha Noi	184	116	0	150	0	**450**
Hai Phong	123	77	0	0	0	**200**
Dien Bien	115	85	150	0	0	**350**
Can Tho	121	79	0	0	0	**200**
Ho Chi Minh City	203	97			142	**442**
Total	**746**	**454**	**150**	**150**	**142**	**1,642**

All survey participants were required to be living with HIV; aged 18 or above;[9] and willing to participate. Participants could only participate in one study group: for example, PWID living with HIV interviewed at an OPC in Dien Bien were not also interviewed as part of the PWID snowball sample group. For this reason, the OPC participants were selected first, and potential participants from the snowball sample group were cross-checked against the list of OPC participants. The survey was based on the principle of informed consent, with each participant being fully informed about the nature of the study, who was involved in it, how the data would be processed and stored, and what the data would be used for and then asked to consent to the collection and processing of their personal data. Participants were also welcome to refuse to be interviewed, to withdraw from the survey, or to refuse to answer a specific question or set of questions, at any time.[10] Every effort was made to ensure that the data collected were kept confidential (i.e. secret), including through the use of safeguards such as the use of unique identifying codes so interviewees' names are never written on the questionnaire; the separate and secure storage of the informed consent forms and the lists of names and the contact details for each interviewee (alongside their unique identifying codes); and the planned destruction of these papers after the finalization of the Stigma Index.

The Stigma Index survey itself is a cross-sectional survey with both quantitative and qualitative (open question) elements. The main data-collection tool, a structured questionnaire (see Annex 3), explored experience of HIV-status-related stigma and discrimination and was designed to collect key information on:

- Respondent experiences over the last 12 months of HIV status-related stigma and discrimination, self-stigmatization and the extent of protection of the rights of PLHIV through law, policy and/or practice.
- Reported specific instances of HIV status-related stigma and discrimination over the last 12 months, focusing on HIV testing, status disclosure and health care provision.
- Shared problems and challenges.

The original questionnaire (written by GNP+/ICW as outlined above) was translated into Vietnamese, where necessary adapted to the Vietnamese context and pilot tested. In addition to the questionnaire, more in-depth interviews were undertaken to gain insight into the detail of the lives of PLHIV; eight case studies were undertaken in four provinces – two each in Can Tho, Ha Noi, Hai

[9] Under Vietnamese law, 18 is the age at which people are judged to have achieved "civil capacity".
[10] While no participants refused to be interviewed or withdrew, some participants did decline to answer questions. This is reflected in the denominators for some of the data analysis.

Phong and Ho Chi Minh City (see Annex 1).[11] An ethical review panel at Ha Noi Medical School approved the study design in September 2011, and data collection was conducted in November and December 2011.

In keeping with the core participatory principles of the Stigma Index, the management of and data collection and analysis for the survey were conducted by members of VNP+, with technical assistance from independent consultants, UNAIDS and WHO. Thirty PLHIV undertook training in interview techniques, including the recording of case studies and facilitating group discussions, using the Stigma Index questionnaire and User Guide. They also received guidance on dealing with difficult emotional situations and referring people for counselling or further sources of advice and information. The fact that the interviewers were openly living with HIV (i.e. they were comfortable disclosing their HIV-positive status to others) helped to provide the interviewees with a supportive environment during the interview process and, it was hoped, to encourage them to talk more openly about their experiences. The process of going through the issues in the questionnaire was designed to be participatory and allow interviewees to think through any issues they might be facing in a comprehensive manner. This was intended to help them to assess their own capacities and opportunities for action in relation to the issues raised. The interview technique was also designed to allow the interviewees to ask questions as they went along to enable them to learn from the interview process. Interviewees were given opportunities to complete a self-assessment at the end of the questionnaire, to discuss issues of concern to them and to receive support in the form of information on referral services.

The analysis of the data was conducted by VNP+ members, and included two sets of logistic regression analysis, with confidence intervals of 95% for each odds ratio. The first was applied to the results from the OPC sample to determine the association of predictor variables (sex, age, years of living with HIV, current relationship status, risk behaviours, education, employment status, yearly income and place of abode) and experience of stigma and discrimination. For each predictor variable and each covariate, two nominal logistic regressions were performed: one that was unadjusted, and one that was adjusted for the following demographic covariates: sex, age, education and yearly income. The second, also applied to the results from the OPC sample, sought to describe the association between self-stigmatization and demographic, social and economic factors. Comparisons between the provinces were undertaken but with the exception of access to work, health and education, no meaningful results were found.

Following the data analysis, three meetings were held to validate the findings. The first two meetings were held in tandem with discussions to elicit input from PLHIV to Viet Nam's forthcoming pilot Treatment 2.0 programme, and took place in Dien Bien (29 to 30 March 2012) and Can Tho (08 to 09 May 2012). The participants to the meetings were PLHIV, peer educators and home care workers, some of whom had been involved in the study. The third meeting took place in Ha Noi on 19 to 20 June 2012, and consisted of 2 half-day meetings, one with PLHIV from Ha Noi and Ho Chi Minh City involved in the study and, the following day, with these PLHIV and other stakeholders, including the Government. Input, including additional further anecdotal evidence, from these meetings has been incorporated into this report.

Finally, an important point to remember is that the time frame for the questions about experiences of stigma and discrimination was 'within the past 12 months' (as opposed to 'ever').

[11] The majority of respondents interviewed for the case studies were women, despite the fact that women only constitute 38% of the OPC sample. According to VNP+, this is because the women interviewed contracted HIV from their husbands and are therefore perceived as "victims"; they also experienced considerable stigma and discrimination from their husbands' families and the community.

As one of the study's objectives is to measure changes in levels of stigma and discrimination over time, VNP+ intends to conduct the Stigma Index again in late 2013 to gauge whether efforts to reduce stigma and discrimination are having an impact. The validation meetings provided valuable input for the planning of the next study.

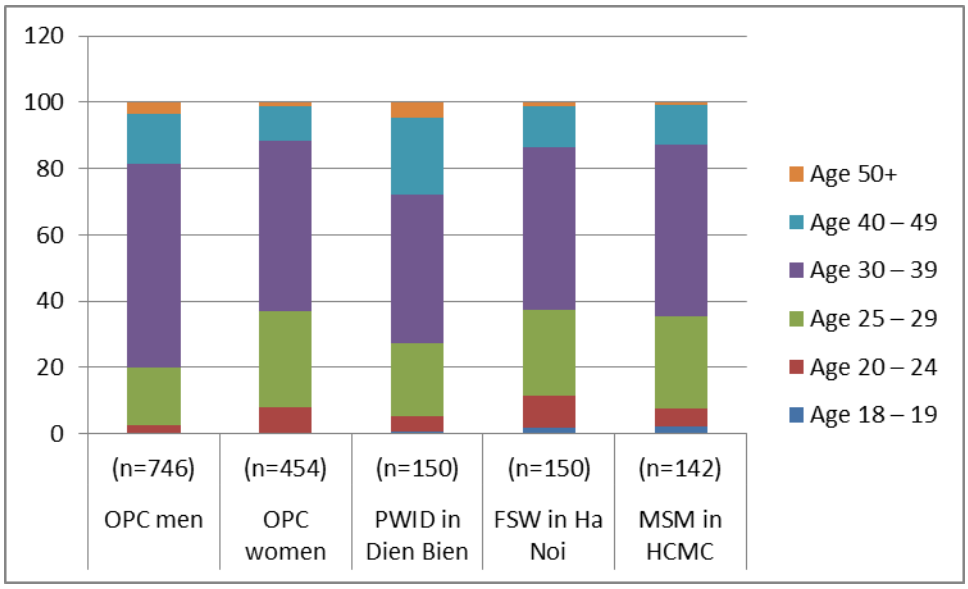
3. Demographics, socio-economic status and vulnerability

As mentioned above, the random selection of 1,200 people enrolled in OPCs and 442 members of key populations at higher risk of transmission was intended to properly represent both the general and specific populations of PLHIV in Viet Nam. Those interviewed as part of the OPC sample, however, by definition had access to services and therefore do not necessarily represent those who do not.

3.1 Age, geographical distribution, current relationship status and children

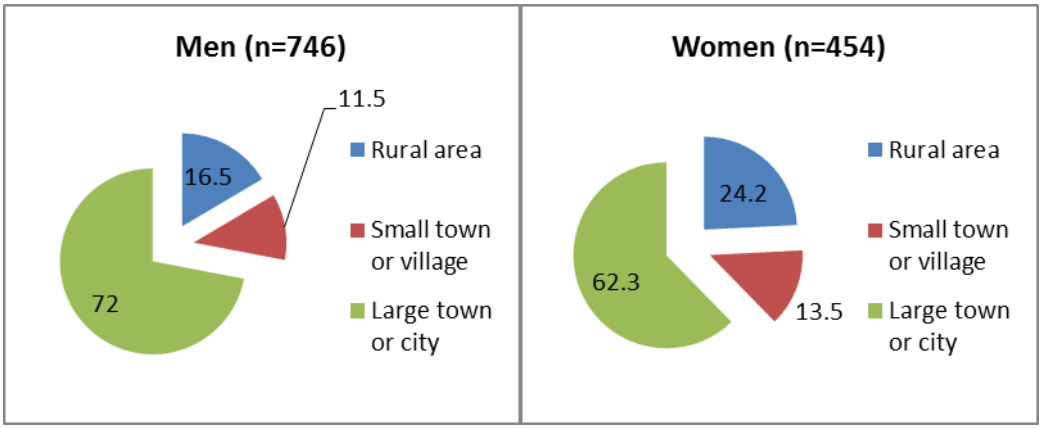
Among the PLHIV in the OPC sample, the majority of respondents were male (736 men or 62.2%), with 37.8% (454) women; this is an accurate reflection of Viet Nam's epidemic as it is currently understood. This pattern is more extreme among the PWID snowball sample in Dien Bien, with only 5% women among the 150 people interviewed, reflecting a more general gendered pattern of drug use. Of 142 MSM interviewed in HCMC, 14 identified themselves as transgender. The majority of respondents from all four samples were aged between 30 and 39 years, with a further substantial proportion aged between 25 and 29 years. In the OPC sample, proportionally, there were more younger women than younger men, and more men than women aged above 30 – which may indicate a slight shift in the epidemic. There were also some young FSW in Ha Noi and MSM in HCMC (2.0% and 2.1% respectively in the 18-19 year category) in the samples.

Figure 1: Age distribution of PLHIV



The majority of respondents in the OPC sample lived in large towns or cities, where access to HIV services may be assumed to be greater. The MSM and FSW interviewed as part of the snowball samples by definition lived in the large cities of HCMC and Ha Noi, while the snowball-sampled PWID lived in the province of Dien Bien which is a poorer, mountainous province with greater challenges in access to services.

Figure 2: Geographical distribution among the OPC sample



Marital and family status is of considerable social importance in Viet Nam, with divorce increasing but still not widespread.[12] Women living with HIV without husbands may be more vulnerable to social and economic pressures, and less protected from stigma and discrimination. Respondents were asked their current relationship status, with just over half of those in the OPC sample reporting they were married or cohabiting and living in the same household. Among the PWID in Dien Bien and the FSW in Ha Noi, slightly less than half reported they were married or cohabitating with a partner, but only 15.5% of MSM in Ho Chi Minh City reported that they were in this situation. Nearly 21% of the FSW in Ha Noi were divorced or separated.

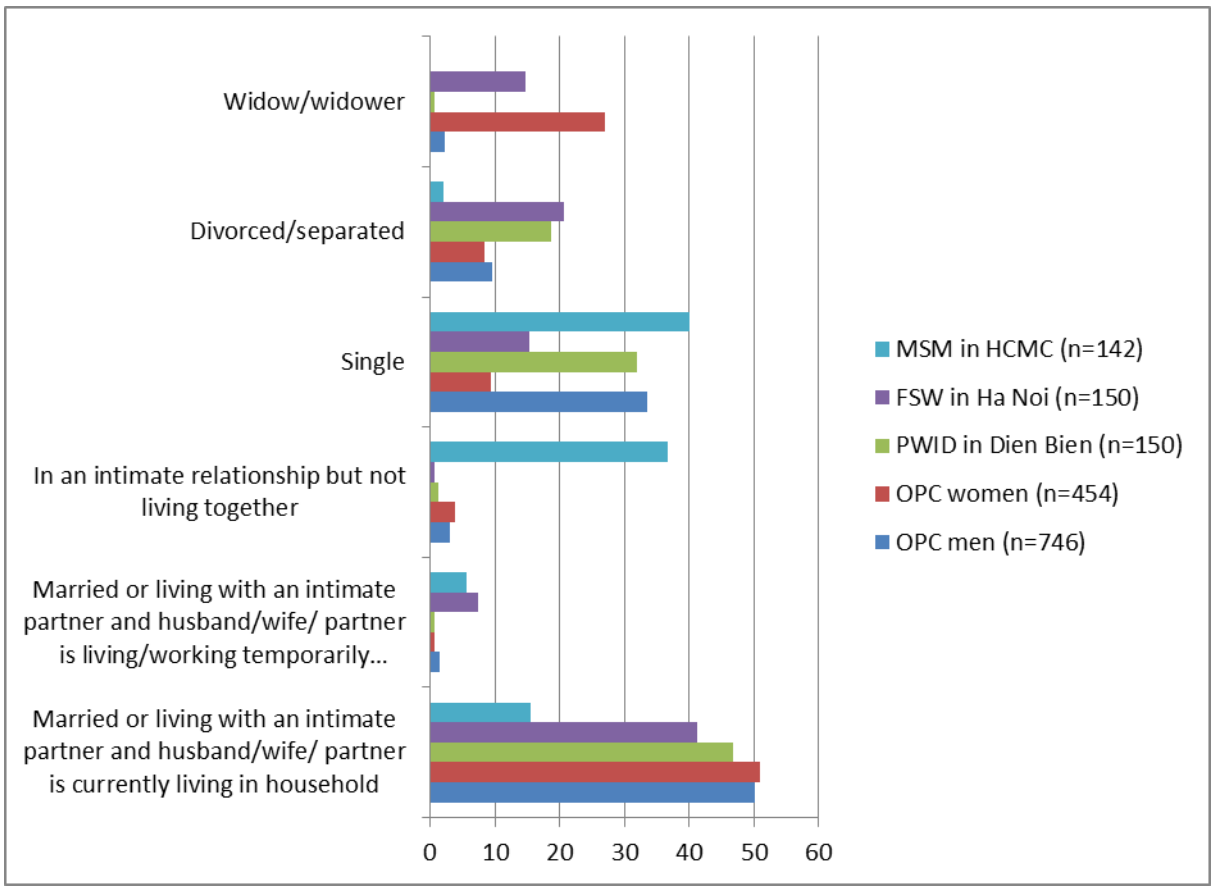
A high proportion of women – 26.9% in the OPC sample, and 14.7% of the FSW in Ha Noi – stated that they were widows, potentially indicating intimate partner transmission of HIV by (now-deceased) husbands. There is evidence that intimate partner transmission of HIV from high-risk men to their long-term female partners is a concern for HIV-prevention efforts in Viet Nam.[13] The Stigma Index also provided anecdotal evidence for this, with PLHIV in Can Tho[14] believing that as many as 30% of PLHIV in Can Tho were infected by their intimate partners – mainly male to female. Although this number may not be scientifically sound, it reflects to some extent the perceived gravity of the problem.

[12] Viet Nam Population and Housing Census 2009: Age-Sex Structure and Marital Status of the Population in Viet Nam. Ministry of Planning and Investment, General Statistics Office, 2009. http://vietnam.unfpa.org/webdav/site/vietnam/shared/Census%20publications/6_Monograph-Age-Sex-Structure.pdf. Accessed 17 June 2012

[13] Measuring Intimate Partner Transmission of HIV in Viet Nam: A data triangulation exercise. UNAIDS and UN Women, Viet Nam, 2012.

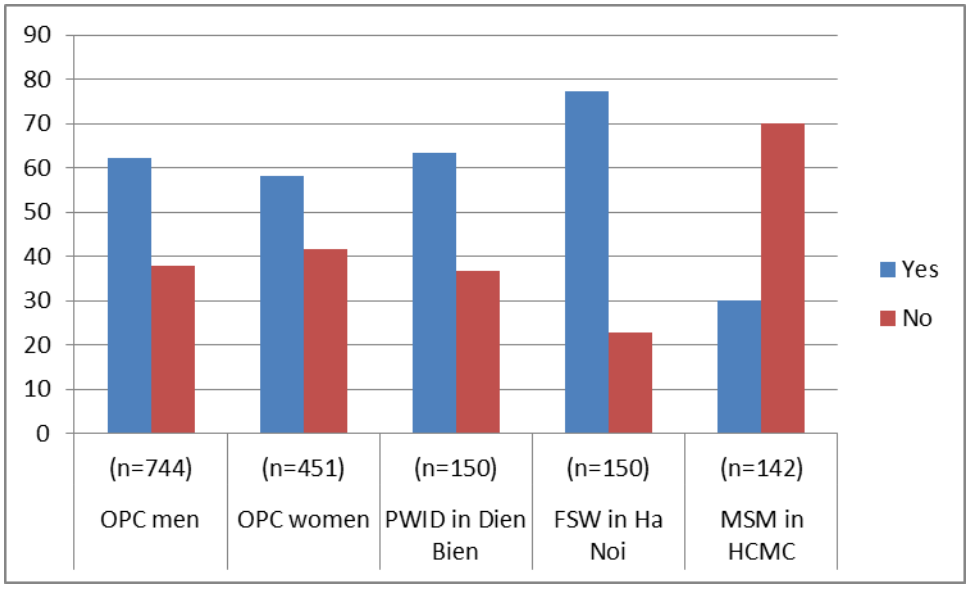
[14] Responses from a meeting of PLHIV in Can Tho, 08-09 May 2012, held in part for the purpose of validating the Stigma Index findings.

Figure 3: Current relationship status



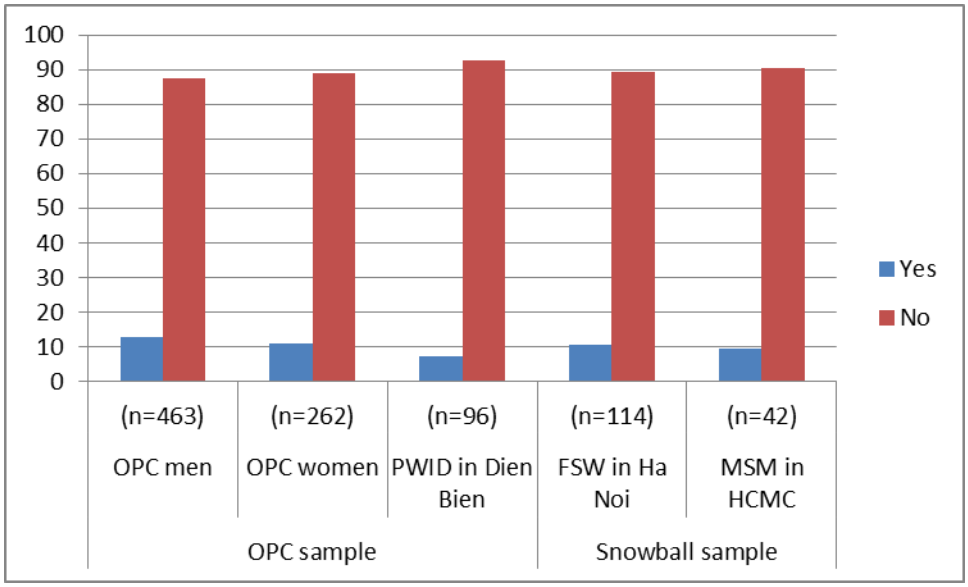
Two-thirds of all respondents reported that they had one child or more, with the exception of MSM in Ho Chi Minh City, of whom only 30% had any children. Slightly more OPC-sampled men than women had children (62.1% versus 58.3%), but considerably more FSW in Ha Noi had children than women from the OPC sample (77.3% vs 58.3%).

Figure 4: Respondents with one child or more



Among OPC-sampled respondents who said they had children, approximately 12% had children known to be HIV-positive. Among HIV-positive FSW in Ha Noi with children, about 10% of the children were HIV-positive, and among PWID in Dien Bien and MSM in Ho Chi Minh City with children, less than 10% were HIV-positive. These relatively low rates of children living with HIV may reflect the recent scale-up of Viet Nam's prevention-of-mother-to-child-transmission (PMTCT) programme. Out of the 1,909 pregnant women who were identified as HIV-positive during pregnancy, 1,707 mothers and 1,733 babies received ARV prophylaxis in 2011.[15] Preliminary steps have also been taken to include PMTCT as part of routine antenatal care, to refer HIV-positive pregnant women and those who have delivered babies to HIV clinics for follow-up and treatment and to expand early infant diagnosis: in 2011, 1,804 infants received a virological test and were referred to pediatric care services, and 3,261 out of an estimated 3,934 children living with HIV were receiving ART.[16]

Figure 5: Respondents' children known to be HIV-positive

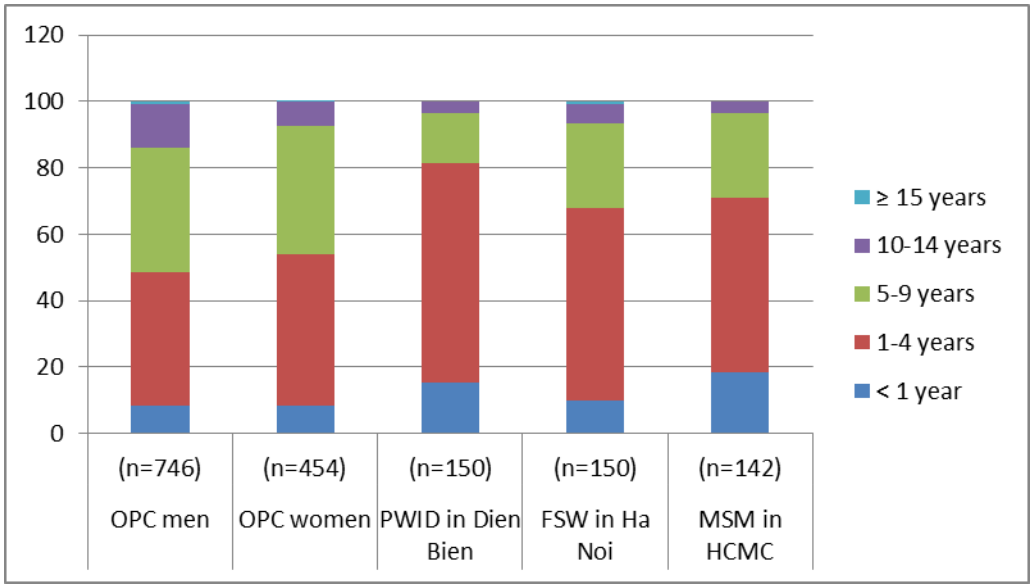


3.2 Years of knowledge of HIV status

Respondents were asked how long they had known their HIV status. The majority of respondents had been diagnosed within the last four years. Within the OPC sample, 8.3% learned they were living with HIV within the last year, and 42.3% were diagnosed between one and four years. About one-third of OPC respondents were diagnosed between five and nine years ago, and about one in ten have known they were HIV-positive for more than 10 years. The HIV-positive diagnoses among the risk group snowball samples were more recent, especially among PWID in Dien Bien. The difference may be due to the fact that ART coverage is higher within the OPC sample. Less than 1% of each category of respondent (and no PWID in Dien Bien or MSM in Ho Chi Minh City) had known their status for 15 years or more.

[15] Viet Nam Universal Access Report 2011.
[16] Ibid.

Figure 6: Years of knowledge of HIV status



3.3 Risk behaviours

All respondents were asked about whether they were currently engaging or had ever engaged in HIV-related risk behaviours, as well as about other aspects of their lives which might make them more vulnerable to HIV. In the case of Viet Nam, injecting drug use, sex work and male same-sex sexual activity are highly stigmatized behaviours in and of themselves, with drug use and sex work subject to administrative detention in Centres for Treatment, Labour and Social Labour. The HIV risk linked with these behaviours in the context of a concentrated epidemic has served to further stigmatize those who engage in them.

Many people in the OPC sample - 67.3% of men, and 9.3% of women - reported current or past injecting drug use. This finding supports the existing body of data suggesting that injecting drug use is the main mode of HIV infection in Viet Nam.[17] Injecting drug use also appeared to be less difficult for individuals to reveal to interviewers. As anticipated, among the OPC sample, very few women (3.1%) said that they had ever undertaken sex work, with even fewer men (0.5%). At the same time, very few men in the OPC sample (0.7%) said they had ever had sex with a man, with even fewer categorizing themselves as gay.[18] When asked about this data, PLHIV in Can Tho[19] thought that PLHIV may hide their risk behaviours (or 'identities'). It was felt this was particularly the case for sex workers, many of whom are married and do not want to admit that they sell sex, even to peer educators.

[17] See, for example: Viet Nam AIDS Response Progress Report 2012. National Committee for AIDS, Drugs and Prostitution Prevention and Control, 2012.

[18] MSM in Viet Nam may identify/be identified as *bóng kin* ("hidden") or *bóng lộ* ("conspicuous") (and there are further sub-categories). It is believed that many *bóng kin* may be married and have children, which is borne out by the survey results. See for example: Male homosexual identities, relationships and practices among young men who have sex with men in Vietnam: Implications for HIV prevention. Duc Anh Ngo, Michael W. Ross, Ha Phan, Eric A. Ratliff, Thang Trinh and Lisa Sherburne, AIDS Education and Prevention, 2009 June; 21(3):251-265. http://www.ncbi.nlm.nih.gov/pubmed/19519239. Accessed on 17 June 2012.

[19] Responses from a meeting of PLHIV in Can Tho, 08-09 May 2012, held in part for the purpose of validating the Stigma Index findings.

Mobility – voluntary or otherwise – can lead to vulnerability, particularly where people are not registered in their new place of residence and cannot therefore access health and other necessary services or employment. Refugees, internally displaced people and migrant workers may also face stigma and discrimination from local residents and authorities.[20] Among the OPC sample, only a small proportion indicated that they were internally displaced (1.7% of men and 2.4% of women); or migrant workers (0.7% of men and 2.9% of women).

In Viet Nam, members of indigenous populations (in this case, ethnic minorities) may face particular problems in accessing HIV (and other) services due to language barriers (many, particularly women, do not speak or read Vietnamese), geography (many live in mountainous, hard-to-reach areas), poverty and discrimination on the basis of their ethnicity.[21] A total of 35.7% of women in the OPC sample stated that they were members of an ethnic minority, most of whom lived in Dien Bien province where the population has a higher proportion of such minorities. Only 9.4% of men in the OPC sample responded in the same way. It is unclear why there was such a higher proportion of ethnic minorities among the women in the OPC sample, although it was suggested that this might be influenced by the fact that nearly 79% of the women interviewed in Dien Bien said they lived in rural areas (versus 66% of the men).[22]

It should be noted that a substantial proportion of respondents stated that they did not belong to any risk group – 44.4% of women and 22.3% of men.

[20] For more information on mobility and HIV in Viet Nam, see for example: Mobility and HIV Vulnerability in Viet Nam. Canada South East Asia Regional HIV/AIDS Programme, 2008. http://www.inthealth.ku.dk/reach/resources/mobilityeng.pdf/. Accessed 17 June 2012.

[21] For more information on ethnic minorities in Viet Nam and their issues in accessing services, see for example: Country Social Analysis: Ethnicity and Development in Viet Nam. Summary Report. The World Bank, 2010. http://siteresources.worldbank.org/INTEAPREGTOPSOCDEV/Resources/499760ESW0Whit1C10VietnamSummary1LR.pdf. Accessed on 23 June 2012.

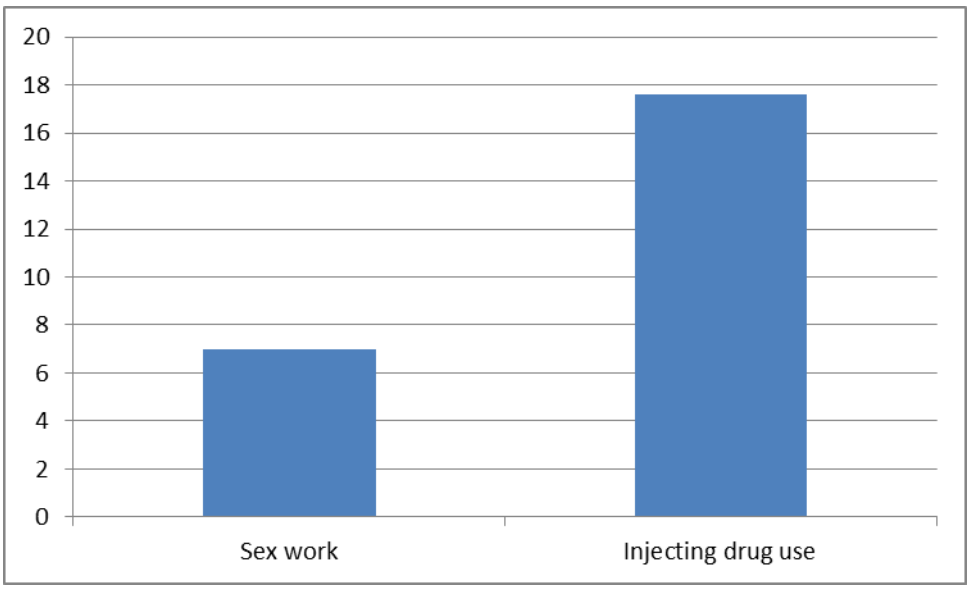
[22] This suggestion was made by PLHIV in Dien Bien at a meeting held on 29-30 March 2012, in part for the purpose of validating the Stigma Index findings.

Figure 7: Respondent self-identified category (OPC respondents only; multiple-answer question)

3.4 Multiple risk behaviours

For those people interviewed as part of the snowball samples of PLHIV – PWID, MSM and FSW – there is a possibility that, if they engage in more than one type of risk behaviour, they may be multiply stigmatized or discriminated against. Their responses to the questions regarding risk behaviour are therefore important. MSM reported the highest levels of both injecting drug use (17.6%) and sex work (7%). Very few of the other respondents reported additional risk behaviours. Only 0.7% of the PWID in Dien Bien said that they had undertaken sex work, and injecting drug use among FSW in Ha Noi was also very low at 1.3%. No PWID described themselves as either men who have sex with men or gay and no FSW identified themselves as gay.

Figure 8: Multiple risk behaviours: MSM

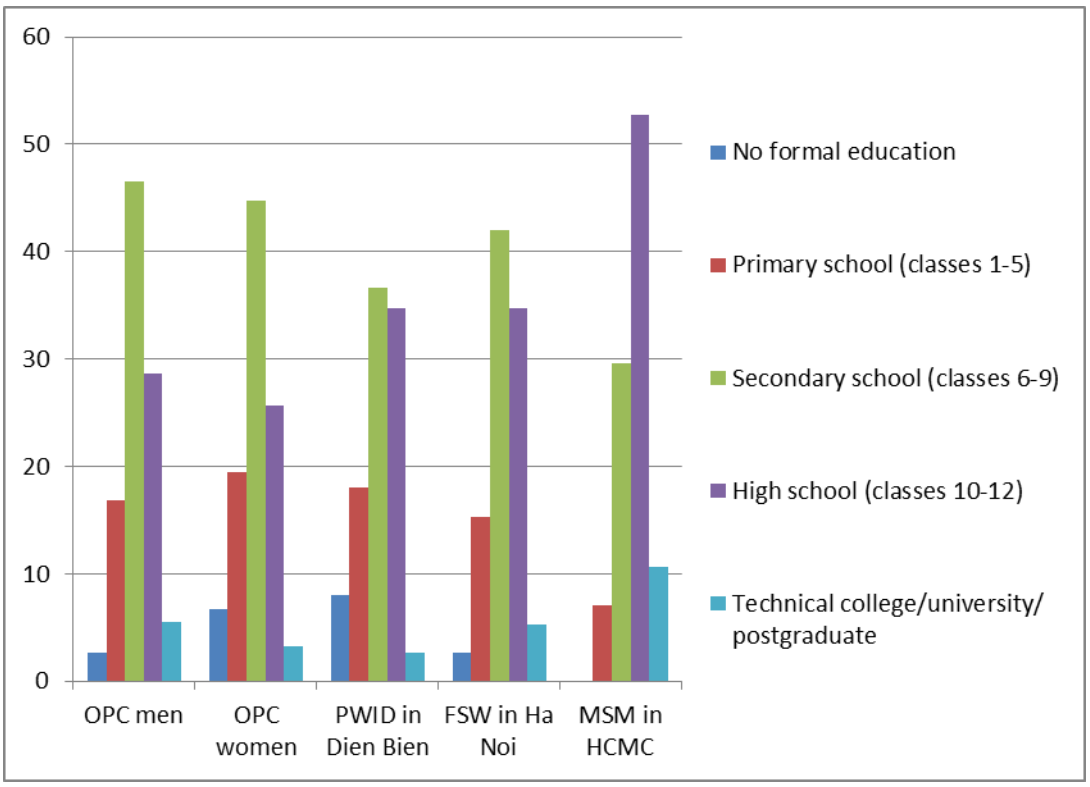


Very few of the snowball sampled respondents identified themselves with other potentially stigmatizing factors: only 0.7% of respondents of PWID in Dien Bien and FSW in Ha Noi were also internally displaced, while 0.7% of PWID in Dien Bien said that they were migrant workers. Similarly, 1.3% of PWID in Dien Bien and 0.7% of MSM in Ho Chi Minh City) reported ever being incarcerated. These results are somewhat surprisingly low – particularly the figure of 0% of FSW in Ha Noi – given that drug users and sex work are subject to administrative detention in Centres. It could be that respondents who spent time in administrative detention centres did not consider themselves former prisoners.

3.5 Economic and educational status

Knowing the economic and educational status of PLHIV is vital to understanding their ability to afford health care, good nutrition and adequate living conditions and to access knowledge and information. Across all samples, more than two-thirds of respondents had completed secondary school. Within the OPC sample, slightly more men than women had completed higher levels of education. Among the snowball samples, MSM in Ho Chi Minh City had the highest level of education, and PWID in Dien Bien had the lowest.

Figure 9: Educational status

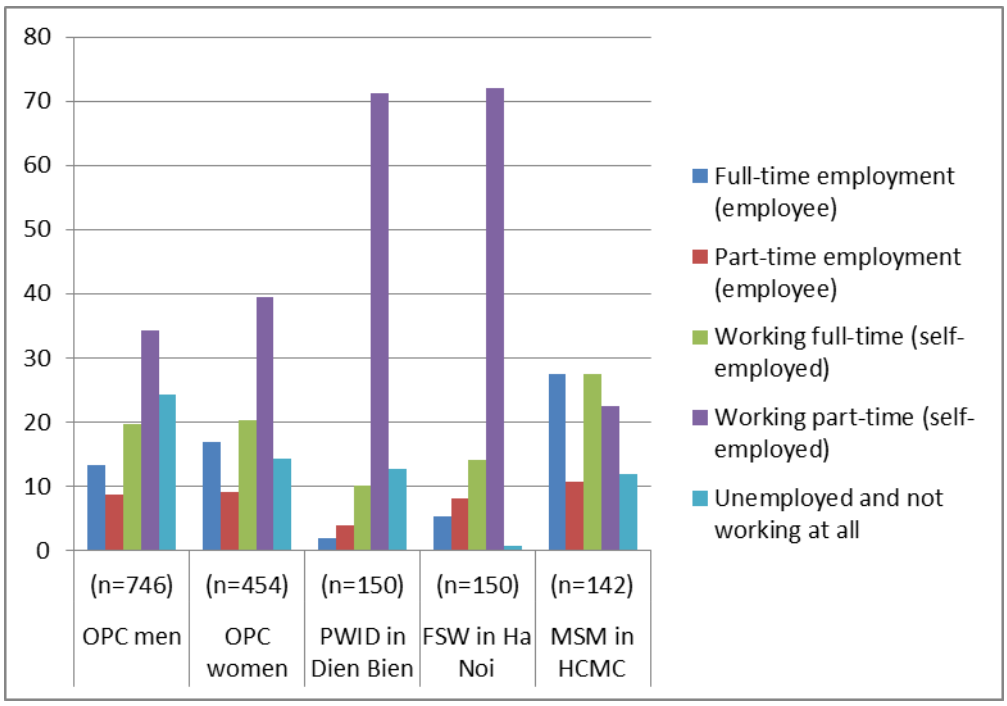


Among OPC respondents, 34.4% were currently in full-time employment while 45.1% worked part-time, either as employees or self-employed. More women than men in the OPC sample were in employment of some kind, despite their lower educational status. Among the snowball samples, only 12% of PWID in Dien Bien and 19.3% of FSW in Ha Noi were working full-time (as employees or self-employed), while MSM in Ho Chi Minh City had the highest rate of reported full-time work at 55%, in keeping with their higher educational attainments.

The majority of respondents were self-employed, either full- or part-time: 56.1% of OPC respondents and 50% of MSM, with a very large proportion of FSW in Ha Noi (87%) and PWID in Dien Bien (81.3%). Meanwhile, unemployment rates among all respondents, except FSW in Ha Noi, were higher than national unemployment rates in 2009 (6.5%) and 2010 (2.9%).[23]

[23] www.indexmundi.com/g/g.aspx?c=vm&v=74 accessed at 11:14 on 04 May 2012

Figure 10: Employment status



The household income of the majority of all respondents was between 2 and 5 million Viet Nam Dong (VND) per month.[24] In the OPC sample, men earned more than women. Meanwhile, the household income of almost a third of both women in the OPC sample and PWID in Dien Bien was less than 2 million VND per month. Although MSM in Ho Chi Minh City had, overall, higher educational achievements and proportionally more secure employment than other respondents, fewer MSM (18.2%) lived in households with incomes over 5 million VND per month than FSW in Ha Noi (among whom the proportion was 21.3%), and more in households with incomes under 2 million VND. Very few PWID in Dien Bien lived in households with incomes over 5 million VND. Among the OPC sample, widowed women had lower household incomes than non-widowed women, with more than half living in households with incomes under 2 million VND per month.

[24] According to the General Statistics Office, monthly PER CAPITA income in 2010 was 1,367,000 VND. Results of the Viet Nam Household Living Standards Survey 2010. General Statistics Office, 2010. http://www.gso.gov.vn/default_en.aspx?tabid=515&idmid=5&ItemID=12426 Accessed 18 June 2012

Figure 11: Monthly household income levels

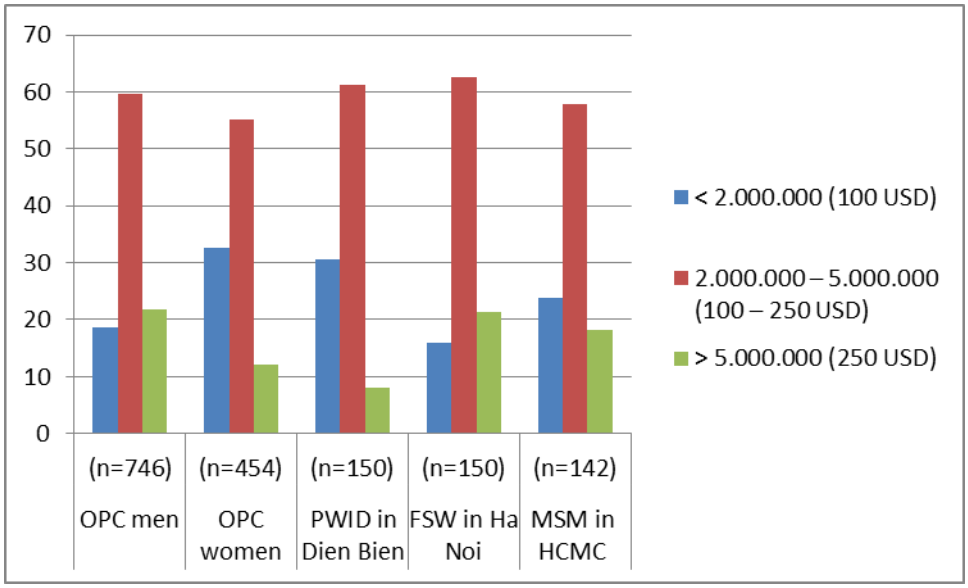
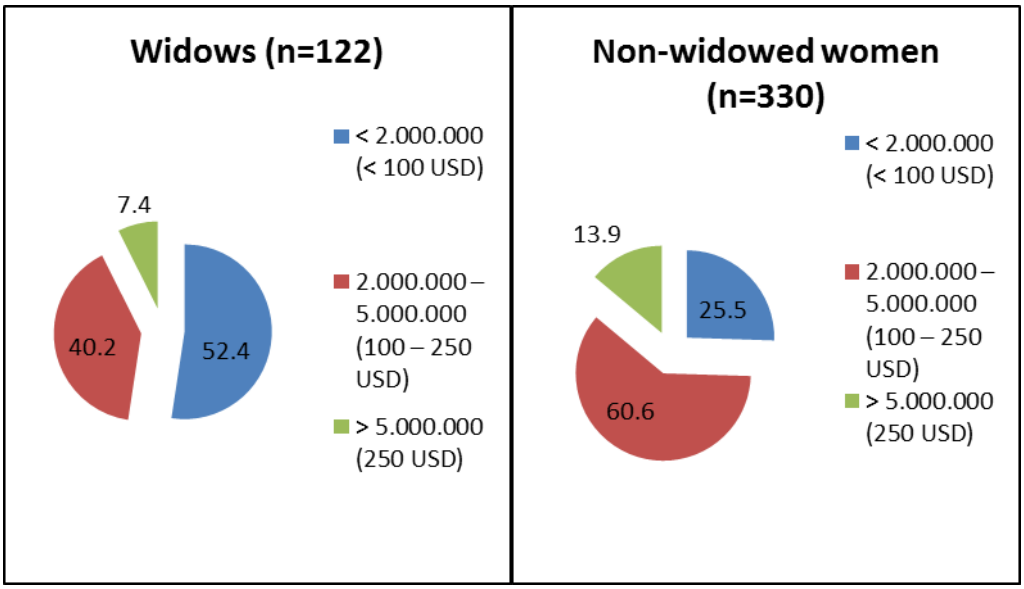


Figure 12: Monthly household income levels of widowed and non-widowed women in the OPC sample



4. Stigma and discrimination

4.1 Rights, laws and policies

The Law on HIV and other laws and policies[25] provide protection for the specific rights of PLHIV in Viet Nam: these include voluntary testing, confidentiality, and the right to education, work, health care and non-discrimination. They also provide mechanisms for legal redress in the event of any

[25] Including the *1992 Constitution of the Socialist Republic of Viet Nam (amended 25 December 2001),* the Law on Gender Equality (No. 73/2006/QH11), the Law on Domestic Violence Prevention and Control (No. 02/2007/QH12) and the Law on Child Protection, Care and Education (No. 25/2004/QH11).

violation of these rights. For example, *Decree No. 69/2011/ND-CP* on handling administrative violations in health prevention, the medical environment and HIV/AIDS prevention and control provides support for the enforcement of the Law on HIV. The Decree sets specific sanctions for providing incorrect information about HIV, for preventing people from accessing treatment and care, and for various forms of discrimination against PLHIV (including restricting access to health services, employment and education). It also provides for specific sanctions where the rights to testing, counselling or privacy have been violated.

Notwithstanding these safeguards, all categories of respondents reported violations of their rights, with extremely high rates of such abuse among FSW in Ha Noi (42.0%) and PWID in Dien Bien (35%). More women in the OPC sample (21.1%) reported rights violations than OPC-sampled men (17.5%). MSM in Ho Chi Minh City reported the fewest abuses (11.3%) but more MSM than other respondents were not sure whether they had suffered violations of their rights (7%).

Among the snowball sample, the right to non-discrimination was by far the most violated. Among the PWID in Dien Bien who reported rights violations, 80.4% reported abuse of the right to non-discrimination, as did 70.4% of the MSM in Ho Chi Minh City and 67.7% of the FSW in Ha Noi who reported rights abuses. Over half of the OPC sample who reported having their rights violated also reported suffering discrimination. Many respondents also reported violations of their right to privacy and confidentiality (see below). The survey also showed that 23.3% of the FSW in Ha Noi and 11% of OPC-sampled respondents who reported rights abuses had been forced to follow medical or health-related procedures (including taking an HIV test).

Figure 13: Violation of respondents' rights as people living with HIV

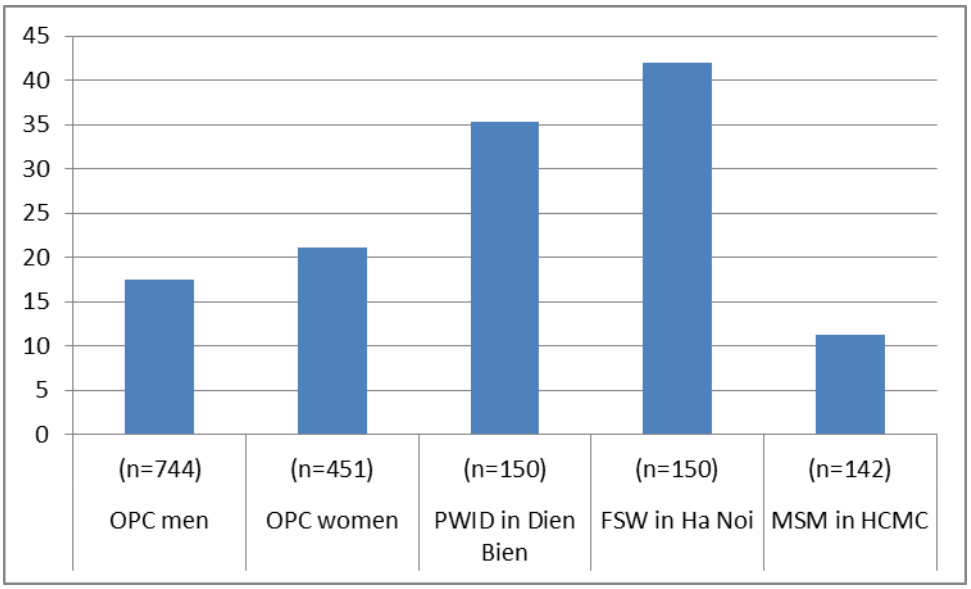
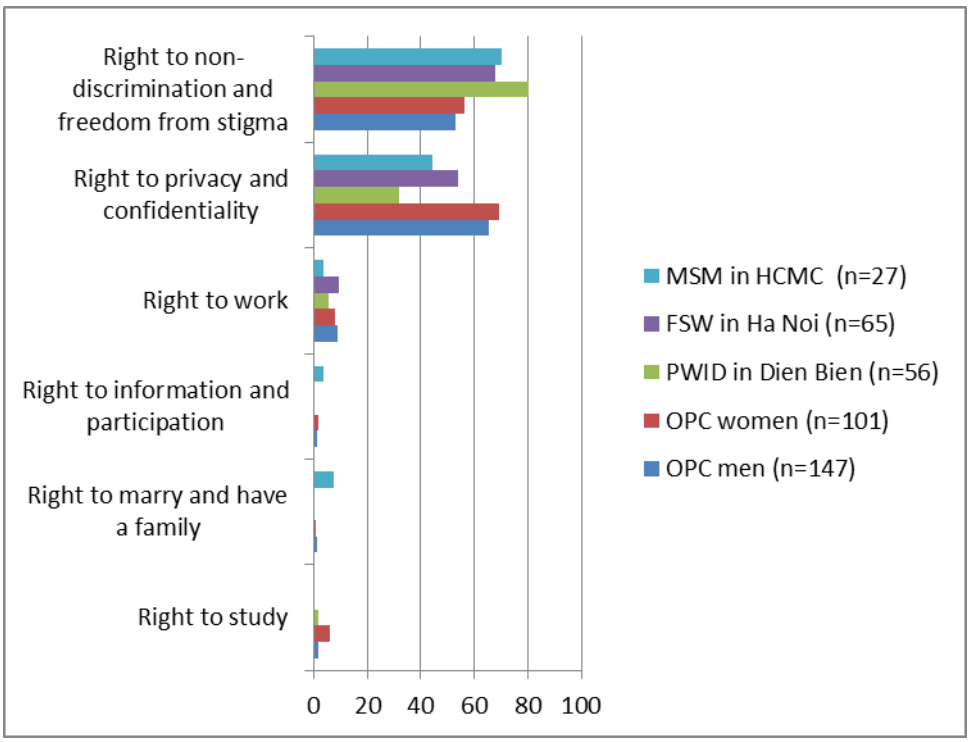


Figure 14: Type of rights violations experienced by respondents (multiple-answer question)



When faced with violations of their rights, the vast majority of respondents did not seek legal redress. However, nearly 27% of PWID in Dien Bien did seek legal redress, and more women in the OPC sample and FSW in Ha Noi did so than OPC sampled men and MSM in Ho Chi Minh City.

> I asked local policemen and neighbours to help me [when my rights were violated], but when they came, my husband and his family told them that nothing had happened, it was only a family conflict. I also asked the Women's Union and People's Committee for help, but I haven't found any solution. To be honest, I've lost confidence that anyone can help me.
>
> **Case study: Woman living with HIV in Ho Chi Minh City**

The most common reason for not seeking legal redress was a lack of confidence in the success of the process, particularly among MSM in Ho Chi Minh City (60%) and FSW in Ha Noi (36.2%). Among PWID in Dien Bien, the most common reason was that they were advised against doing so (22.0%), while 13.8% of FSW in Ha Noi also received such advice. Insufficient financial resources and a perception that the process was too bureaucratic were also cited as reasons for not going to law.

Figure 15: Incidence of seeking legal redress for any abuse of rights

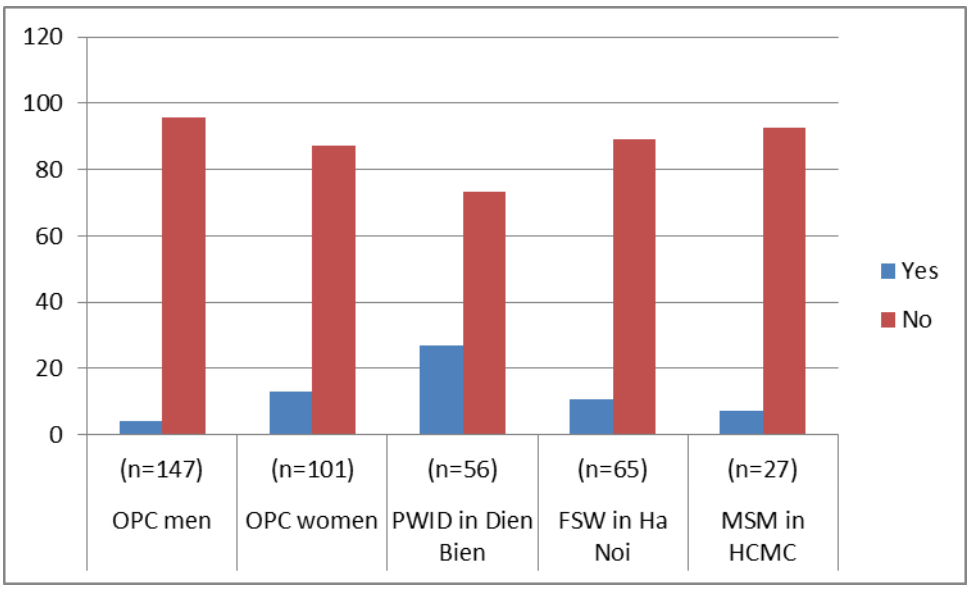
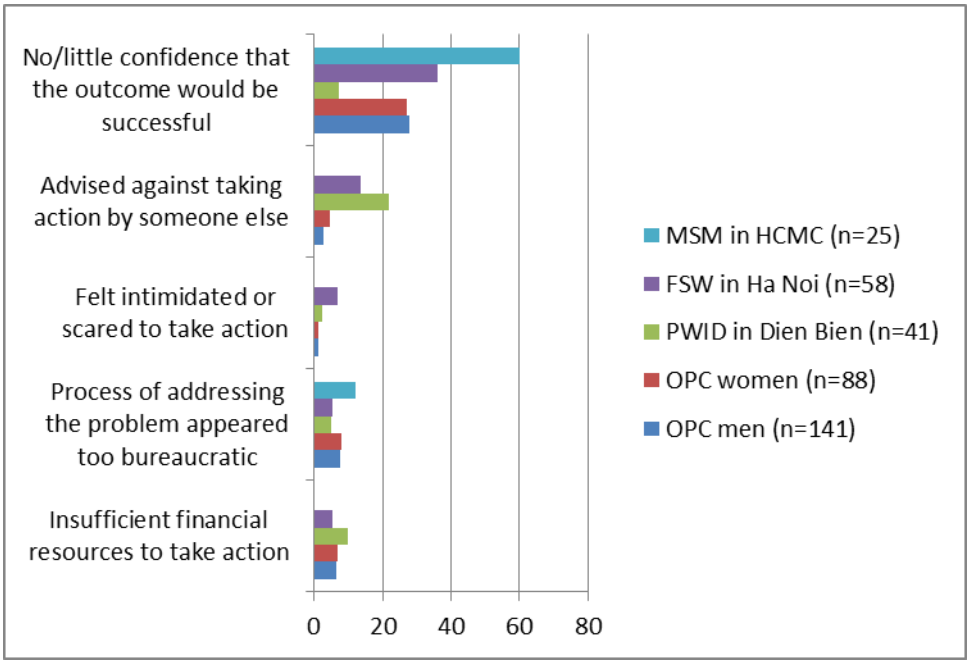


Figure 16: Reason(s) for not trying to seek legal redress (multiple-answer question)[26]



4.2 Testing and diagnosis

HIV testing allows people to make informed decisions about their lives, take the necessary measures to adapt their lifestyle or change behaviours that put them or others at risk, and access medical care. The earlier people are tested and diagnosed, the earlier people living with HIV can start protecting others – including sexual partners, other people who inject drugs and unborn children – and taking antiretroviral therapy (ART). The WHO has recommended earlier ART initiation as a way of improving health outcomes for PLHIV, as well as reducing deaths and the transmission of HIV from mothers to

[26] Not included: respondents who answered 'none of the above'.

children.[27] As ART reduces viral loads, it can also reduce the likelihood of transmission of the virus, and is therefore also an important tool for HIV prevention.

However, despite the importance of HIV testing, many people at risk of HIV do not get tested for many reasons: lack of access to HIV testing and counselling services, fear of stigma and discrimination, fear that the test will be positive, fear of disclosure, and lack of access to treatment. Many do not seek an HIV test until they are clearly ill with severe opportunistic infections and a very low CD4 cell count. A total of 52.7% of those who started ART in 2010 had a CD4 count of less than 100 cells/mm^3,[28] while the WHO recommends the initiation of ART for all PLHIV with a CD4 count of ≤350 cells/mm^3.[29]

The Law on HIV provides guidance and protection regarding HIV testing, and includes provisions that testing must be voluntary and take place with the informed consent of the person involved (Article 27); that employers are not allowed to ask job applicants to take an HIV test or produce a test result (Article 14); and that educational establishments are not allowed to request students/participants/candidates to take an HIV test or produce a test result (Article 15). Decision No. 647 on Promulgation of Voluntary HIV Counselling and Testing also states that HIV testing must be voluntary. There are exceptions to the rule on voluntary testing: under the Law on HIV, Article 28, compulsory HIV testing shall be conducted in cases where there is an official request for judicial appraisal or a decision of an investigative body, a people's procurer or a people's court; the Minister of Health shall issue regulations on compulsory HIV testing in certain necessary cases for diagnosis and treatment purposes; and the Government shall issue a list of occupations and professions requiring HIV testing before recruitment. Decree No. 108-2007-ND-CP (Article 20(1)) also details occupations requiring HIV testing before recruitment.

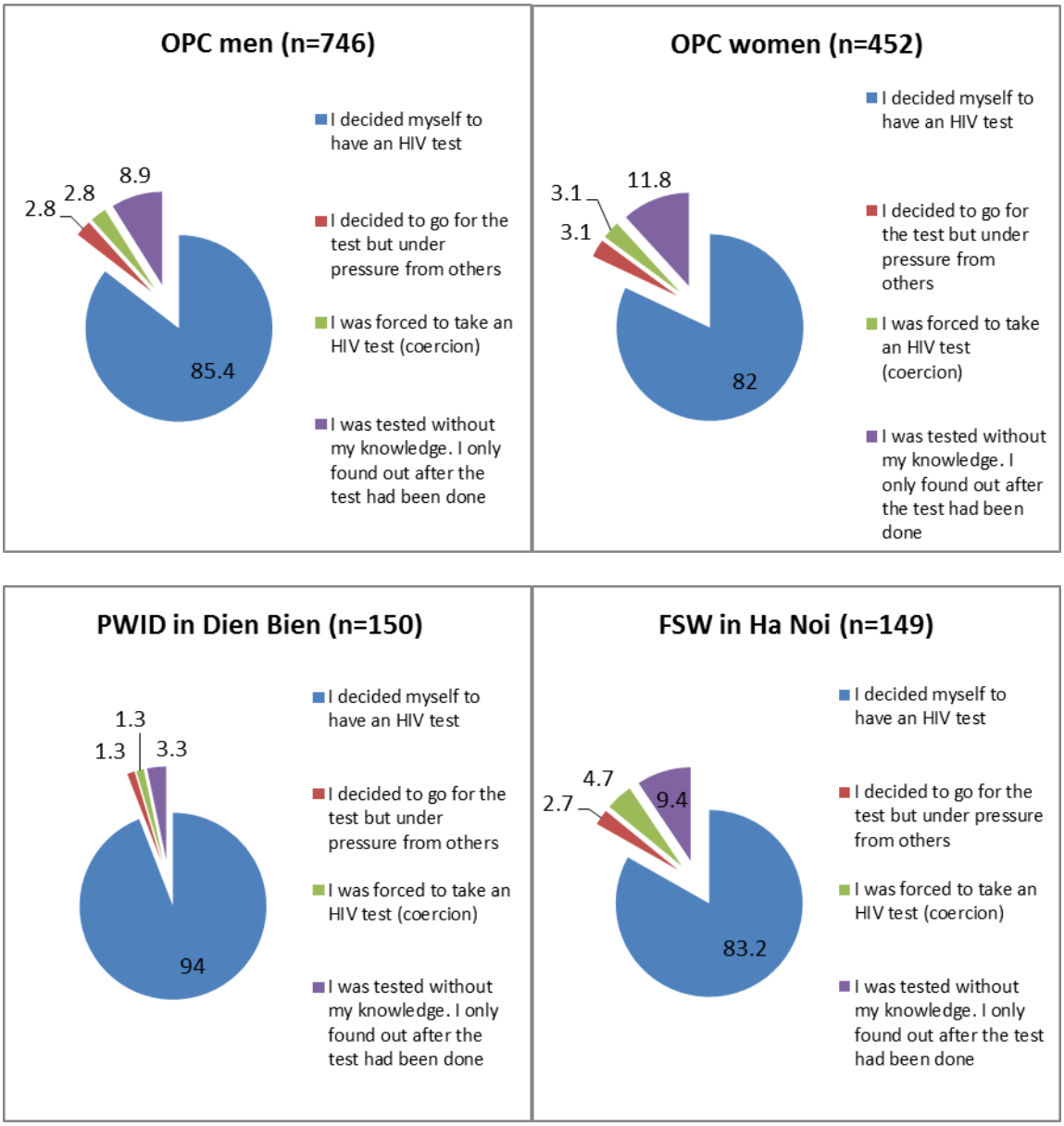
The data show that most of the respondents made the decision to take a test themselves. However, some respondents felt under pressure to make the decision, including 8.5% of the MSM in Ho Chi Minh City. Three per cent of the OPC sample reported that they were coerced into testing. FSW in Ha Noi reported the highest levels of coercion at 5%. Also of concern, one in ten of the OPC sample were tested without their knowledge or consent and only informed of the result afterwards. Within the snowball samples, 9.4% of FSW in Ha Noi were tested without their knowledge or consent, as were 5.7% of MSM in Ho Chi Minh City and 3.3% of PWID in Dien Bien. The survey did not ask who put pressure on or forced PLHIV to take a test.

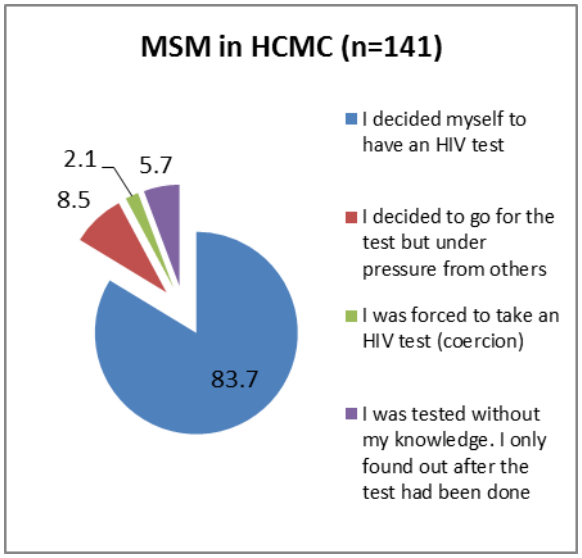
[27] Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach: 2010 revision. World Health Organization, 2010. http://www.who.int/hiv/pub/arv/adult2010/en/index.html Accessed on 18 June 2012.

[28] Viet Nam AIDS Response Progress Report 2012. National Committee for AIDS, Drugs and Prostitution Prevention and Control, 2012 http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/progressreports/2012countries/ce_VN_Narrative_Report.pdf. Accessed 17 June 2012.

[29] Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach: 2010 revision. World Health Organization, 2010. http://www.who.int/hiv/pub/arv/adult2010/en/index.html Accessed on 18 June 2012.

Figure 17: Was the decision to be tested up to you?





Respondents were asked to give their reason(s) for being tested for HIV, with the option of choosing more than one reason. Among the OPC sample, the most common reason given was a referral due to suspected HIV-related symptoms, with more women than men saying they had been referred for this reason (35.6% versus 27.8%). The high proportion of referrals may be evidence of a relatively strong health system. It is also encouraging that only 2.6% of men and 0.9% of women said that they had taken an HIV test for employment-related reasons.

At the same time, 11.7% of men and 9.1% of women were tested following the positive result of a wife, husband, partner or family member, while 12.0% of men and 10.6% of women said that they had been tested because of the illness or death of a husband, wife, partner or family member. Nearly a quarter of men and over 20% of women said that they "just wanted to know". It is conceivable that a proportion of these respondents chose to be tested because they had recently engaged in a risk behaviour or been exposed to infection, or thanks to Viet Nam's information, education and communication and behaviour change communication programmes, particularly since there was no way for respondents to reflect either of these options in their answer to the question. Relatively few OPC-sampled women (6%) gave pregnancy as the reason for an HIV test; strangely, some male respondents (7.4%) also gave pregnancy as a reason, presumably referring to their wives' pregnancies. Very few OPC respondents (1.8%) said that they took the test to prepare for marriage or a sexual relationship.

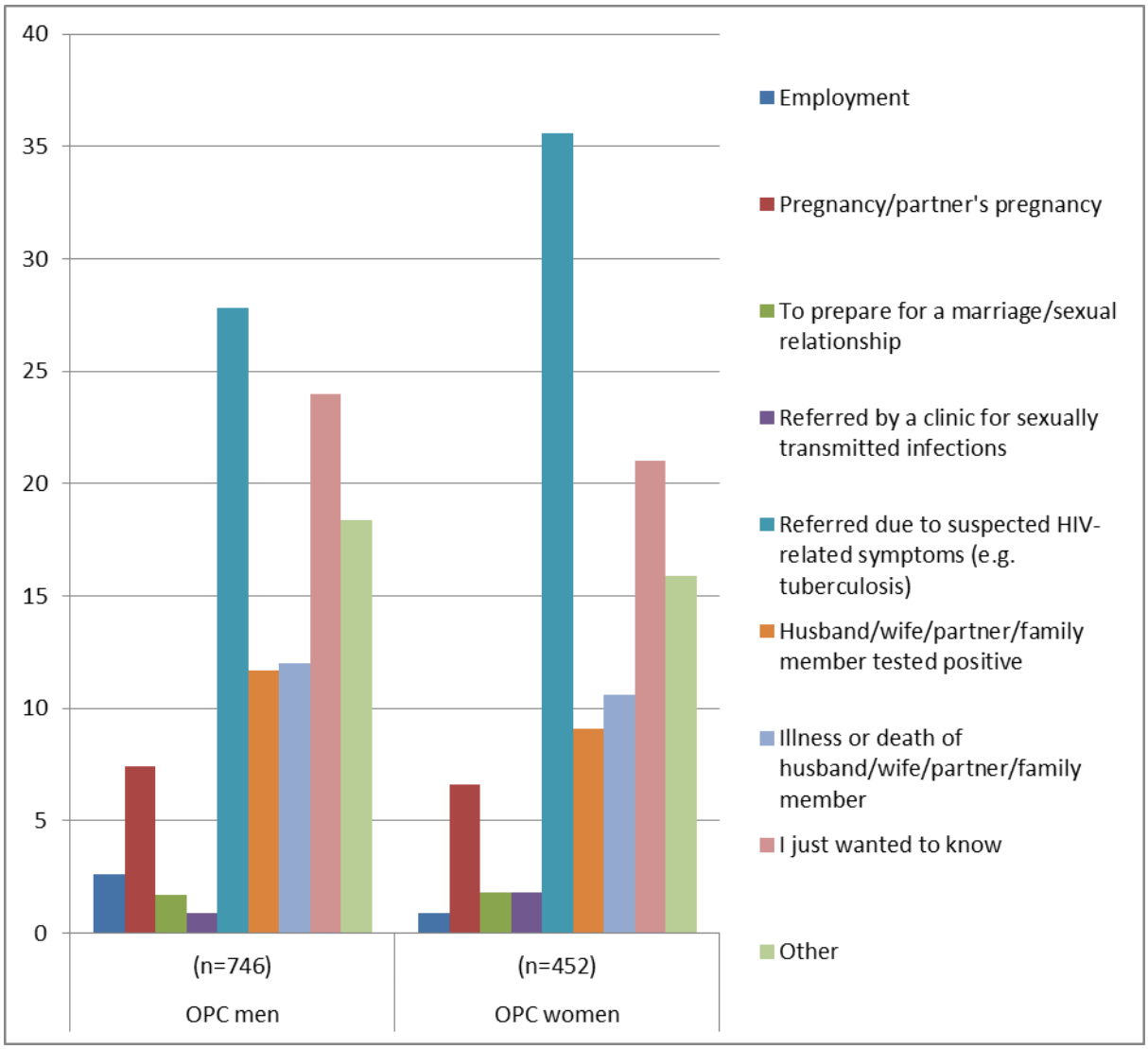
Among the snowball-sampled respondents, FSW in Ha Noi gave the widest range of reasons for HIV testing, with 19.5% of them giving HIV-related symptoms, 16.8% giving the illness or death of a spouse, partner or family member and 14.1% giving the HIV-positive status of a spouse, partner or family member as compelling reasons to get tested. Nearly 31% of MSM in Ho Chi Minh City also cited referrals due to suspected HIV-related symptoms as a reason for testing, as did 22.7% of PWID in Dien Bien. Seventeen per cent of MSM in Ho Chi Min City also said that they got a test because a spouse or partner tested positive. Again, it is likely that these people tested late.

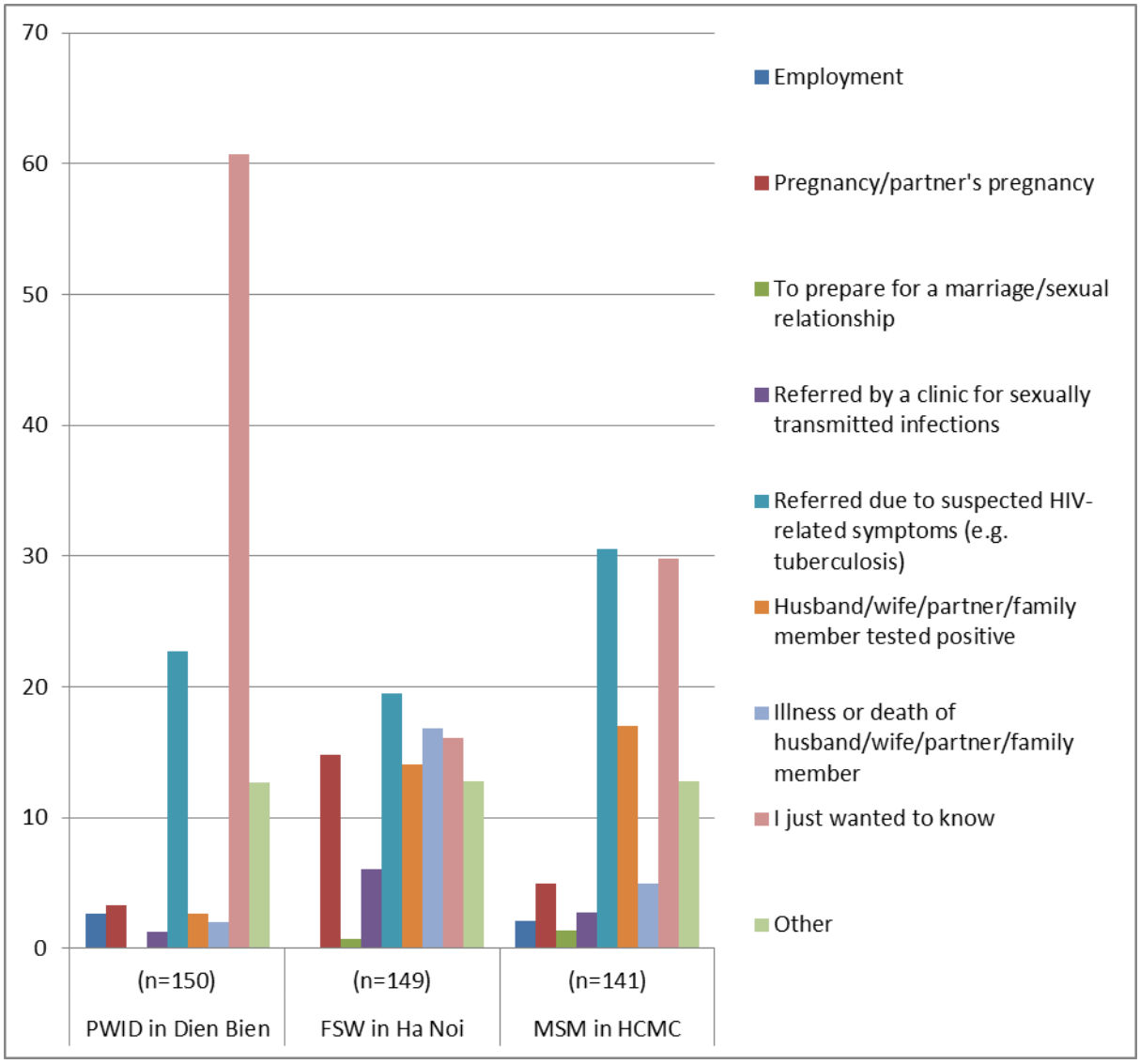
The most common response among PWID in Dien Bien was that they 'just wanted to know' (60.7%) – again, it is possible that this is linked with risk behaviour – with nearly 30% of MSM in Ho Chi Minh City but only 16.1% of FSW in Ha Noi citing this reason.

Again, despite the law, over 2% of PWID in Dien Bien and MSM in Ho Chi Minh City said that they had taken a test for employment-related reasons (no FSW in Ha Noi cited this reason). Finally, a greater proportion of FSW in Ha Noi (14.8%) tested for pregnancy-related reasons than did women

in the OPC sample, while FSW and MSM in Ho Chi Minh also said they had been referred by a sexually transmitted infections clinic (6.1% and 2.8% respectively).

Figure 18: Reasons given for HIV testing (multiple-answer question)





In addition to answering the specific questionnaire questions, respondents were asked to provide feedback on the positive aspects and challenges of testing. Positive aspects cited by some respondents included the availability of both pre- and post-test counselling, as well as mental health support; accessible, suitable and good quality test and treatment services (with some respondents saying that services had improved); free testing; and enthusiastic, considerate, friendly and sincere health staff, who did not stigmatize or discriminate. Some respondents also said that their results had been provided to the appropriate people.

Y's partner died of TB and so she decided to get tested and discovered her positive status. Y wore a face mask throughout the interview in case she was seen by someone she knew.

Case study: Woman living with HIV in Hai Phong

However, some respondents said that their health problems were too serious to enable them to go to a clinic for testing, while others said that they were very nervous, scared or lacking in confidence, and that it was difficult to accept a positive test result. Despite these fears, some respondents reported a lack of pre- and post-test counselling, or insufficient or unclear counselling, or a lack of consistent mental health support. Others said that they lacked information on available testing and health services, or that the testing process was unclear. For certain respondents, access to health services was difficult, and/or the administration process was very complicated, even unnecessarily

so, with long waiting times for examinations and tests. Some reported a lack of information-sharing between clinics and hospitals, resulting in people having to take the same test at different locations. Respondents also said that some tests were not free (where they were conducted outside clinics). Some respondents said that health care providers at the district level needed further skills development. Finally, some respondents reported incorrect test results, the unavailability of viral load tests or not being told their test results.

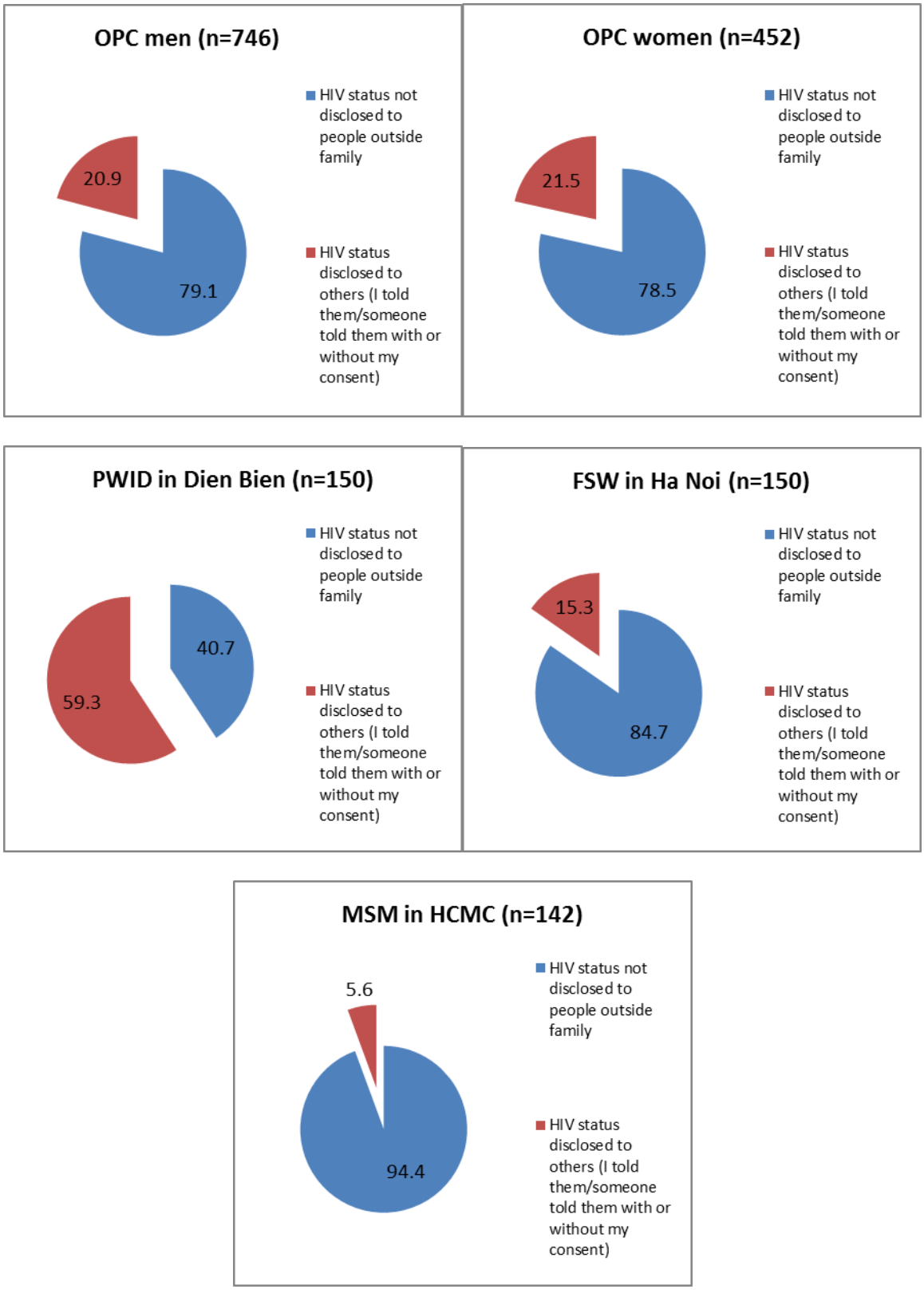
4.3 Disclosure and confidentiality

While voluntary disclosure of HIV status can provide valuable public health benefits, particularly for the sexual partners of PLHIV, and improve care and treatment outcomes for PLHIV, it may also lead to stigma and discrimination. Where disclosure is involuntary – that is, where HIV status is revealed without the consent of the person involved – this not only breaches the rights of the individual but can have particularly serious impacts. Viet Nam's 2006 Law on HIV[30] provides for the protection of the rights of PLHIV in this respect, including their right to have their privacy respected (Article 4), and more specifically prohibits making public the name, address and image of PLHIV or disclosing information on a person's HIV status to another without their consent (Article 8). Article 30 of the Law on HIV provides for exceptions to Article 8, specifying that HIV test results can be disclosed to the tested person; their spouse; their parents or guardian if they are minors or have lost their civil capacity; staff members who provide counselling and inform people of their results; people responsible for providing care and treatment for PLHIV at medical establishments and in educational establishments, reformatories, social relief establishments, prisons or detention camps; and certain people involved in compulsory testing. These people are required to keep this knowledge confidential. Article 4 also provides for the obligation of PLHIV to inform their spouses or fiancé/fiancée of their status.

Very few PLHIV reported that they had revealed their status outside their own family. For nearly 80% of respondents in the OPC sample, and an even greater proportion of FSW in Ha Noi and MSM in Ho Chi Minh City, nobody outside their family knows about their HIV status. However, only 40.7% of PWID in Dien Bien had kept their status confidential within their family.

[30] *Law on HIV/AIDS Prevention and Control No. 64/2006/QH11*.

Figure 19: Summary: disclosure of HIV status

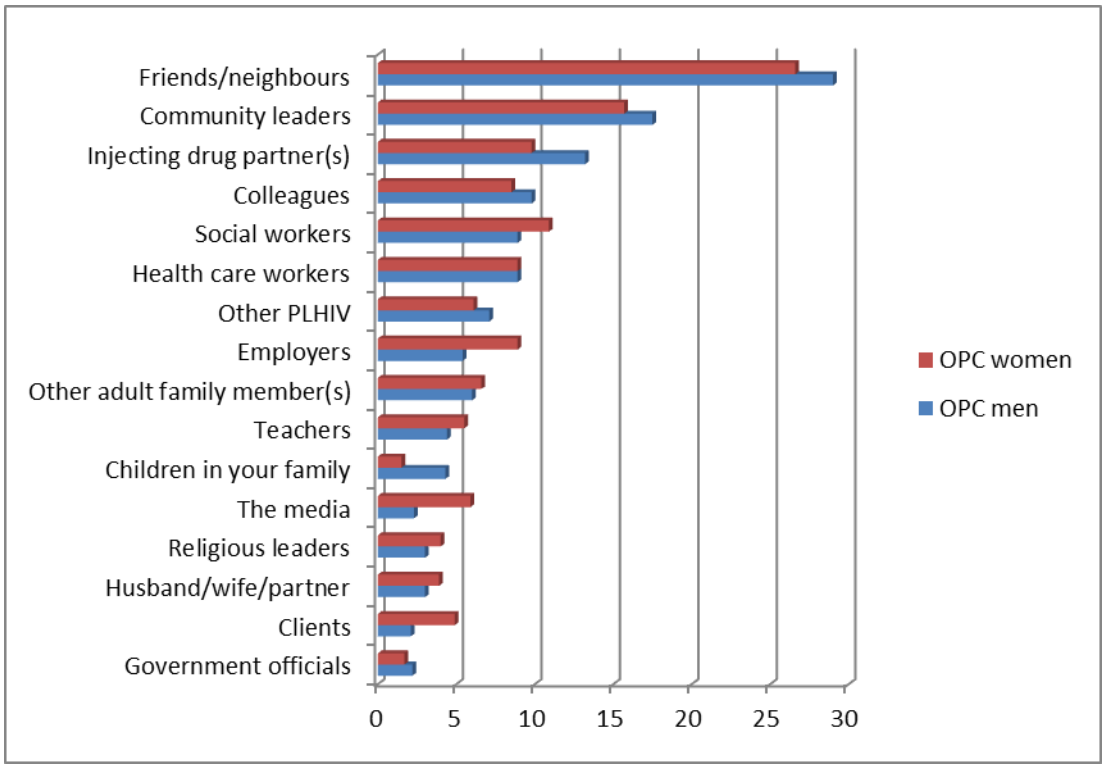


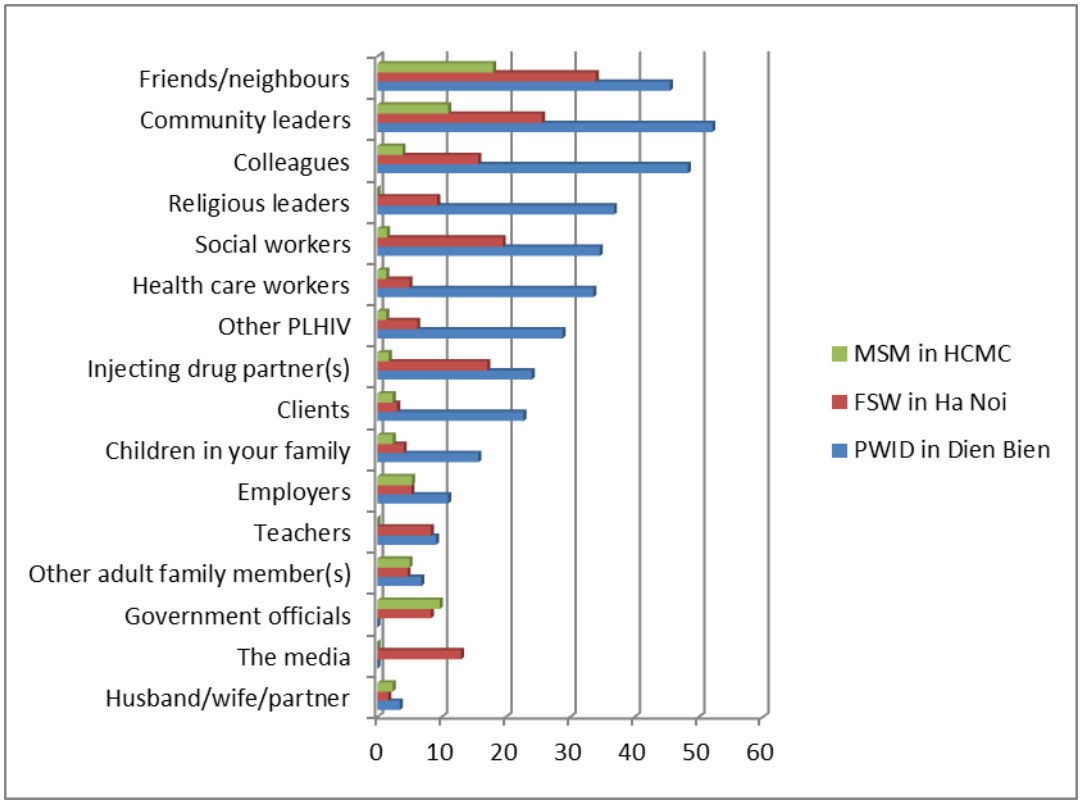
Unfortunately, among those whose status was known, a substantial proportion reported that their status was disclosed without their consent. More than half of the PWID in Dien Bien reported

disclosure without consent; FSW in Ha Noi were also likely to have their status disclosed without their consent. This may be due to social perceptions of and sanctions for sex work and drug use. MSM in Ho Chi Minh City were the least likely to undergo such disclosure. Up to 28% of OPC-sampled respondents said their status had been disclosed without their consent. Similarly, when asked about violations of their rights, many respondents quoted the right to privacy and confidentiality. Among OPC sample respondents who reported such violations, 65.3% of men and 69.3% of women reported abuse of this right. Among the snowball-sampled respondents who reported rights violations, over half of the FSW in Ha Noi, 44.4% of the MSM in Ho Chi Minh City and 32.1% of the PWID in Dien Bien specifically mentioned this right.

Friends and neighbours were most likely to be told of a PLHIV's status without their consent, with over 28% of OPC-sampled respondents, 45.5% of PWID in Dien Bien, 34% of FSW in Ha Noi and 18% of MSM in Ho Chi Minh City reporting such disclosure. Both OPC respondents (16.8%) and snowball-sampled respondents also reported high levels of disclosure without consent to community leaders: 52.1% of PWID in Dien Bien, 25.6% of FSW in Ha Noi, and 11% of MSM in Ho Chi Minh City. These high levels may be linked to community-level stigma and discrimination, such as gossip (see below). Indeed, one of the case study respondents spoke of her fears of disclosure due to the proximity of her house to the clinic, and the fact that her husband and his family told people in the community. Injecting drug partners were also likely to be told the respondents' status without consent, as were employers, health care and social workers.

Figure 20: Disclosure of HIV status without consent





Generally speaking, among the snowball samples, PWID in Dien Bien and FSW in Ha Noi are least likely to conceal their status from others (or be able to conceal their status), with the PWID even more likely to disclose their status or have it disclosed for them. However, MSM in Ho Chi Minh City are very likely to hide their status from others.

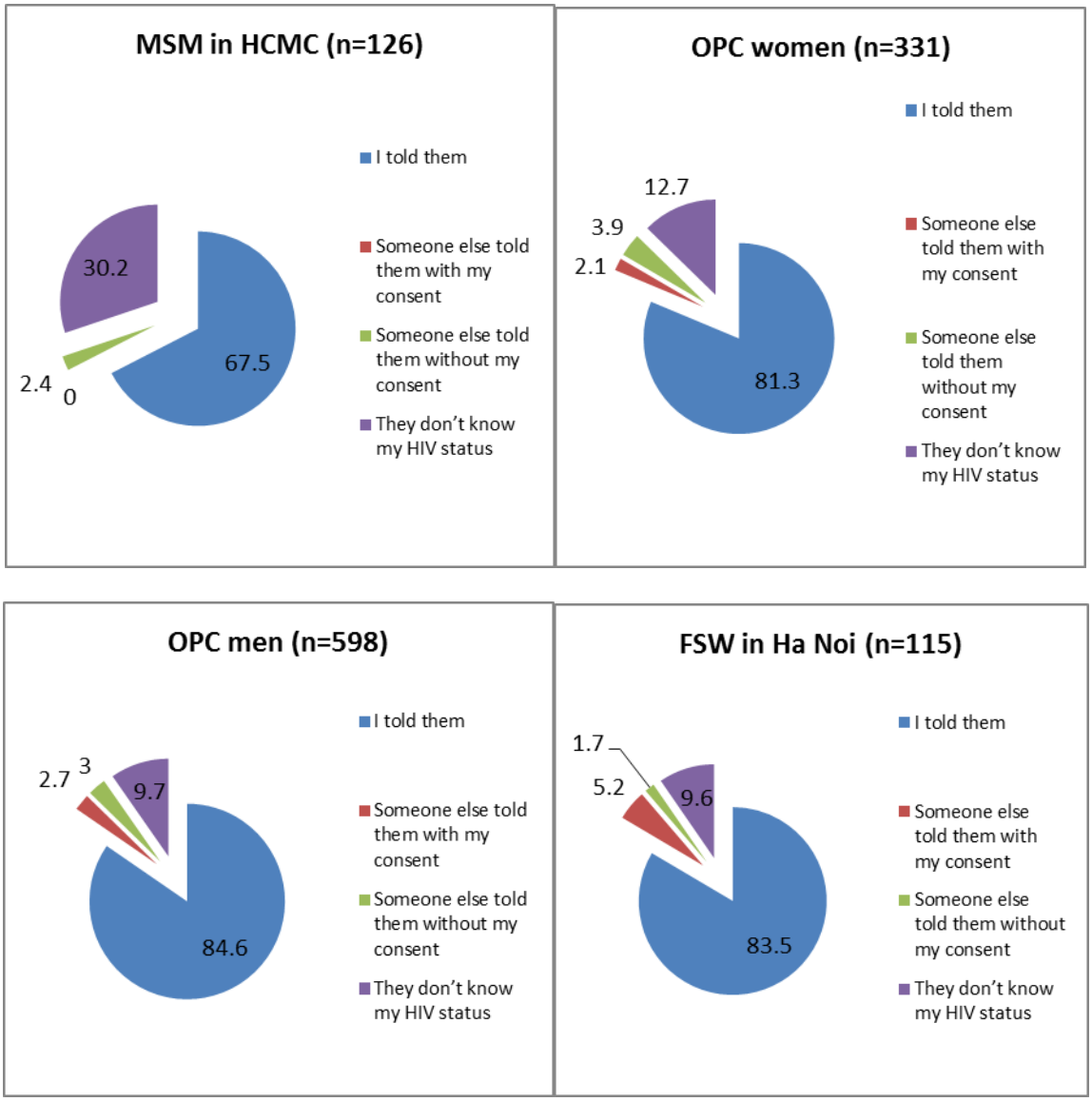
Y's physical and mental health are bad, and she is frightened of having her status revealed. She hides her status because she is afraid of being fired by her employer. Y also does not dare to reveal her status to her partner because she is scared of being abandoned.

Case study: Woman living with HIV in Hai Phong

A large majority of all respondents in the survey told their spouse or partner of their HIV status themselves, or gave their consent for them to be told. However, nearly 13% of OPC-sampled women and 1 in 10 OPC-sampled men and FSW in Ha Noi reported that their spouse/partner did not know their HIV status; the same is true of over 30% of MSM in Ho Chi Minh City. This is not only in contravention of the Law on HIV but hiding one's status from their sexual partners may serve to fuel intimate partner transmission: recent data show that consistent condom use is dramatically higher in Viet Nam when the woman in the relationship is aware that her male partner is living with HIV, and when the man living with HIV is aware that his female partner is HIV negative.[31]

[31] Measuring Intimate Partner Transmission of HIV in Viet Nam: A data triangulation exercise. UNAIDS and UN Women, Viet Nam, 2012.

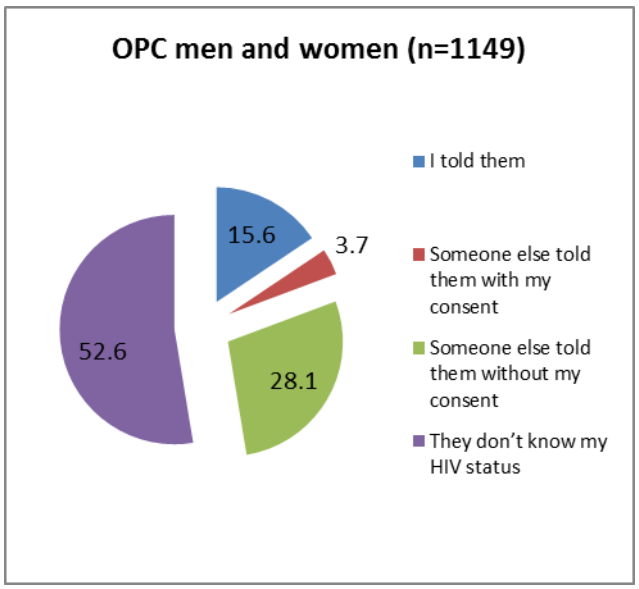
Figure 21: Disclosure of HIV status to spouse or partner



The majority of respondents also told other adult family members about their status. Among the snowball sample, PWID in Dien Bien were the most likely to do this, and only 2% said that their families did not know their status (2.7% said that their partners did not know). The families of FSW in Ha Noi and MSM in Ho Chi Minh City were less likely to know their status.

As discussed above, the disclosure of HIV status to friends and neighbours was disproportionately non-consensual. Despite this, nearly 75% of MSM in Ho Chi Minh City, over half of the OPC-sampled respondents and 46.3% of FSW in Ha Noi said that their friends/neighbours did not know their status and relatively few respondents disclosed their status to friends and neighbours themselves. However, a higher proportion (23.8%) of PWID in Dien Bien did so and only 20.3% of these respondents said that their neighbours/friends did not know their status.

Figure 22: Disclosure to friends and neighbours (OPC respondents)



Among the snowball samples, FSW in Ha Noi were the most likely to tell their colleagues about their HIV status (45.1%). A total of 81.8% of MSM in Ho Chi Minh City and over 60% of OPC-sampled respondents said that their colleagues did not know their status at all. Employers were even less likely to be told HIV status, particularly by OPC-sampled respondents and MSM in Ho Chi Minh City.

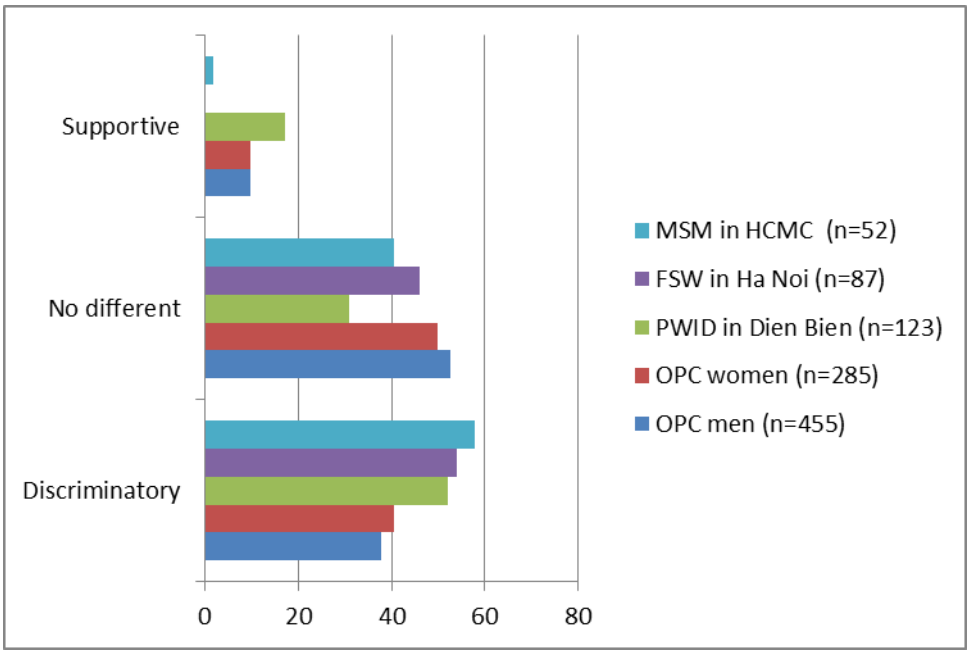
4.4 Familial and social experiences of stigma and discrimination

The support of family and community is particularly crucial for both the physical and mental well-being of PLHIV. Stigma can mean that PLHIV are isolated from their families and social structures, or prevented them from accessing services necessary to their health and welfare.

Family and community reactions to HIV status

Respondents were asked about the reactions of family, friends and colleagues when they first found out about the respondent's HIV status. Friends and neighbours of PLHIV (to whom their status is often disclosed with their consent) are consistently the most discriminatory, particularly towards MSM in Ho Chi Minh City (57.7%), FSW in Ha Noi (54%) and PWID in Dien Bien (52%). Nearly 39% of OPC respondents (and more women than men) also reported such a reaction. In addition, few friends and neighbours seem to have been actively supportive, with no FSW in Ha Noi and only 1.9% of MSM in Ho Chi Minh City reporting supportive reactions.

Figure 23: Reactions of friends/neighbours when they first found out the respondent's HIV status (not including people who responded "not applicable")



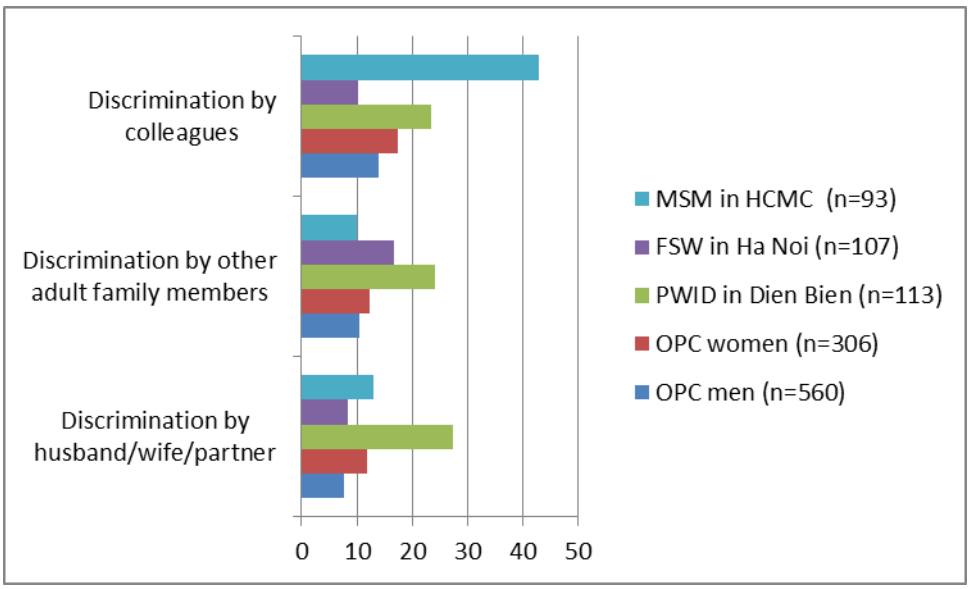
Similarly, a large proportion (42.9%) of MSM in Ho Chi Minh City reported that colleagues had a discriminatory reaction on learning their status, while 23.5% of PWID in Dien Bien also reported negative reactions. FSW in Ha Noi reported the lowest level of discriminatory reactions from colleagues (10.3%). An average of 15.2% of OPC respondents (more women than men) reported discriminatory reactions.

The husbands, wives and partners (27.4%) and family members (24.1%) of PWID in Dien Bien also seem to have been discriminatory. Among other respondents, spouses and partners seem to have shown the least discrimination, although levels are still worrying, with MSM in Ho Chi Minh City (12.9%) and women from the OPC sample (11.8%) most often reporting such reactions. FSW in Ha Noi also seem to have suffered more from discrimination from family members (16.7%).

My two younger brothers became addicted to drugs, and died of AIDS-related diseases in 2004 and 2008 respectively. This might be why my father often scolded us and shouted, whenever he faced any business difficulties, "If you catch any diseases, you should kill yourself on the street. Don't come home, keep this house peaceful and quiet!" I've been obsessed with what my father said for years.

Case study: Man living with HIV in Can Tho

Figure 24: Discriminatory reactions on first finding out the respondent's HIV status



The case studies show how this discrimination can manifest itself. The women interviewed reported a variety of extremely discriminatory and stigmatizing behaviours on the part of their families-in-law, including being forced to move away from the family home; not being allowed to share the family's implements or participate in family meals or work; arguments; being reported to the police on false charges; threats of disclosure; a lack of support and help; the withholding of inheritance; and verbal abuse. One woman said that her family's only concern when she was hospitalized with a premature baby was the baby's HIV status. In addition, some women saw high levels of discrimination from their husbands. In one case, this was based on the husband's accusation of infidelity on discovering her HIV status, and both the woman and her children suffered from his and his family's anger. Other women also said that their children had been stigmatized and discriminated against.

> Once their family discovered X and her husband's HIV status, their family forced them to live separately. Whenever they touched anything, their parents-in-law were afraid that they could transmit the virus to others and looked at the couple suspiciously.
>
> In addition, X was isolated and verbally assaulted by her husband's family, especially her parents-in-law. They did not let her do any housework; when she invited them to eat an orange they did not dare to eat it because they were afraid of HIV transmission.
>
> **Case study: Woman living with HIV in Hai Phong**

Gossip, insults, harassment, assault and exclusion

Respondents were asked to identify incidents of stigma and discrimination from other people, with questions relating specifically to gossip, verbal insults, harassment, verbal and physical assault and social exclusion. Many survey participants reported suffering these forms of stigma and discrimination. It should be noted that these forms of stigma and discrimination may be most likely to happen at the community level, and it is possible that this can be linked to the high rates of disclosure without consent to friends/neighbours and community leaders (see above).

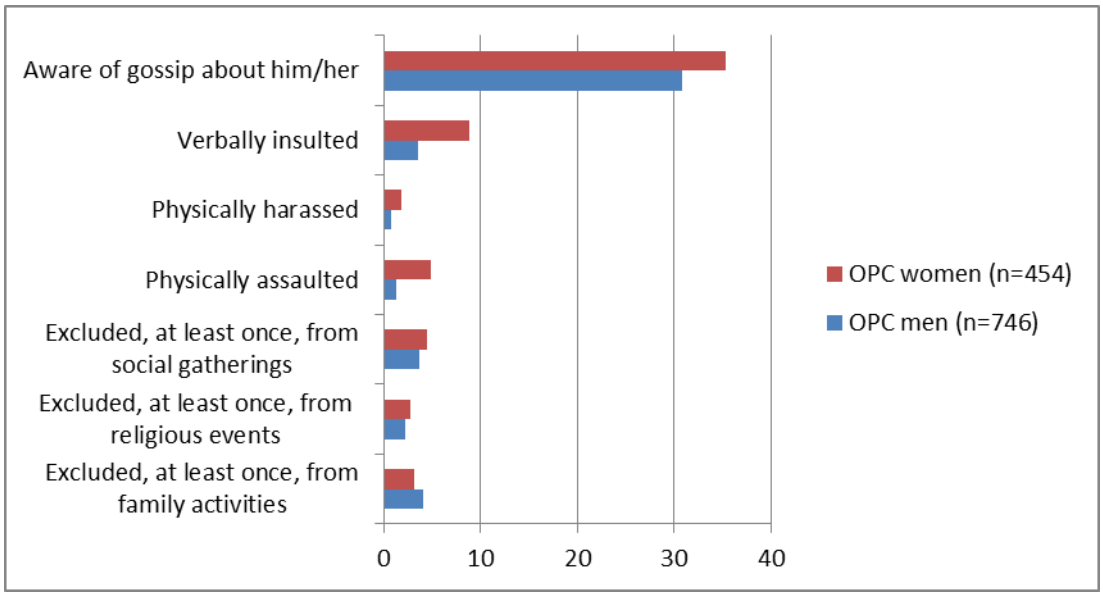
There also seems to be a gendered element in some experiences of stigma and discrimination. OPC-sampled women were consistently more likely than OPC-sampled men to report such experiences,

including verbal insults and physical assault. Among the snowball samples, FSW in Ha Noi reported the highest levels of specific instances of stigma (with the exception of gossip).

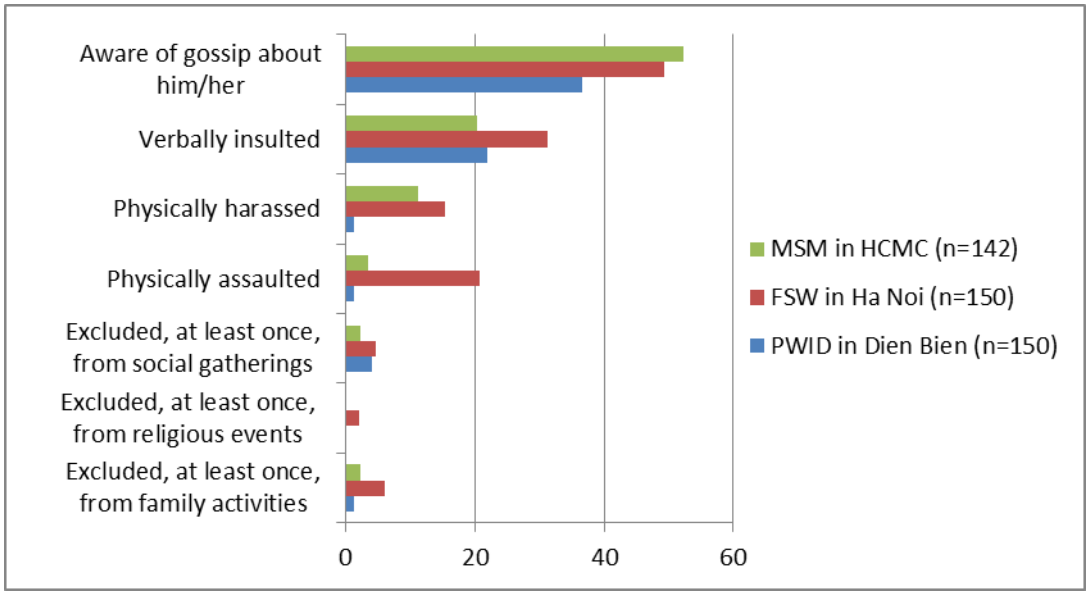
> When he found out my HIV status, my husband was the first person to display stigmatizing and discriminatory attitudes. When I had symptoms, I went for an HIV test. I told my husband about this, He immediately blamed this on my own wrongdoing, accusing me of contracting HIV from an extra-marital partner. Then he got angry, and his family followed his example, discriminating against my two children and myself.
>
> **Case study: Woman living with HIV in Ho Chi Minh City**

At the same time, respondents were also asked whether they believed these incidents were related to their HIV status or to other factors. It was clear that – particularly among the snowball-sampled respondents – their HIV status was often not perceived to be the only or even primary reason for them.

Figure 25: Experiences of stigma and discrimination in the last 12 months[32]

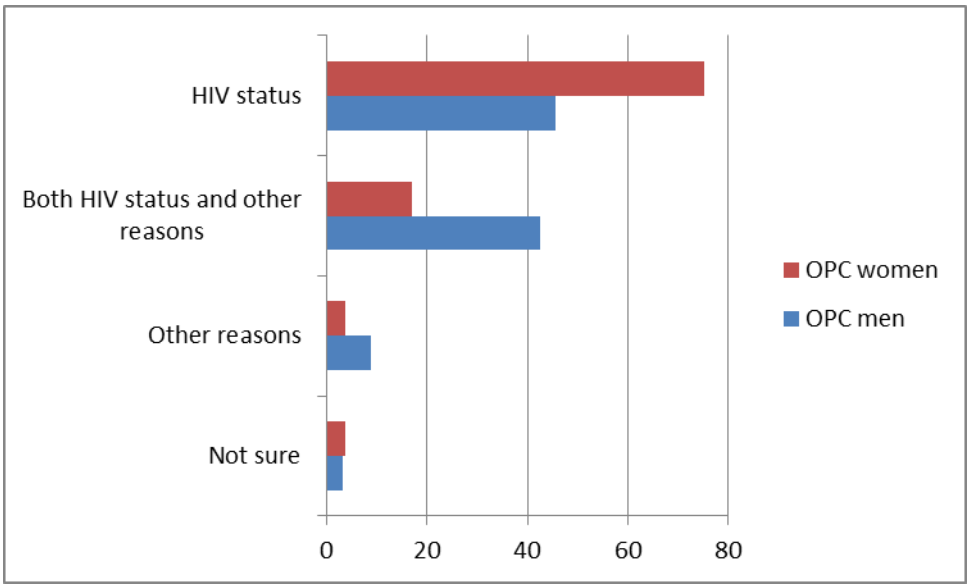


[32] Those who answered "one" or "a few times" or "often" were recorded as answering "yes – have at least one experience of stigma/discrimination".



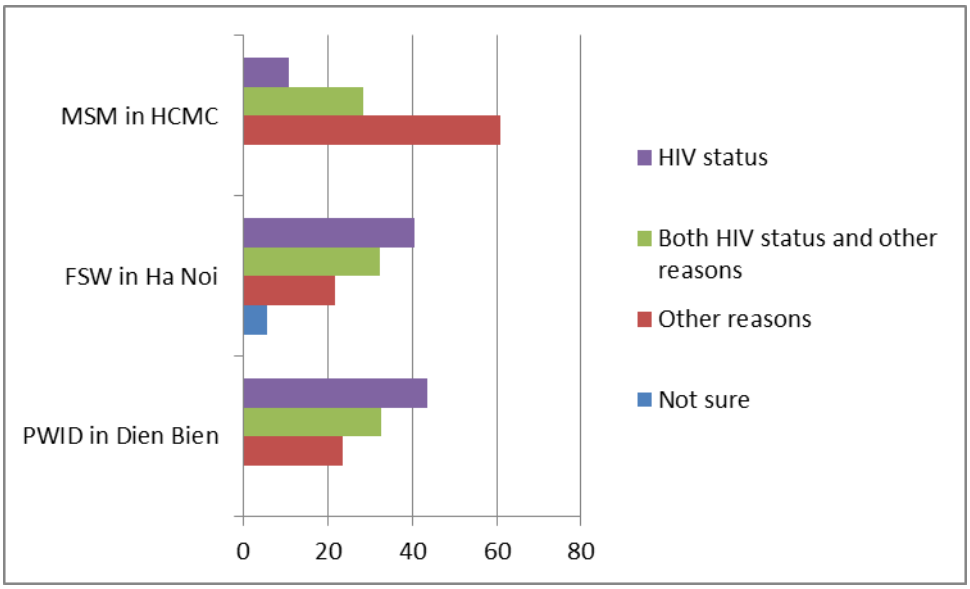
By far the most commonly reported form of stigmatization of PLHIV was gossip, particularly for those in the snowball samples. Around a third of OPC respondents said that they were aware of gossip about them, with more women (35.3%) than men (30.8%) reporting gossip. Of these respondents, almost all the women (92.4%) ascribed the gossip to their HIV status alone or to both HIV status and other reasons, and 88.2% of the men also did so. The case studies also reveal the effects of community stigma on PLHIV and their families, with a man in Can Tho suffering because his parents are very concerned about village gossip and the impact of his status on the family business. In his case, too, his risk behaviour – injecting drug use – may have intersected with his status to create additional stigma.

Figure 26: OPC respondents: reasons for gossip



Among the snowball samples, more than half of the MSM in Ho Chi Minh City interviewed (52.2%) said that they were aware of being gossiped about, although the majority ascribed this gossip to reasons other than their HIV status. Of the 49.3% of FSW in Ha Noi and 36.7% of PWID in Dien Bien who reported gossip, only 40.5% and 43.6% respectively said it was exclusively because of their HIV status, with over half citing 'other reasons' or both 'HIV and other reasons'.

Figure 27: Snowball-sampled respondents: reasons for gossip

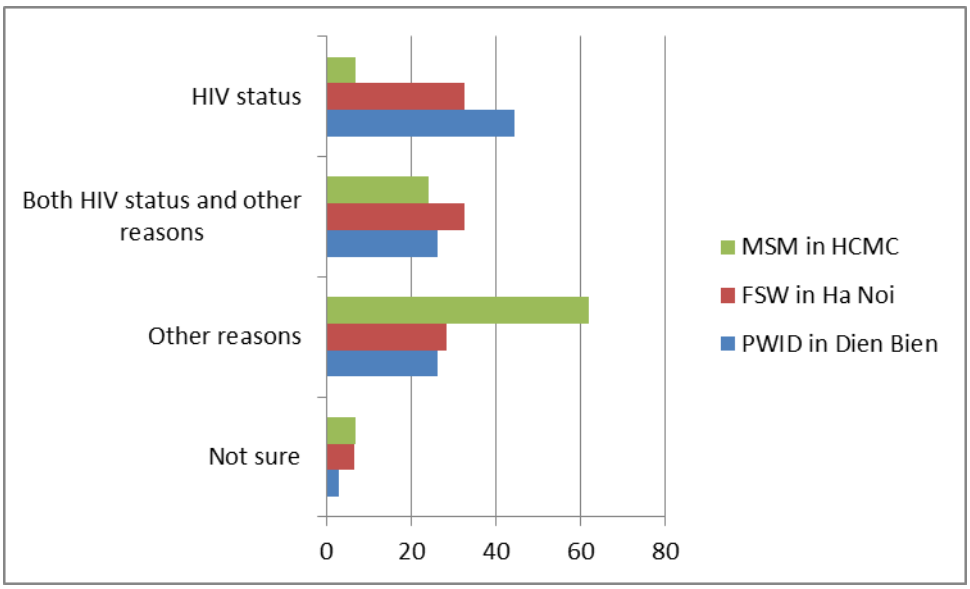


Meanwhile, verbal insults were a particular problem for the snowball-sampled respondents. Over 31% of FSW in Ha Noi and more than 20% of both PWID in Dien Bien and MSM in Ho Chi Minh City reported being verbally insulted. While a substantial proportion of both PWID in Dien Bien (44.4%) and FSW in Ha Noi (32.6%) attributed the insults to their HIV status alone, 'other reasons' were also important. Again, the majority of MSM in Ho Chi Minh City ascribed the insults to 'other reasons'. Only 5.6% of OPC-sampled respondents reported verbal insults, although more than twice as many women did so than men.

My husband got into a fight with his sister and she reported to the police that we had a scheme to steal family property. Since then, his sister often assaulted us verbally and did not allow us to touch anything in the house. She also told the village Women's Union and neighbours about our HIV status; as a result, they changed their attitudes. Once when I got wet, I entered the house to get a dry towel, but my sister-in-law reported me to the police for stealing and asked us to leave the house.

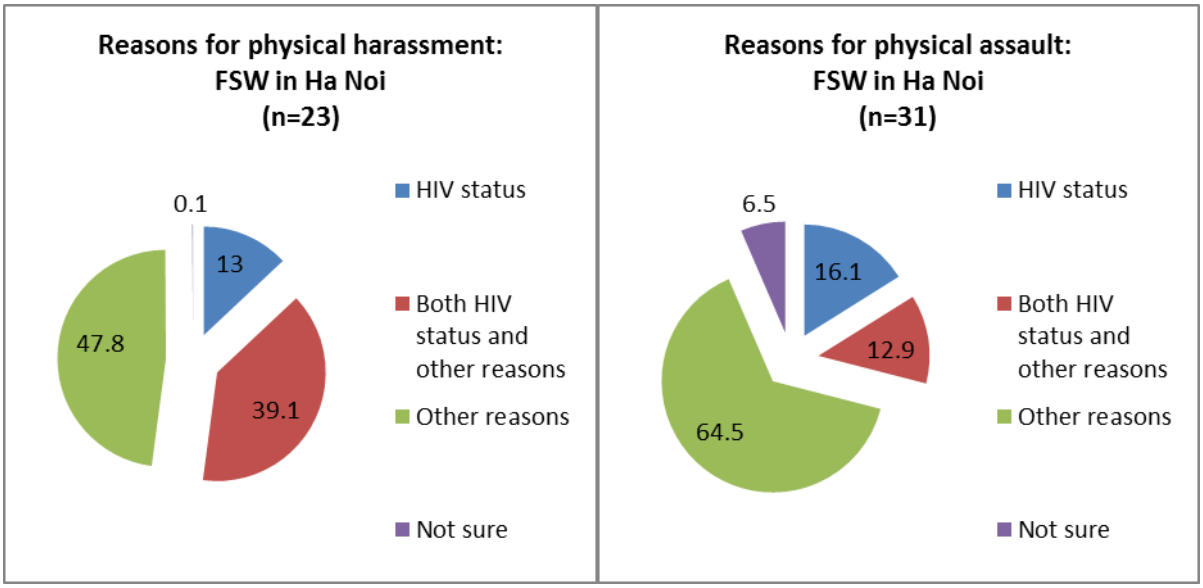
Case study: Woman living with HIV in Can Tho

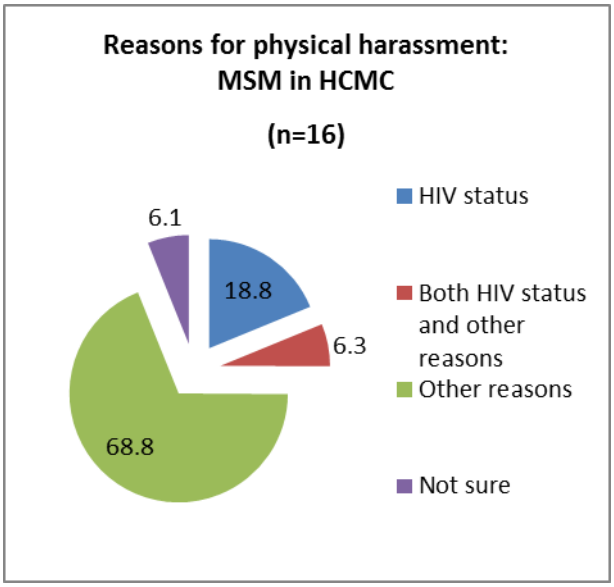
Figure 28: Snowball-sampled respondents and reasons for verbal insults



Over 15% of the FSW interviewed said that they had been physically harassed and nearly 21% stated that they had been physically assaulted at least once in the past 12 months. However, in both cases their HIV status was not the major reason given. Similarly, of the 11.3% of MSM in Ho Chi Minh City who had been physically harassed, most (68.8%) attributed the violence to reasons other than HIV status.

Figure 29: Snowball-sampled respondents and physical harassment or assault





Exclusion seems to be less of a reported problem, although FSW in Ha Noi again reported being excluded more often than did the other snowball-sampled risk groups.

'Other reasons' for these forms of stigma and discrimination

As noted above, HIV status was often not perceived to be the only or even primary reason for these types of stigma and discrimination, particularly among the snowball-sampled respondents.

Where respondents identified 'other reasons' for stigma and discrimination, they were asked to specify the major other reason.[33] The results mirror those outlined in the section on respondents' backgrounds, where respondents self-identified categories of behaviour or situation. For example, OPC-sampled women – more of whom identified themselves as belonging to an ethnic group – reported far higher rates of ethnic-group based stigma and discrimination than OPC-sampled men. Predictably, injecting drug use, sex work and sexual orientation were the most often reported 'other reasons' for stigma and discrimination, particularly among PWID in Dien Bien, FSW in Ha Noi and MSM in Ho Chi Minh City respectively. Injecting drug use was also a factor reported by OPC-sampled men, a similar proportion of whom identified themselves as having formerly injected or as currently injecting drugs. In the context of Viet Nam's concentrated epidemic, however, where these behaviours are stigmatized for their association with HIV as well as in and of themselves, stigma and discrimination for these reasons may not be entirely unrelated to HIV-based stigma.

Logistic regression analysis of the OPC-sampled data (see Annex 2, Table 35) also showed that reported risk behaviours were significantly associated with PLHIV's experience of stigma and discrimination. The results also demonstrated that the primary targets of HIV-related stigma are both PLHIV and those who are perceived to be HIV-positive or associated with HIV. The analysis links drug use, membership of an indigenous population and sex work with stigma and discrimination. In particular, PLHIV who reported undertaking sex work were nearly four times likely to report stigma and discrimination than others.[34]

In addition, the analysis showed that current relationship status, residence and employment status were significantly associated with the experience of stigma and discrimination. People who were

[33] Since respondents were only asked this question once, the data cover all of these categories of stigma and discrimination (namely gossip, insults, physical harassment or assault and exclusion).
[34] OR=3.59; 95%CI=1.29-10.0

married or cohabiting but not living with their spouse experienced more than twice the stigma and discrimination experienced by people who currently live with their husband/wife/partner.[35] Moreover, people living in a rural area or in a small town were 1.6 times more likely to experience stigma and discrimination than those living in a large city. Finally, people who were unemployed seemed to face more stigma and discrimination than people who were currently working, and self-employed people were 0.76 times less likely to face stigma and discrimination than unemployed people.[36] These findings were supported by additional anecdotal evidence from PLHIV[37] who said that poverty was a major contributing factor to stigma and discrimination.

4.5 Self-stigmatization

Respondents were also asked to describe how they were feeling about themselves. The results show that a large number of the PLHIV interviewed are stigmatizing themselves in various ways: among the OPC sample, around 44% of all respondents reported feeling ashamed.

There are clear gender differences in the responses. Women were five times more likely to blame others for their situation than men, as well as more likely to feel suicidal. However, the men were nearly four times more likely to feel that they should be punished, more than twice as likely as women to feel guilty and one and a half times more likely to blame themselves. During peer reviews of the data, many PLHIV involved in the study believed that these differences may be attributed to the fact that many men assume they were infected because of risky behaviour (such as drug use or unprotected sex with sex workers), while many women assume that they were infected by their spouses (and therefore did nothing 'wrong').[38] This may also help to explain why 24.2% of men but 18.2% of women reported low self-esteem.

When Y discovered her HIV status, she was shocked. Due to a lack of information and knowledge, she isolated herself and did not engage in her family's daily activities, such as cooking, because she was afraid that 'normal' contact might transmit the virus to others. She always felt under pressure and panicky. She was initially reluctant to seek more information about HIV or ways to take care of herself, or to seek out HIV care and support services.

Case study: Woman living with HIV in Hai Phong

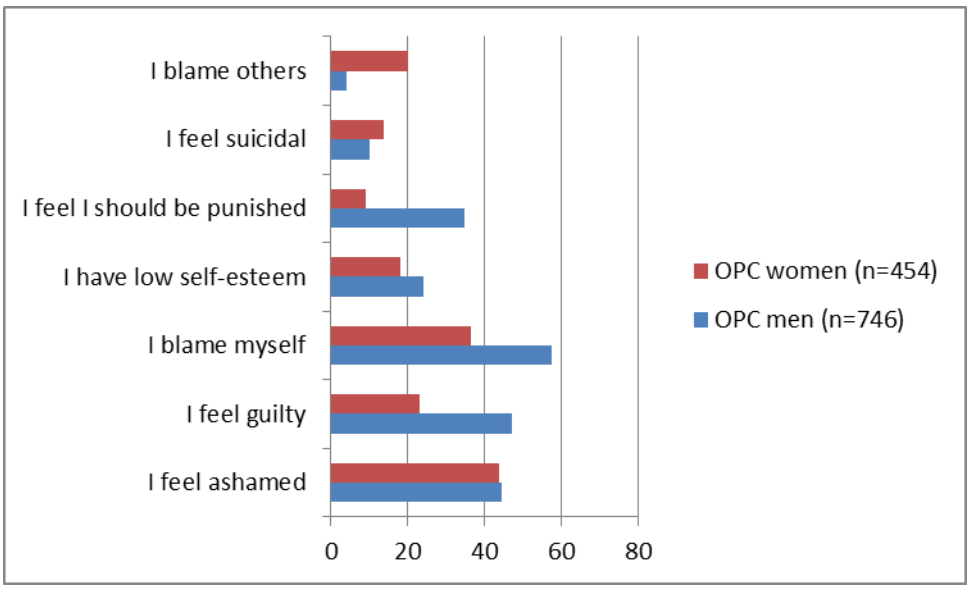
[35] OR=2.52; 95%CI=1.40-4.55

[36] OR=0.76; 95%CI=0.56-1.03

[37] Anecdotal evidence presented at a meeting of PLHIV in Ha Noi on 19-20 June 2012 for the purpose of validating the Stigma Index findings.

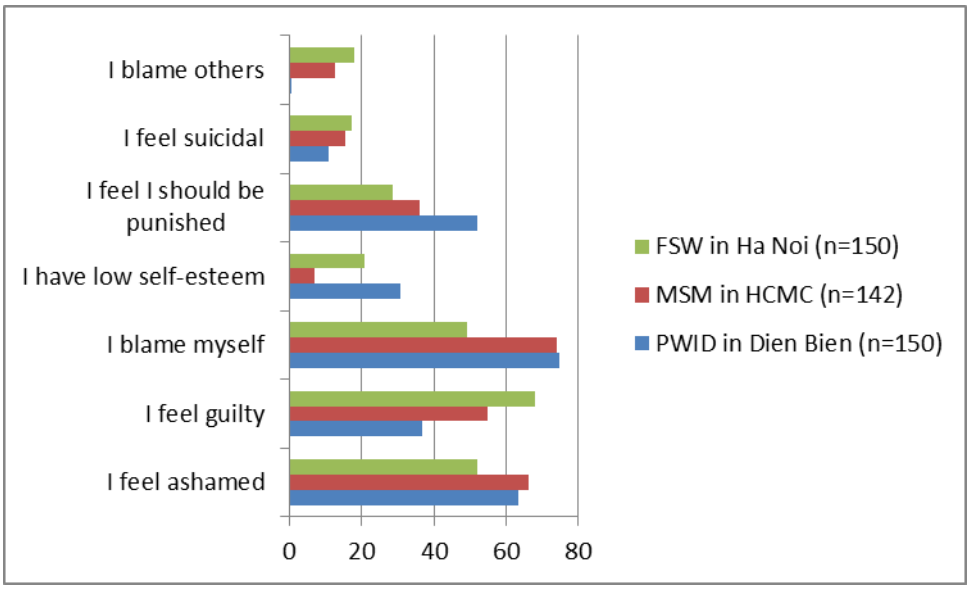
[38] This hypothesis was presented and agreed at a meeting of PLHIV in Dien Bien, 29-30 March 2012, held in part for the purpose of validating the Stigma Index findings.

Figure 30: Self-stigmatization among the OPC respondents



High levels of self-blame, guilt and shame were found among the snowball-sampled respondents. A gendered pattern was also evident among the responses, with the FSW in Ha Noi also more likely to report blaming others and feeling suicidal than either PWID in Dien Bien[39] or MSM in Ho Chi Minh City. However, unlike the OPC women, they were also most likely to feel guilty. PWID in Dien Bien and MSM in Ho Chi Minh City were also more likely than FSW in Ha Noi to feel shame, to blame themselves and to think they should be punished. MSM in Ho Chi Minh City reported the fewest feelings of low self-esteem (at only 7%) and the PWID the most.

Figure 31: Self-stigmatization among snowball-sampled respondents



[39] For the purposes of this gender comparison, it should be remembered that 95% of these respondents were male.

These feelings – as well as pressure and stigma from others - can lead PLHIV to make decisions about their lives which have negative impacts on their ability to seek care and support from others, including medical care, their ability to care for themselves and their personal and family lives. For example, PLHIV in Can Tho[40] reported that self-stigma and fear of stigma mean that PLHIV do not dare to go to health facilities, or that they travel long distances for their health care in order to avoid stigma (even if they have never experienced stigma and discrimination). One woman interviewed for the case studies said that her lack of knowledge about HIV led her to isolate herself from her family despite her feelings of panic; she was also reluctant to find out more about HIV or how take care of herself, or to seek out HIV care and support services.

The most commonly reported decision of this kind was the decision not to get married – particularly among the snowball-sampled respondents: 78% of MSM in Ho Chi Minh City, 70% of FSW in Ha Noi and nearly 67% of PWID in Dien Bien reported having taken this decision. Nearly half of the OPC-sampled population reported the same, with more women than men making this decision.[41] Respondents also reported deciding not to have any (or more) children, with 23.9% of MSM in Ho Chi Minh City, 22.7% of FSW in Ha Noi and 19.3% of OPC-sampled women taking this decision, and slightly fewer OPC-sampled men and PWID in Dien Bien.

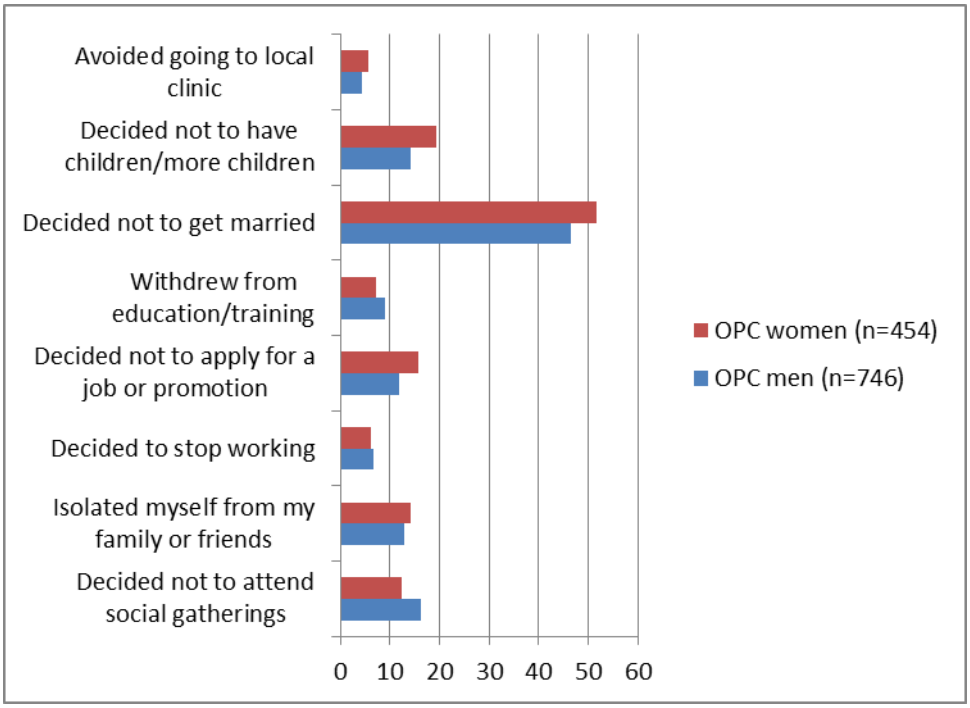
Social isolation was another result of HIV status-related decision-making, with 28% of PWID in Dien Bien and 22.5% of MSM in Ho Chi Minh City deciding not to attend social gatherings; more men than women among the OPC sample took the same decision (16.4% versus 12.4%). Respondents also reported isolating themselves from family and friends – particularly MSM in Ho Chi Minh City (25.4%) and FSW in Ha Noi (18.7%).

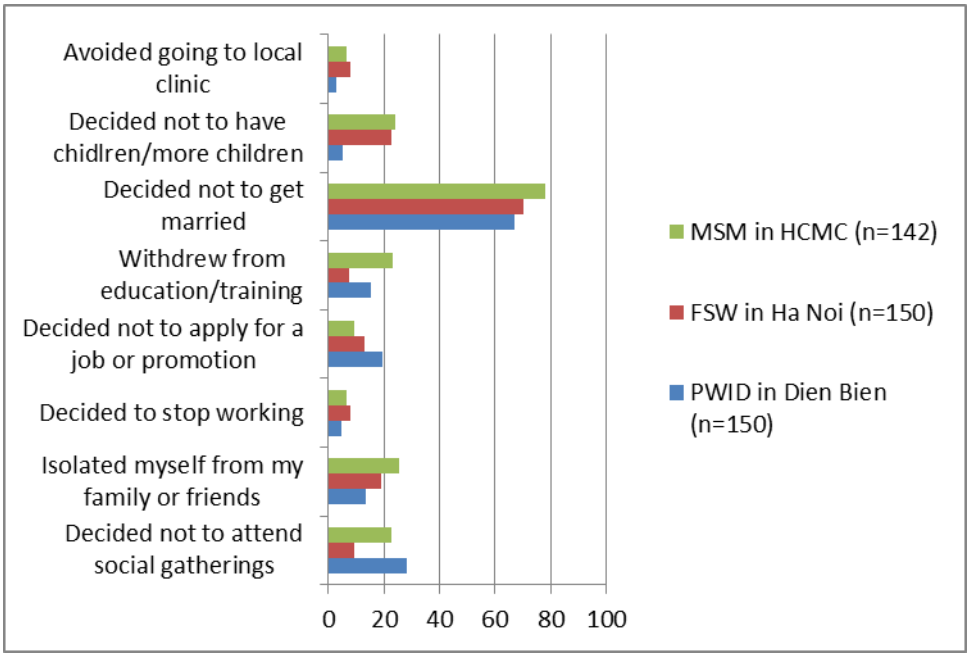
Respondents also took decisions that would impact on their livelihoods, with 23.2% of MSM in Ho Chi Minh City and 15.4% of PWID in Dien Bien withdrawing from education or training; 8% of FSW in Ha Noi deciding to stop work (and over 6% of OPC-sampled respondents and MSM in Ho Chi Minh City deciding the same); and 19.3% of PWID in Dien Bien, 15.7% of OPC-sampled women and 12.7% of FSW in Ha Noi deciding not to apply for a job or promotion.

[40] Responses from a meeting of PLHIV in Can Tho, 08-09 May 2012, held in part for the purpose of validating the Stigma Index findings.

[41] These results do not correspond with the figures of how many respondents are actually married (or in a partnership). It is possible that the decision was taken but reversed and respondents are reporting a reaction rather than a final decision.

Figure 32: Decisions made or actions taken as a result of respondent's HIV status





A logistic regression model was applied to the results from the OPC sample in an attempt to describe the association between self-stigmatization and demographic, social and economic factors (see Annex 2, Table 38). The analysis found that PLHIV who were living with a spouse or partner were 1.5 times more likely to self-stigmatize than PLHIV who were single.[42] Self-stigmatization was also found to be significantly higher among PLHIV who identified themselves as having formerly injected, or

[42] OR=1.51; 95%CI=1.09-2.09

currently injecting, drugs,[43] and among those with lower educational attainments.[44] PLHIV who are currently working were less inclined to self-stigmatize than those who are not working at all.[45]

4.6 Access to work, health and education services

Because of the stigmatization of HIV, and despite legal protection for the rights of PLHIV to work, health and education, HIV status can impact on access to employment opportunities, progress at work, health care and education, making it more difficult for PLHIV to take care of themselves. Respondents were asked about these issues, and whether – in their opinion – decreased access could be attributed to the fact that they were living with HIV.[46]

The survey results show that FSW living with HIV in Ha Noi consistently face major challenges in access to work, health and education services than other respondents. Over 20%, for example, had been forced to change their residence or been unable to rent accommodation during the previous 12 months, of whom half stated this was either directly or indirectly related to being HIV-positive. Another 16.2% of FSW said that they had lost a job/source of income, and again 50% attributed this to the fact that they were living with HIV. Nearly 8% of them had been denied health services.

Among the OPC-sampled respondents, work-related issues were the greatest challenge – 10.4% reported having lost a job/source of income in the previous 12 months, 30% of whom attributed this to their HIV status. Of these respondents, 14.9% said that they faced discrimination from their employer or colleagues, 28.4% stated that they felt obliged to stop working due to poor health and 10.5% said both of the above; 46.3% gave other reasons. Around 5% of respondents from the OPC sample said that they had been refused a promotion or changed job description; more women than men reported this. Indeed, in the OPC sample women were more likely to face discrimination in terms of residence/accommodation, employment (despite more women overall being in employment of some kind), education and health services than men.

> B had side effects from the [ARV] drugs and needed to go to hospital for treatment. Unfortunately, this was revealed to her employer. She was stunned when her supervisor asked to talk with her; he was sympathetic but asked her to resign. Although she begged him, saying that she would not do anything to transmit the virus to co-workers, he refused to let her stay. She could not forget what the supervisor said to her: "Why don't you find another job? Why do you want to stay here? I can't accept you working here" - although she was both competent and responsible at work.
>
> **Case study: Woman living with HIV in Ha Noi**

Similar results obtained in the snowball sample: 9.7% of the MSM in Ho Chi Minh City interviewed said that they had lost a job/source of income, of whom 33.3% said it was because of their HIV status, while PWID in Dien Bien also reported more employment-related issues than other problems.

It should be noted that work-related issues transcend employment type and can also affect self-employed PLHIV (who constitute the majority across all categories of respondent). For example, a

[43] OR=2.39; 95%CI=1.81-3.16
[44] OR=1.89; 95%CI=1.05-3.41
[45] OR=0.59; 95%CI=0.39-0.91; and OR=0.51; 95%CI=0.35-0.73
[46] At the validation meeting of PLHIV in Ha Noi, 19-20 June 2012, the point was raised that restricted access related to HIV status could be "self-inflicted", for example if PLHIV self-stigmatize or suffer a crisis of confidence because of their status.

woman working from home looking after other people's children saw the majority of her clients remove their children from her care once her HIV status was discovered.[47]

> When we organized my brothers' funerals, the village spread rumours and gossip about the fact that someone in my family had died of AIDS. They speculated about the HIV status of the whole family. This meant that very few clients came to have tea at my family's shop.
>
> **Case study: Man living with HIV in Can Tho**

In addition to the 20% of FSW who had been forced to change residence or been unable to rent accommodation, 8.4% of MSM in Ho Chi Minh City and 8% of OPC women reported the same. Anecdotal evidence from Can Tho[48] indicates that in this province, such discrimination is more likely to happen in rural areas.

Around 4% of OPC sampled women, PWID in Dien Bien and FSW in Ha Noi said that their children had been denied education. A total of 3% of PWID in Dien Bien also reported being dismissed from educational institutions themselves.

> X's second child is not HIV-positive, but her grandmother could not believe that the child had not caught the virus because she carries her mother's blood. When this daughter started at kindergarten, the school asked X to show them her most updated test result. However, they refused the blood test result that confirmed her negative status when she was 18 months old and took her to the clinic for another blood test.
>
> **Case study: Woman living with HIV in Hai Phong**

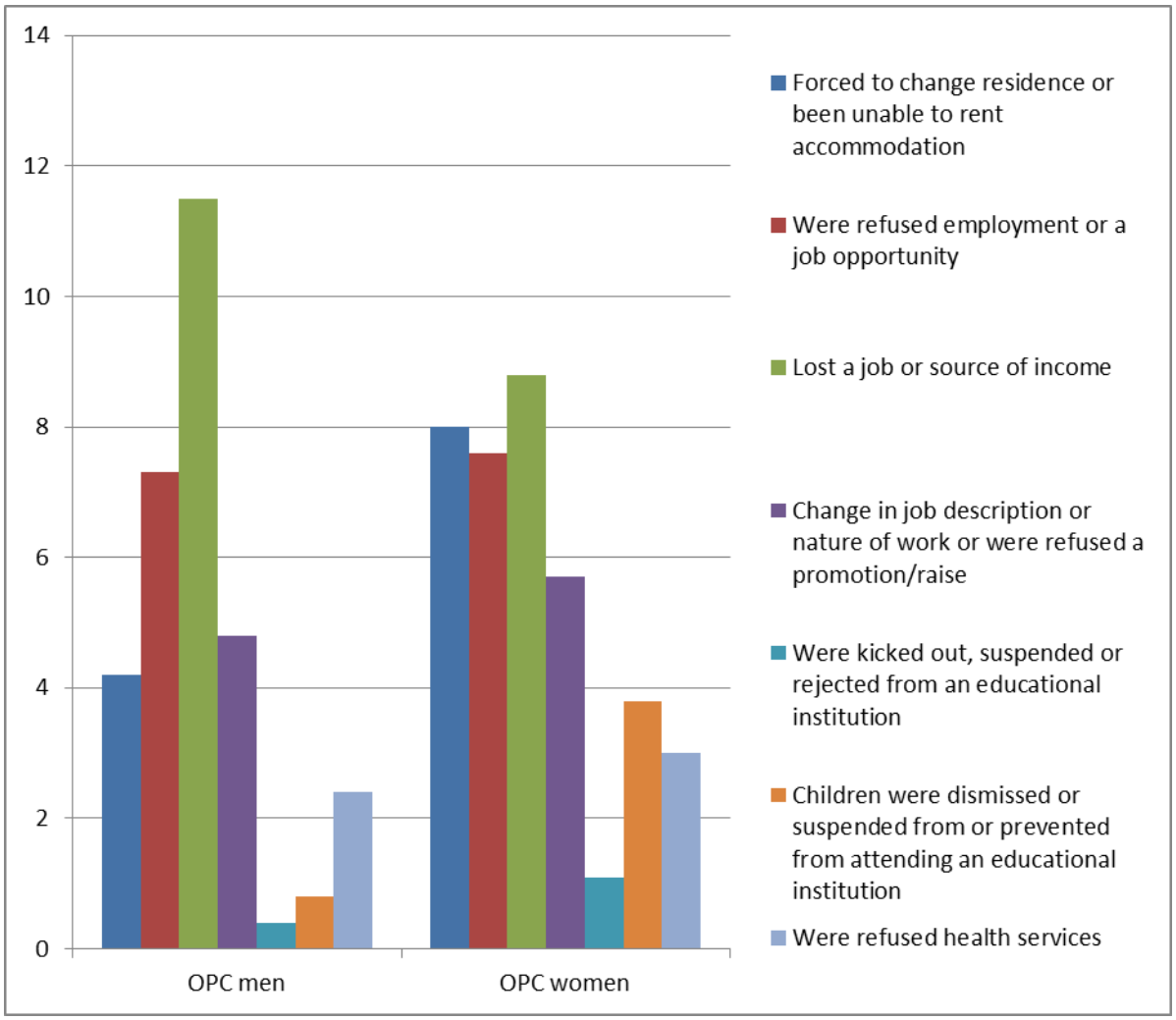
With regard to health services, relatively few PLHIV reported being denied access, although again, among the snowball samples, FSW reported the highest levels at 7.9%. These findings were confirmed by PLHIV in Can Tho,[49] who said that the Law on HIV had reduced discriminatory treatment in health facilities. However, these PLHIV added that despite this improvement, there may be issues regarding the quality of care and the attitude of health care workers: while doctors are reportedly not discriminatory, at least in Can Tho, some nurses and other health workers reportedly are. In addition, these PLHIV said that procedures and documentation requirements are complicated, making it difficult for PLHIV to access services. However, other respondents described enthusiastic, open and friendly doctors and health staff and a lack of stigma and discrimination; frequent medical examinations, comprehensive consultations and sufficient information on regimes and potential side-effects.

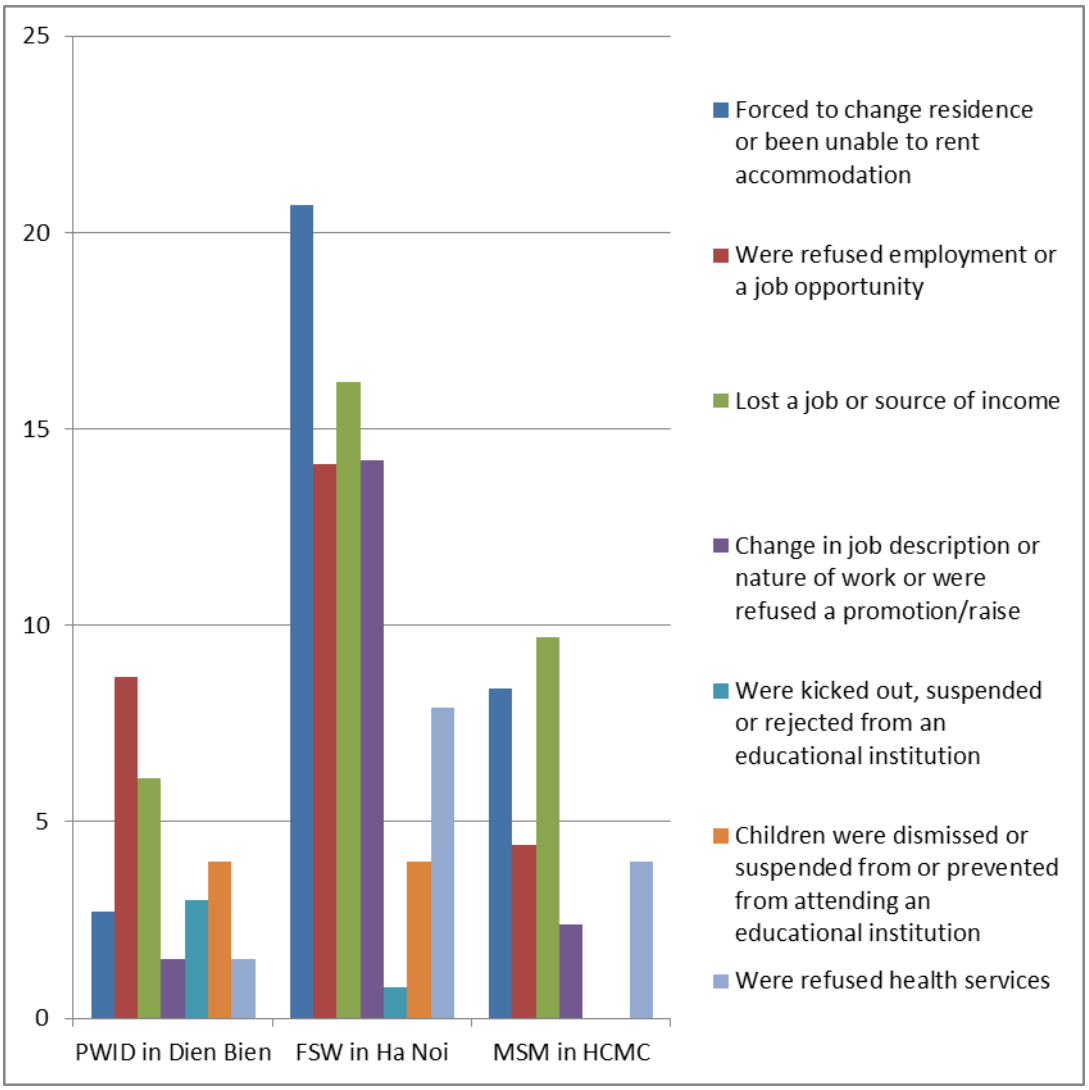
[47] Anecdotal evidence presented at a meeting of PLHIV in Ha Noi on 19-20 June 2012 for the purpose of validating the Stigma Index findings.

[48] Responses from a meeting of PLHIV in Can Tho, 08-09 May 2012, held in part for the purpose of validating the Stigma Index findings.

[49] Responses from a meeting of PLHIV in Can Tho, 08-09 May 2012, held in part for the purpose of validating the Stigma Index findings.

Figure 33: Challenges when accessing work, health and education services (respondents experienced difficulties at least once in the previous 12 months)

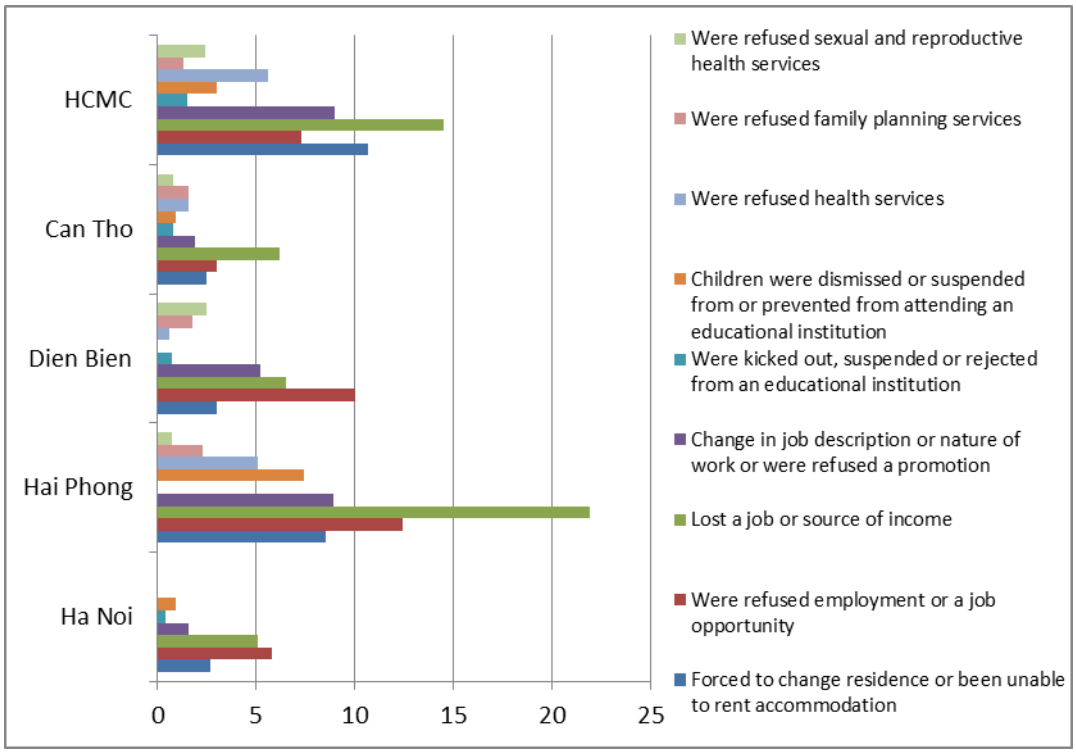




Access to work, health and education services: provincial differences

In order to ascertain where in Viet Nam PLHIV were facing the greatest challenges with regard to accessing income-generating opportunities and health and education services, the data from OPC responses was disaggregated by province. Generally speaking, OPC respondents in Hai Phong experienced the greatest challenges in accessing these services, followed by those in HCMC. Those in Ha Noi and Can Tho experienced the least problems. OPC respondents in Dien Bien – the poorest of the provinces – faced particular barriers to employment and to sexual and reproductive health services. Knowing where people are facing these issues will help provinces to formulate better policy.

Figure 34: Challenges in accessing work, health and education services: comparison between provinces (respondents experienced difficulties at least once in the previous 12 months) (OPC respondents only)



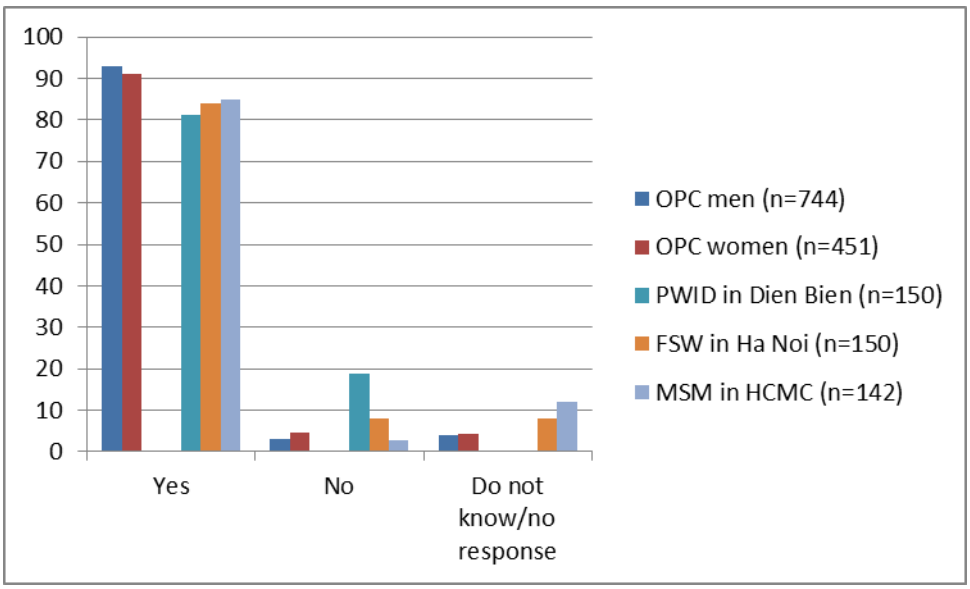
4.7 Access to treatment

Respondents were asked to describe their current state of health, whether they were currently undergoing antiretroviral therapy (ART), whether they felt they had access to ART (even if not currently undergoing treatment) and whether they had been able to discuss HIV-related treatment with a health care professional during the previous 12 months.

Access to ART is reportedly very high, although responses may be biased as the PLHIV who were the source of the random sample had been recruited from pre-ART/ART registration lists. With this bias in mind, reported ART access is unsurprisingly higher than the 2011 national coverage estimate of around 53%.[50] At the same time, PWID, MSM and FSW in the snowball samples also reported high levels of access to ART. Indeed, more respondents in all categories felt they had access to treatment than were actually taking it: 92.9% of OPC-sampled men (versus 80.4% under treatment), 91.1% of OPC-sampled women (versus 84.9%), 85% of MSM in Ho Chi Minh City (versus 73.6%), 84% of FSW in Ha Noi (versus 54.7%) and 81.3% of PWID in Dien Bien (versus 55.3%). However, nearly 19% of PWID in Dien Bien did not feel they could access the programme, and 12% of MSM in Ho Chi Minh City did not know about it.

[50] Viet Nam AIDS Response Progress Report 2012. National Committee for AIDS, Drugs and Prostitution Prevention and Control, 2012 http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/progressreports/2012countries/ce_VN_Narrative_Report.pdf. Accessed 17 June 2012.

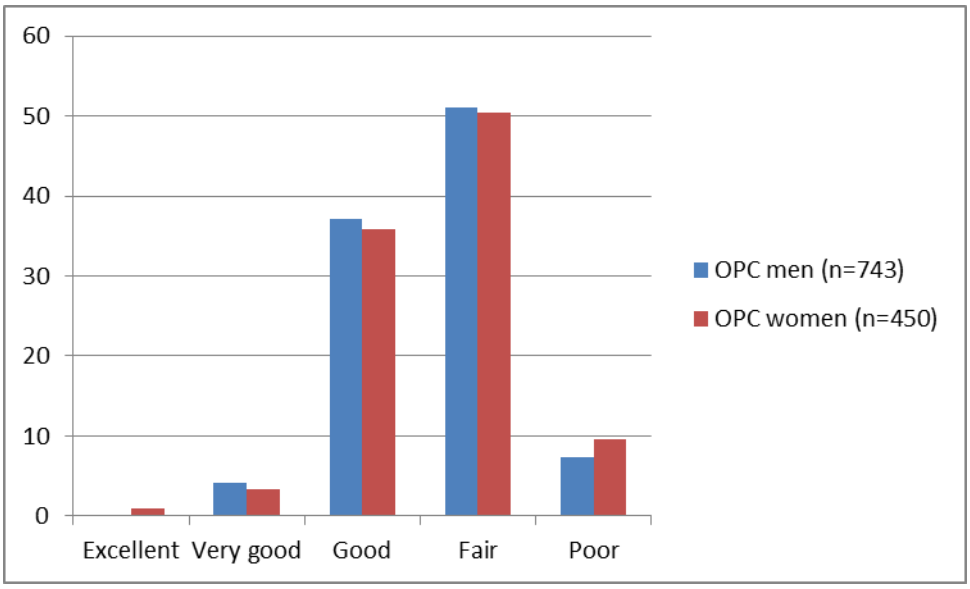
Figure 35: Access to antiretroviral therapy, even if not currently taking it



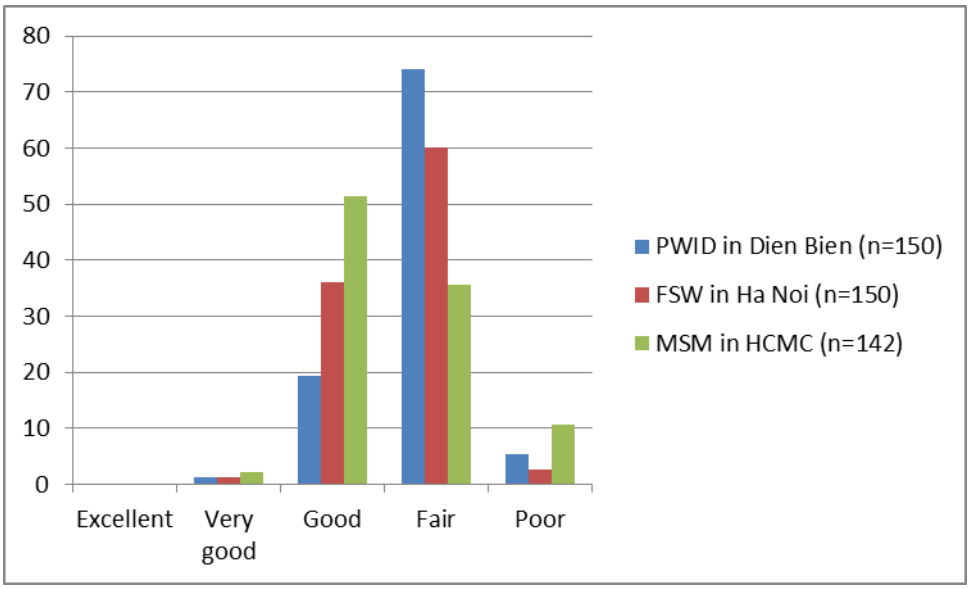
Most OPC-sampled respondents assessed their state of health as 'good' or 'fair', with very few describing their health as 'excellent' or 'very good'. At the extremes of the scale, more women than men among the OPC sample rated their health as either excellent or poor (0.9% versus 0.1% and 9.6% versus 7.4% respectively).[51]

Among the snowball samples, no respondents assessed themselves as being in excellent health, and very few respondents had very good health. A majority of PWID from Dien Bien (74.0%) and FSW from Ha Noi (60.0%) rated their health as 'fair' (the category below 'good'). MSM in Ho Chi Minh City saw themselves as in both better (51.4% had good health) and worse health (10.7% had poor health) than the other groups.

Figure 36: Respondent self-evaluation of current health status

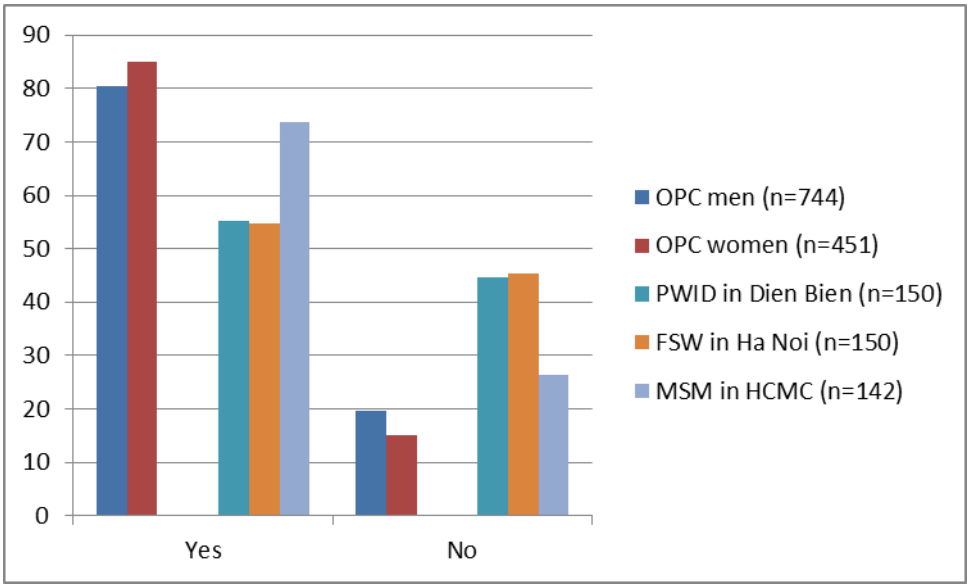


[51] There seems to be no correlation between self-assessed health and either income or years of living with HIV.



Of the people interviewed at OPC, an encouraging 84.9% of women and 80.4% of men were currently undergoing ART. However, among the snowball samples, only 55.3% of PWID in Dien Bien and 54.7% of FSW in Ha Noi were. MSM in Ho Chi Minh City were more likely to be taking ART (73.6%) than either PWID in Dien Bien or FSW in Ha Noi (but less likely than those in the OPC sample) – which may relate to their positive self-assessments of their health. Those who were receiving ART outlined a number of positive aspects, including physical and psychological health benefits, improving treatment outcomes and a lengthened lifespan and the fact that ART programmes are free, of good quality and easy to access.

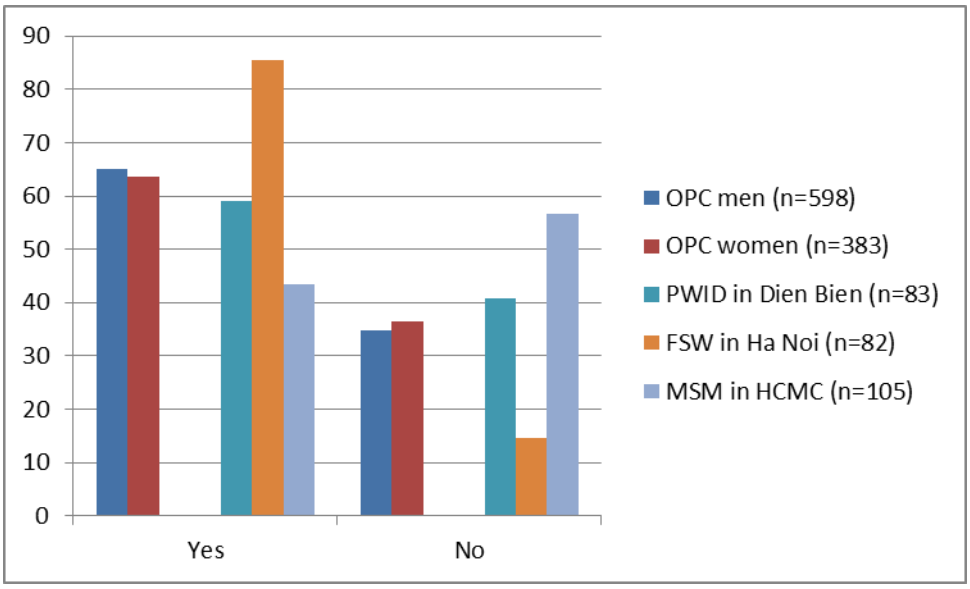
Figure 37: Respondents currently taking antiretroviral therapy



Among the respondents who are currently taking ART, a64.4% interviewed at OPC said that they had discussed their HIV-related treatment with a health care professional in the last 12 months. Among the snowball sampled PLHIV, 59.1% of PWID in Dien Bien taking ART had had such discussions, while only around 43.4% of MSM in Ho Chi Minh City had. This may indicate that – particularly for the

MSM in Ho Chi Minh City – there may be some issues surrounding the quality of care provided. In contrast, a very high number of FSW in Ha Noi on ART (85.4%) had discussed their treatment.

Figure 38: Discussions with health care professionals in the past 12 months about HIV-related treatment



Once they had completed their responses to the survey questions, respondents were asked to provide additional information on their experiences of treatment and access to treatment. Some raised concerns about ART programmes, including the availability of ARV medicines or quality ARV medicines; the side-effects of ARV medicines; drug resistance; the length of treatment; the cost of the drugs and what will happen if free drugs are no longer available; and the risk of disclosure. Some said that hospitalization costs were prohibitively high. Respondents also mentioned work-related issues including difficulties in reaching clinics because of distance or need to take leave; stigma at work; and the impacts of adherence on work schedules, especially for those who work at night. Some respondents reported a lack of improvement in health or were too ill to undertake the programme. Others experienced problems with adherence because of forgetfulness or because they injected drugs.

When her husband died, X's parents-in-law did not take care of their grandchildren, and when she and her daughters fell ill, they looked after themselves without any help from her husband's family… X worries about the future of her children and that ARV treatment will no longer be provided free of charge. Without free ARV drugs and other health care services for PLHIV, and with no money, she will not survive for long and will not be able to take care of her children.

Case study: Woman living with HIV in Hai Phong

With regard to the quality of services in the programmes, some respondents reported stigma and discrimination from doctors and other health staff, including gossip and unpleasant attitudes. Others said that examinations were inadequate, with little opportunity for discussion of treatment or side-effects, or that regimen decisions were taken on the basis of clinical symptoms rather than testing. Others stated that a lack of information about the drugs they were taking, including side-effects and the different regimens available, and/or an inability to read doctors' instructions caused problems. In addition, some said that the programme was difficult to access, with overly complicated enrolment and administration requirements, and that waiting times at clinics were too long. Finally,

others raised the concern that treatment is still only initiated for those whose CD4 counts are under 200.[52]

Among those who are not in an ART programme, several respondents said that they were not aware of the programmes or did not have any information about them, with some learning about ART provision for the first time during the interview. Among those who did know of the programmes, some felt they were easy to access and did not perceive any problems, with some saying they knew that people had benefited from ART; others commented on the enthusiastic and kind attitudes of doctors at the clinics they had witnessed, or stated that they had sufficient knowledge of the programmes and ARV drugs. However, others were worried about the potential adverse effects of ART on their health, did not want to be treated because of a fear of the cost, or felt they could not arrange their time to attend the clinic or adhere to treatment. Others did not want treatment at all, while some said they would buy their own medicines rather than taking the free ART from the programmes.

4.8 Reproductive health services

The advice given to PLHIV with regard to their reproductive health options was reportedly limited and in some cases predicated on the idea that PLHIV should not have children. In addition, where such advice was given, there seems to have been some element of coercion involved, including predicating access to treatment on certain contraceptive choices.

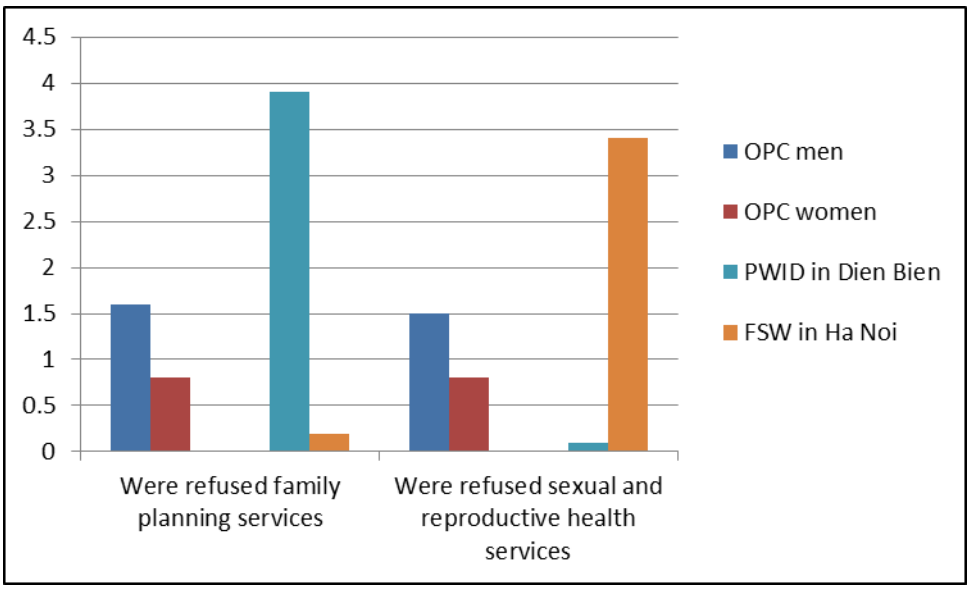
Y said that the quality of the OPC was good but that she had a problem with a counselling session at which the doctor advised her not to have a baby. She worries about how long she can maintain her health and whether she can get access to free-of-charge ARV treatment and other health services for PLHIV.

Case study: Woman living with HIV in Hai Phong

Respondents were asked if they faced any restrictions to access to family planning, reproductive and sexual health services. Very few respondents reported outright denial of family planning or sexual and reproductive health services. Among the OPC sample, it was only 1.2%. PWID in Dien Bien reported the highest levels of denial of family planning services (3.9%), while OPC women and FSW reported the lowest levels. Meanwhile, a total of 3.4% of FSW in Ha Noi said that they had been denied sexual and reproductive health services. No MSM in Ho Chi Minh City reported being refused either type of service.

[52] Viet Nam has adopted 2010 WHO guidelines on the initiation of antiretroviral therapy (ART) for all PLHIV, including pregnant women living with HIV, with a CD4 count of ≤350 cells/mm^3 and for those with WHO clinical stage 3 or 4 if CD4 testing is not available. Earlier initiation of ART improves health outcomes, reduces mortality and can contribute to the prevention of transmission.
Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach: 2010 revision. World Health Organization, 2010.
http://www.who.int/hiv/pub/arv/adult2010/en/index.html Accessed on 18 June 2012.

Figure 39: Denial of family planning and sexual and reproductive health services

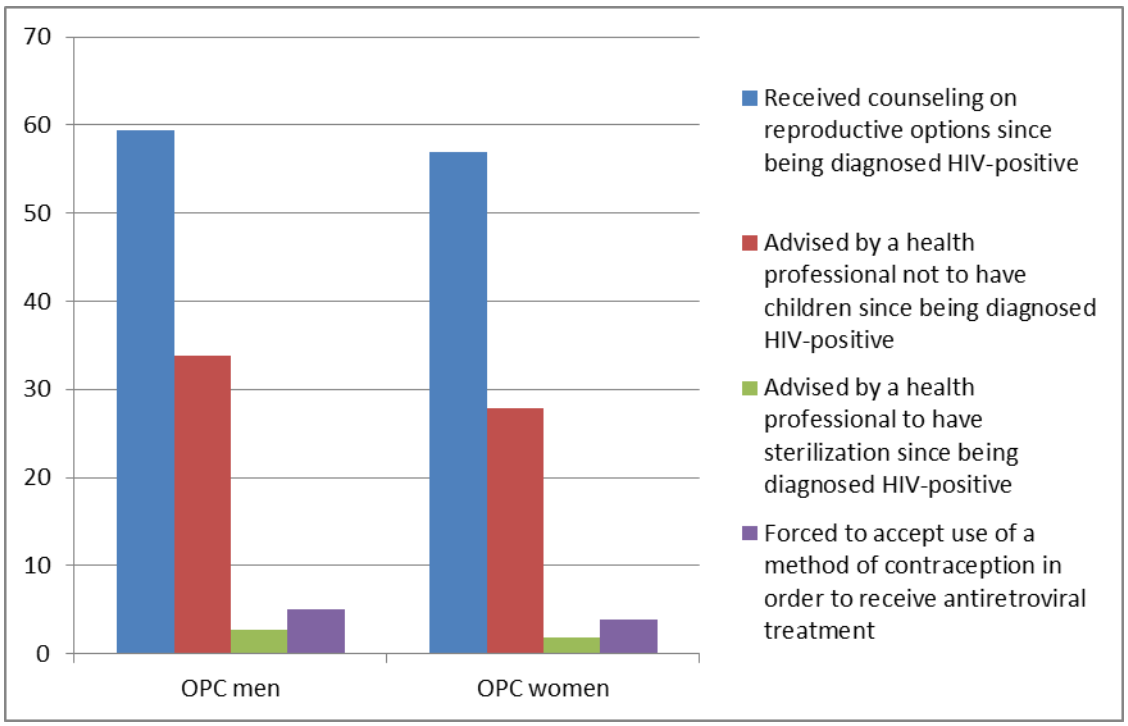


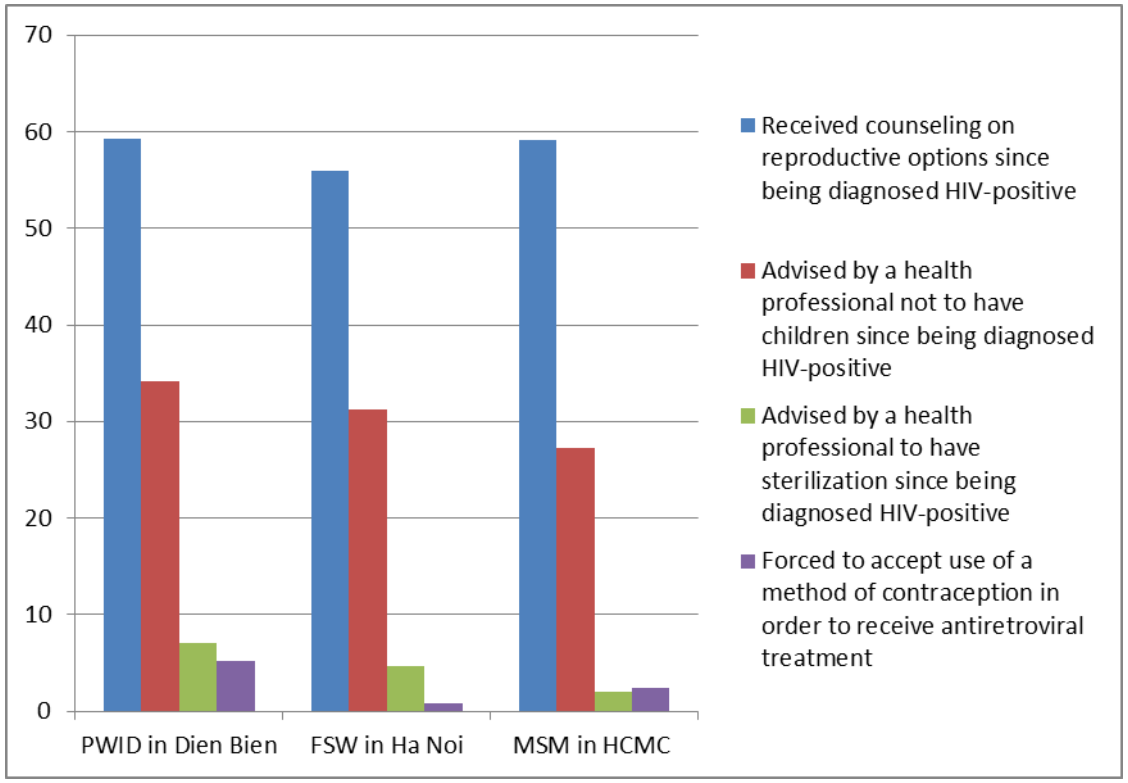
Around 60% of respondents who had spoken to a health provider within the past year had received advice on their reproductive health options. One-third of these respondents were advised not to have children at all. Respondents also reported worrying levels of obligatory contraception. Around 5% of the OPC sample and the PWID in Dien Bien were told to use contraception or be denied access to treatment. It is unclear whether this obligation was for consistent condom use to prevent sexual transmission of HIV, or for wider contraceptive methods to prevent the possibility of both spousal transmission and mother-to-child transmission. The percentage was lower among MSM in Ho Chi Minh City (2.4%) and lowest among FSW in Ha Noi, at 0.8%.

At the same time, some snowball-sampled respondents reported being advised by a health professional to undergo sterilization – 7% of PWID in Dien Bien and 4.7% of FSW in Ha Noi. These rates are higher than national rates of sterilization: 3.8% of women and 0.3% men used sterilization for contraception in 2010, with slightly fewer (3.3% and 0.2% respectively) in 2011.[53] Men in the OPC sample (2.7%), as well as women (1.8%), also reported such advice.

[53] 1/4/2010 population change and family planning survey: Major Findings. General Statistics Office, 2003-2010.

Figure 40: Advice from health professionals on reproductive options





5. Conclusions

The Stigma Index survey data clearly show that PLHIV in Viet Nam face considerable stigma and discrimination, with a very high proportion of all respondents reporting that their right to live free of discrimination had been violated.

The data also show that HIV status is not the only challenge for PLHIV. In the context of Viet Nam's concentrated epidemic, stigma is attached both to HIV status and to risky behaviours which are stigmatized in and of themselves, as well as perceived to increase HIV risk – injecting drug use, sex work and homosexual activity. Many survey respondents (but particularly snowball-sampled key populations) reported their perception that their behaviours create more stigma and discrimination than their HIV status, or create 'double stigma' in conjunction with their status. Injecting drug use was the most commonly reported reason for non-HIV related stigma and discrimination.

The survey confirms that the health system has successfully scaled up HIV-related services, with high access to ART and many HIV tests resulting from health care referrals. Stigma and discrimination by health care providers is reportedly low. However, stigma and discrimination is much higher outside health care settings. Many PLHIV struggle to maintain sustainable livelihoods: unemployment among PLHIV is high, and many reported losing a job or being forced to change the nature of their job, as well as stigma in the workplace. Others – particularly FSW in Ha Noi and women in the OPC sample – reported having been forced to change residence or unable to rent a home. There is also evidence that some PLHIV and their children have been denied access to education.

In addition, many of the most egregious examples of stigma and discrimination seem to occur outside institutional settings, in the family or community, with friends and neighbours the greatest source. Gossip was the most frequently reported form of stigmatization, with verbal insults and physical assault more common among women than men. Perhaps for this reason, most PLHIV have not revealed their HIV status outside their own family and a significant proportion said that their spouse or sexual partner did not know their status. This stigmatization of HIV and of HIV-related behaviours affects PLHIV in terms of social insecurity and isolation, which can be compounded by self-stigmatization.

The data also identify major areas of concern for PLHIV which will need to be taken into account in future law/policy making, service delivery and law enforcement. Firstly, despite legal protection of the right to confidentiality, the serostatus of PLHIV – and particularly that of PWID – is being disclosed without their consent: a large proportion of OPC respondents, FSW in Ha Noi and MSM in Ho Chi Minh City reported non-consensual disclosure to neighbours, while many PWID in Dien Bien reported such disclosure to community leaders. Fear of disclosure without consent may serve as a barrier to people being tested for HIV.

Secondly, respondents reported coerced testing or testing without prior knowledge – again, this breaches the legal right of individuals to voluntary testing and may dissuade others from undergoing tests. Very few PLHIV have sought legal redress for either of these violations of their rights, or their right to non-discrimination.

Thirdly, there is evidence that some PLHIV are receiving inadequate, inaccurate or coercive reproductive health advice. Respondents reported being advised not to have children or to undergo sterilization, or obliged to use contraception.

6. Recommendations

The survey data, as well as discussions with survey respondents, VNP+ leaders and stakeholders who participated in the three validation meetings, revealed concrete ways to better combat stigma and discrimination and improve the lives of PLHIV in Viet Nam.

In many cases, protective legislation already exists. However, greater efforts are needed to ensure adherence to the law and the implementation of related policies. This may require further training and education for national and provincial health care and government workers. In these regards, the recent *Decree No. 69/2011/ND-CP* on handling administrative violations in health prevention, the medical environment and HIV/AIDS prevention and control provide welcome support for the enforcement of the Law on HIV. In addition, PLHIV will need greater support in seeking legal redress for violations of their rights, such as being forced out of a job or one's home due to HIV status.

Since much of the stigma and discrimination against PLHIV in Viet Nam appears to originate from within their immediate communities (i.e. family, friends and neighbours), social and community education and mobilization are required. Furthermore, given the incidence of 'double stigma' and behaviour-related stigma and discrimination, efforts are also needed to address these at the community level. For example, education should include knowledge about both HIV and risk behaviours to counter community fears that contribute to stigma. Community and mass organizations should also be further engaged in responding to stigma and discrimination at the local level.

Specific recommendations arising from the survey include:

Confidentiality

- Additional efforts are needed to protect the confidentiality of PLHIV – especially in the delivery of health care and social services.
- Additional efforts are needed to ensure that all HIV tests are taken after obtaining informed consent.
- "Treatment as prevention" efforts (such as the new Treatment 2.0 pilot) must include ways to protect confidentiality during the transition from testing to pre-ART to ART enrolment.

Family, society and community

- The role of self-help groups, including VNP+, needs to be strengthened in order to provide stronger peer support to PLHIV to build their confidence, reduce self-stigma and learn about the law and regulations that protect against stigma and discrimination.
- Additional efforts are required to protect female sex workers and other women living with HIV from verbal and physical abuse.
- PLHIV need additional employment support, focused on building sustainable livelihoods, and ensuring that employers cannot dismiss PLHIV because of their HIV status.

Treatment and health care

- Affordable HIV treatment programmes should be maintained and include:
    - Free or easily affordable CD4 count and viral load tests
    - Earlier initiation of antiretroviral treatment in line with WHO recommendations
    - Free or easily affordable medications to reduce side-effects and opportunistic infections
    - Shorter waiting times and increased numbers of well-trained health care providers
- Health care services provided to PLHIV should include reproductive and family planning services, including options to safely have children.

ANNEX 1: Case Studies

Case study 1: Woman living with HIV in Can Tho

I got married two years ago. My husband was a construction engineer and we were happy, but a year ago he discovered that he was HIV-positive. His family was very scared, especially his older sister. I was the only person who took care of him. The doctor advised me to go for HIV testing and I got a negative result. My parents-in-law advised me not to abandon my husband.

When he got better, they did not want us to come back home but rented a house for us 40 km away from their home because they were afraid of being infected by us. My mother-in-law visited us once and sat at a distance to ask about our health.

Gradually my husband's health recovered and he wanted to return to work. He asked his parents for their permission to come back to their house because his office was nearby, and they agreed. Unfortunately, I discovered I was HIV-positive when we returned to their home. They found out and asked us to leave the house. My husband got into a fight with his sister and she reported to the police that we had a scheme to steal family property. Since then, his sister often assaulted us verbally and did not allow us to touch anything in the house. She also told the village Women's Union and neighbours about our HIV status; as a result, they changed their attitudes. Once when I got wet, I entered the house to get a dry towel, but my sister-in-law reported me to the police for stealing and asked us to leave the house.

We went to visit my parents during the Tet holiday, but when we came back, she threw all of our assets out of the house and threatened to inform my parents of our status. My parents live in Ca Mau and people there are still scared of HIV. My mum suffers from heart disease and I am afraid that the news would give her a shock. We were forced to go to live with my parents to avoid our status being disclosed to them.

Case study 2: Man living with HIV in Can Tho

I had rented my own house since 2003, but in 2009 I came back home to live with my family, having discovered my HIV status and got divorced from my wife.

My two younger brothers became addicted to drugs, and died of AIDS-related diseases in 2004 and 2008 respectively. This might be why my father often scolded us and shouted, whenever he faced any business difficulties, "If you catch any diseases, you should kill yourself on the street. Don't come home, keep this house peaceful and quiet!" I've been obsessed with what my father said for years.

When we organized my brothers' funerals, the village spread rumours and gossip about the fact that someone in my family had died of AIDS. They speculated about the HIV status of the whole family. This meant that very few clients came to have tea at my family's shop. So my mother asked me: "Could you please go back to the house so that I can do business? If you stand outside, people will be frightened that you have HIV."

My mother's always worried that people will find out about my HIV status, and afraid of the rumour that my family members died of AIDS. She was particularly frightened by, and obsessed with, the fact that two of her sons died of AIDS and had come to her tea shop. Now the situation has improved; more and more people come to have tea at the shop. That's why she didn't want me to stand in front of the tea shop.

I don't sit at the same table with family members and I use my own dishes. When my family has parties, I don't sit with them. My family doesn't forbid me to sit with them, but I can feel that they don't like it when I do. That's also why I use my own dishes.

Sometimes I want to leave the family and find a job so that I don't have to stay in the house, so that I can prevent my mother from suffering and stop my own obsession with the things my father says.

I have stopped using drugs and am undertaking treatment.

Case study 3: Woman living with HIV in Ha Noi

In 2007, in a crackdown against sex workers, I was arrested and sent to an administrative detention centre. I discovered I was pregnant during my health check at the centre. I was returned to my community, but unfortunately people there did not accept me. With no money and no support, I went back to Ha Noi to re-engage in sex work. While there, a man agreed to marry me so that my baby could have a father.

I was still selling sex during my sixth month of pregnancy in order to earn a living for myself and my husband and to save money for giving birth. When I was eight months pregnant, I got severe stomach pains and thought I was in labour. I went to a clinic and was then transferred to two different hospitals. Eventually I was given an emergency operation for enteritis; my baby was born prematurely and had to be taken to a special care unit. During this emergency, my husband called my family so they could visit my – perhaps for the last time – while I was unconscious for the operation. In whispers, they asked whether my baby had contracted HIV.

When I woke up, there was nobody at my side, and I felt desperate. The nurses helped me to clean myself of blood from the operation; sometimes my husband came to visit me. When I felt better, I had to take care of myself. I was deeply unhappy that my premature baby was alone in another hospital with no care and support from my family. When I was released from the hospital, I collected my baby on my own. I held my weak baby to me; I had no money in my pocket. Then I dried my tears: because I had to earn a living, I needed to engage in sex work to make money to feed myself, my baby and even my husband. Now my baby is 5 years old and my life is less difficult, I want to divorce my husband.

Case study 4: Woman living with HIV in Ha Noi

B currently lives with her husband and child. When she discovered her HIV status in 2006, she was very upset because no-one wanted to talk to her. She was disappointed when she asked her close friend [to test her reaction] whether she thought that she might have HIV. Her friend did not reply, and then kept her distance from her and did not talk with her as she had before.

She has had side effects from the [ARV] drugs and needed to go to hospital for treatment. Unfortunately, this was revealed to her employer. She was stunned when her supervisor asked to talk with her; he was sympathetic but asked her to resign. Although she begged him, saying that she would not do anything to transmit the virus to co-workers, he refused to let her stay. She could not forget what the supervisor said to her: "Why don't you find another job? Why do you want to stay here? I can't accept you working here" - although she was both competent and responsible at work.

B felt stuck and could not find any support. She lacked confidence due to her poor health and was worried that she was not able to take care of her little boy. She was often criticized and disrespected by her husband due to her inability to make money. This led to self-stigma and depression, and she decided to kill herself. Luckily, she was found in time and survived.

Currently, thanks to good health care, her condition has improved and she participates in a care and support group at the clinic. She now feels more confident and has recently found work that helps her, to a certain extent, to take care of her family, although it is a low-income job.

Case study 5: Woman living with HIV in Hai Phong

Once their family discovered X and her husband's HIV status, their family forced them to live separately. Whenever they touched anything, their parents-in-law were afraid that they could transmit the virus to others and looked at the couple suspiciously.

In addition, X was isolated and verbally assaulted by her husband's family, especially her parents-in-law. They did not let her do any housework; when she invited them to eat an orange they did not dare to eat it because they were afraid of HIV transmission.

When her husband died, X's parents-in-law did not take care of their grandchildren, and when she and her daughters fell ill, they looked after themselves without any help from her husband's family. Neither she nor her children received any of her husband's inheritance from her parents-in-law.

X's second child is not HIV-positive, but the grandmother could not believe that the child had not caught the virus because she carries her mother's blood. When this daughter started at kindergarten, the school asked X to show them her most updated test result. However, they refused the blood test result that confirmed her negative status when she was 18 months old and took her to the clinic for another blood test.

X is physically weak and continues to have to suffer verbal assaults from her parents-in-law because she is dependent on them. She had to send her older daughter to Thanh Hoa to be taken care of by her parents to have more time to work (at a shoe factory). X conceals her status from her employer and colleagues because she is afraid of being fired. She tries to earn money to give to her parents-in-law and only keeps a small amount of her wages for breakfast, but she is always being asked whether she gives all of the money she earns or whether she keeps some for herself.

X also worries about the future of her children and that ARV treatment will no longer be provided free of charge. Without free ARV drugs and other health care services for PLHIV, and with no money, she will not survive for long and will not be able to take care of her children.

Case study 6: Woman living with HIV in Hai Phong

Y's partner died of TB and so she decided to get tested and discovered her positive status. Y wore a face mask throughout the interview in case she was seen by someone she knew.

When Y discovered her HIV status, she was shocked. Due to a lack of information and knowledge, she isolated herself and did not engage in her family's daily activities, such as cooking, because she was afraid that 'normal' contact might transmit the virus to others. She always felt under pressure and panicky. She was initially reluctant to seek more information about HIV or ways to take care of herself, or to seek out HIV care and support services.

Her family also does not have sufficient information and knowledge, so they are reluctant to touch her or engage with her in daily tasks. Her mother was her only support in escaping her self-stigma to find information about HIV and get access to the OPC.

Y's physical and mental health are bad, and she is frightened of having her status revealed. She hides her status because she is afraid of being fired by her employer. Y also does not dare to reveal her status to her partner because she is scared of being abandoned.

Y said that the quality of the OPC was good but that she had a problem with a counselling session at which the doctor advised her not to have a baby. She worries about how long she can maintain her health and whether she can get access to free-of-charge ARV treatment and other health services for PLHIV. When the free-of-charge treatment programme finishes, she will not be able to afford drugs and this means that she will die. Even if she could afford treatment, she wonders whether ARV treatment is easily accessible.

The interviewer provided her with booklets on HIV care and treatment and the handbook on HIV and the law for her reference and to encourage her to think more positively.

Case study 7: Woman living with HIV in Ho Chi Minh City

I asked local policemen and neighbours to help me [when my rights were violated], but when they came, my husband and his family told them that nothing had happened, it was only a family conflict. I also asked the Women's Union and People's Committee for help, but I haven't found any solution. To be honest, I've lost confidence that anyone can help me.

People around me showed sympathy when they found out my HIV status, but really, they didn't care. In fact, family members stigmatized and discriminated against me more seriously than outsiders. Only my mother cared for me, but she couldn't do much because she was too old.

I know self-help groups of PLHIV, they're very kind and do not cause any difficulties. Thanks to their help, I have received benefits from charity organizations. I have confidence in them, but due to time restraints and family conditions, I haven't joined any group.

I've never been forced by charity organization staff, social workers or OPC health workers to reveal my status. Almost everyone knows my status. However, it's a shame that although People's Committee officials know my situation, when I came to ask for support because I was discriminated against, stigmatized and assaulted by my family-in-law, they only gave me token support.

To be honest, I was afraid that information [about my health] might be leaked, because the clinic is close to my house. Later, though, I felt more confident because my health records have been kept confidential. But I think it's not so important now, because my status is known by almost everyone.

I think that my husband and his family told people about my status. Also, I looked very weak, so people guessed. Of course, they told people my status without my consent. But now it isn't important any more.

When he found out my HIV status, my husband was the first person to display stigmatizing and discriminatory attitudes. When I had symptoms, I went for an HIV test. I told my husband about this, He immediately blamed this on my own wrongdoing, accusing me of contracting HIV from an extra-marital partner. Then he got angry, and his family followed his example, discriminating against my two children and myself. Only my sister-in-law was sympathetic, because her husband was also infected with the virus, but did not expose it publicly except to me. Other people taking ART at the OPC gave me support and sympathy.

If I had the power to decide on how to reduce stigma and discrimination, I would heavily punish those who stigmatize and discriminate against PLHIV, so that no-one would dare to do so.

Case study 8: Woman living with HIV in Ho Chi Minh City

I sought support to address a violation of my rights from local social workers, but none of them could help. I met with and talked to the people who had stigmatized and discriminated against me but it made the situation worse; they shouted at me and threatened me. I told Ms L, a team leader of a local self-help group of PLHIV. Ms L and I met Women's Union staff and they advised us to move to new accommodation and not to make the problem bigger and more serious. I found this advice reasonable and decided to move to a new house. So far, I've found it to have been a good decision.

I can't talk about my husband's attitude to my status because he died. My neighbours knew the situation, they started to obviously isolate me, especially my landlord. She often gossiped about me and then said straight out that I was not a honest person. She did not allow me to use electricity or water. Children of neighboring families were also told by their families not to play with my child. I went to ask for support from a priest, but he said that he could not help at all. I also thought that I would not receive any support from communal People's Committee officials. I was lucky because my mother was not my only source of support. Ms L and other self-help group members encouraged and supported me a lot, and health workers also provided me with warm-hearted care and support. These were my biggest sources of support.

I have never been in the situation where other PLHIV or support groups have advised or forced me to reveal my status. I am willing to reveal my status. Those who really support me without any discrimination and stigma are people who are in the same situation. When I joined a self-help group for PLHIV, I found opportunities to share my experiences.

Once when I went to the People's Committee to submit an application for support, I was advised by a social worker that If I said that I was living with HIV, I would be more likely to receive support. I thought it was a good idea but did not feel under pressure [to disclose my status]. The health workers at the clinic where I was treated did not put any pressure on me [either]; they gave me sympathy and support when I told them about the stigma and discrimination I had experienced.

As far as I know, my health records have been kept confidential and only doctors or health workers know the contents of my file.

My neighbours had the most stigmatizing attitudes and most often discriminated against me, which created the biggest difficulties for my livehood. Only my mother and others in the same circumstances give me support and sympathy.

If I had the power to decide on how to reduce stigma and discrimination, I would set up more groups of people living with HIV and train them in the law and regulations on stigma and discrimination so that they can protect themselves.

ANNEX 2: Source Data Tables

Table 1: Stigma Index participants by province and sampling method

Province	OPC sampling		Snowball sampling			Total
	Male	Female	PWID	FSW	MSM (including transgender)	
Ha Noi	184	116	0	150	0	**450**
Hai Phong	123	77	0	0	0	**200**
Dien Bien	115	85	150	0	0	**350**
Can Tho	121	79	0	0	0	**200**
Ho Chi Minh City	203	97			142	**442**
Total	**746**	**454**	**150**	**150**	**142**	**1,642**

Table 2: Age distribution of PLHIV

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Age 18 – 19	0.1	0.2	0.2	0.7	2.0	2.1
Age 20 – 24	2.4	8.0	4.4	4.7	9.3	5.6
Age 25 – 29	17.6	28.8	21.8	22.0	26.0	27.6
Age 30 – 39	61.5	51.5	57.8	44.7	49.3	52.1
Age 40 – 49	14.8	10.4	13.1	23.3	12.1	11.9
Age 50+	3.6	1.1	2.7	4.6	1.3	0.7
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 3: Geographical distribution among the OPC sample

	OPC sample		
	Men (n=746)	Women (n=454)	Total (n=1200)
Rural area	16.5	24.2	19.4
Small town or village	11.5	13.5	19.3
Large town or city	72.0	62.3	68.3
Total	100.0	100.0	100.0

Table 4: Current relationship status

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Married or living with an intimate partner and husband/wife/ partner is currently living in household	50.1	50.9	50.4	46.7	41.3	**15.5**
Married or living with an intimate partner and husband/wife/ partner is living/working temporarily away from the household	1.5	0.7	1.2	0.67	7.3	5.6
In intimate relationship but not living together	3.1	3.8	3.3	1.34	0.7	36.6
Single	33.5	9.3	24.4	32.0	15.3	40.1
Divorced/separated	9.5	8.4	9.1	18.7	**20.7**	2.1
Widow/widower	2.3	**26.9**	11.6	0.67	14.7	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 5: Respondents with one child or more

Respondents with children	OPC sample			Snowball sample		
	Men (n=744)	Women (n=451)	Total (n=1195)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Yes	62.1	58.3	60.7	63.3	77.3	30.0
No	37.9	41.7	39.3	36.7	22.7	70.0

Table 6: Children of respondents known to be HIV-positive

Children of respondents known to be HIV-positive	OPC sample			Snowball sample		
	Men (n=463)	Women (n=262)	Total (n=725)	PWID (n=96)	FSW (n=114)	MSM (n=42)
Yes	12.7	11.1	12.1	7.3	10.5	9.5
No	87.3	88.9	87.9	92.7	89.5	90.5

Table 7: Years of knowledge of HIV status

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
< 1 year	8.3	8.4	8.3	15.3	10.1	18.3
1 – 4 years	40.4	45.6	42.3	66.0	57.7	52.8
5 – 9 years	37.5	38.5	37.9	15.3	25.5	25.4
10 -14 years	13.0	7.3	10.9	3.3	6.0	3.5
≥ 15 years	0.8	0.4	0.7	0.0	0.7	0.0

Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 8: Respondent self-identified category (multiple-answer question)

	OPC sample		
	Men (n=746)	Women (n=454)	Total (n=1200)
Men who have sex with men	0.7	0.0	0.42
Gay or Lesbian	0.3	0.0	0.2
Transgender	0.0	0.0	0.0
Sex worker	0.5	3.1	1.5
Injecting drug user	67.3	9.3	45.5
Refugee or asylum seeker	0.5	0.2	0.4
Internally displaced person	1.7	2.4	2.0
Member of indigenous population	9.4	35.7	19.3
Migrant worker	0.7	2.9	1.5
Prisoner	7.0	1.1	4.8
Do not belong to above populations	22.3	44.4	30.6

Table 9: Educational status

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
No formal education	2.6	6.7	4.1	8.0	2.7	0.0
Primary school (classes 1-5)	16.9	19.5	17.9	18.0	15.3	7.1
Secondary school (classes 6-9)	46.5	44.8	45.9	36.7	42.0	29.6
High school (classes 10-12)	28.6	25.7	27.5	34.7	34.7	52.8
Technical college/university/postgraduate	5.5	3.3	4.7	2.7	5.3	10.6
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 10: Employment status

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Full-time employment (as an employee)	13.3	16.9	14.6	2.0	5.3	27.5
Part-time employment (as an employee)	8.6	9.1	8.8	4.0	8.0	10.6
Working full-time but self-employed	19.6	20.2	19.8	10.0	14.0	27.5
Working part-time (self-employed)	34.3	39.5	36.3	71.3	73.0	22.5
Unemployed and not working at all	24.3	14.3	20.5	12.7	0.4	11.9

Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 11: Household income levels

	OPC sample			Snowball sample		
Yearly income (VND)	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
< 2.000.000 (equal to 100 USD)	18.6	32.7	23.9	30.7	16.0	23.9
2.000.000 – 5.000.000 (100 – 250 USD)	59.7	55.1	57.9	61.3	62.7	57.9
> 5.000.000 (250 USD)	21.9	12.2	18.1	8.0	21.3	18.2
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 12: Household income levels of widowed and non-widowed women in the OPC sample

Monthly income (VND)	Widows (n=122)	Non-widowed women (n=330)	Total (n=452)
< 2.000.000 (equal to 100 USD)	52.4	25.5	32.7
2.000.000 – 5.000.000 (100 – 250 USD)	40.2	60.6	55.1
> 5.000.000 (250 USD)	7.4	13.9	12.2
Total	100.0	100.0	100.0

Table 13: Reasons given for HIV testing (multiple-answer question)

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=452)	Total (n=1198)	PWID (n=150)	FSW (n=149)	MSM (n=141)
Employment	2.6	0.9	1.9	2.7	0.0	2.1
Pregnancy	7.4	6.6	7.1	3.3	14.8	5.0
Preparation for a marriage/sexual relationship	1.7	1.8	1.8	0.0	0.7	1.4
Referred by a clinic for sexually transmitted infections	0.9	1.8	1.3	1.3	6.1	2.8
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	27.8	35.6	30.7	22.7	19.5	30.5
Wife/husband/partner/family member tested positive	11.7	9.1	10.7	2.7	14.1	17.0
Wife/husband/partner/family member got sick or died	12.0	10.6	11.5	2.0	16.8	5.0
I just wanted to know	24.0	21.0	21.9	60.7	16.1	29.8
Other	18.4	15.9	17.5	12.7	12.8	12.8

Table 14: Was the decision to be tested up to you?

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=452)	Total (n=1198)	PWID (n=150)	FSW (n=149)	MSM (n=141)
I decided myself to have an HIV test	85.4	82.0	84.2	94.0	83.2	83.7
I decided to go for the test but under pressure from others	2.8	3.1	2.9	1.3	2.7	8.5
I was forced to take an HIV test (coercion)	2.8	3.1	2.9	1.3	4.7	2.1
I was tested without my knowledge. I only found out after the test had been done	8.9	11.8	10.0	3.3	9.4	5.7

Table 15: Summary: disclosure of HIV status

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=452)	Total (n=1198)	PWID (n=150)	FSW (n=150)	MSM (n=142)
HIV status not disclosed to people outside family	79.1	78.5	78.9	40.7	84.7	94.4
HIV status disclosed to others (I told them/someone told them with or without my consent)	20.9	21.5	21.1	59.3	15.3	5.6

Table 16: Disclosure of HIV status without consent

	OPC sample			Snowball sample		
	Men	Women	Total	PWID	FSW	MSM
Husband/wife/partner	3.0 (n=598)	3.9 (n=331)	3.3 (n=929)	3.5 (n=113)	1.7 (n=115)	2.4 (n=126)
Other adult family member(s)	6.0 (n=732)	6.6 (n=439)	6.2 (n=1171)	6.8 (n=148)	4.7 (n=150)	5.0 (n=139)
Children in your family	4.3 (n=555)	1.5 (n=325)	3.3 (n=880)	15.7 (n=102)	4.1 (n=122)	2.4 (n=85)
Friends/neighbours	29.0 (n=717)	26.6 (n=432)	28.1 (n=1149)	45.5 (n=143)	34.0 (n=147)	18.0 (n=133)
Other PLHIV	7.1 (n=714)	6.1 (n=430)	6.7 (n=1144)	28.8 (n=146)	6.2 (n=146)	1.4 (n=141)
Colleagues	9.8 (n=419)	8.5 (n=258)	9.3 (n=677)	48.3 (n=87)	15.7 (n=102)	3.9 (n=77)
Employers	5.4 (n=257)	8.9 (n=168)	6.8 (n=425)	11.0 (n=36)	5.3 (n=38)	5.4 (n=56)
Clients	2.1 (n=335)	4.9 (n=204)	3.2 (n=539)	22.7 (n=28)	3.1 (n=96)	2.4 (n=83)
Injecting drug partner(s)	13.2 (n=326)	9.8 (n=193)	11.9 (n=519)	24.0 (n=125)	17.1 (n=41)	1.8 (n=57)
Religious leaders	3.0 (n=200)	4.0 (n=126)	3.4 (n=326)	36.8 (n=19)	9.3 (n=43)	0.0 (n=44)
Community leaders	17.5 (n=349)	15.7 (n=229)	16.8 (n=578)	52.1 (n=73)	25.6 (n=78)	11.0 (n=73)
Health care workers	8.9 (n=729)	8.9 (n=439)	8.9 (n=1168)	33.6 (n=143)	5.0 (n=141)	1.4 (n=141)
Social workers	8.9 (n=710)	10.9 (n=430)	9.6 (n=1140)	34.6 (n=133)	19.5 (n=133)	1.5 (n=131)
Teachers	4.4 (n=113)	5.5 (n=73)	4.8 (n=186)	9.1 (n=11)	8.3 (n=34)	0.0 (n=9)
Government officials	2.2 (n=93)	1.7 (n=58)	2.0 (n=151)	0.0 (n=11)	8.3 (n=12)	9.7 (n=31)
The media	2.3 (n=129)	5.9 (n=102)	3.9 (n=231)	0.0 (n=13)	13.0 (n=23)	0.0 (n=26)

Table 17: How the respondent's husband/wife/partner was informed of respondent's HIV-positive status

	OPC sample			Snowball sample		
	Men (n=598)	Women (n=331)	Total (n=929)	PWID (n=113)	FSW (n=115)	MSM (n=126)
I told them	84.6	81.3	83.4	91.2	83.5	67.5
Someone else told them with my consent	2.7	2.1	2.5	2.7	5.2	0.0
Someone else told them without my consent	3.0	3.9	3.3	3.5	1.7	2.4

They don't know my HIV status	9.7	12.7	10.8	2.7	9.6	30.2

Table 18: How other adult family members were informed of respondents' HIV-positive status

	OPC sample			Snowball sample		
	Men (n=732)	Women (n=439)	Total (n=1171)	PWID (n=148)	FSW (n=150)	MSM (n=139)
I told them	77.2	77.2	77.2	85.8	64.0	69.8
Someone else told them with my consent	4.9	6.2	5.4	5.4	10.0	7.9
Someone else told them without my consent	6.0	6.6	6.2	6.8	4.7	5.0
They don't know my HIV status	11.9	10.0	11.2	2.0	21.3	17.3

Table 19: How friends/neighbours were informed of respondents' HIV status

	OPC sample			Snowball sample		
	Men (n=717)	Women (n=432)	Total (n=1149)	PWID (n=143)	FSW (n=147)	MSM (n=133)
I told them	13.8	18.5	15.6	23.8	12.9	6.0
Someone else told them with my consent	4.3	2.8	3.7	10.5	6.1	1.5
Someone else told them without my consent	29.0	26.6	28.1	45.5	34.0	18.0
They don't know my HIV status	52.9	52.1	52.6	20.3	46.3	74.5

Table 20: How colleagues were informed of respondents' HIV status

	OPC sample			Snowball sample		
	Men (n=419)	Women (n=258)	Total (n=677)	PWID (n=87)	FSW (n=102)	MSM (n=77)
I told them	28.4	26.4	27.6	23.0	45.1	14.3
Someone else told them with my consent	1.7	2.3	1.9	2.3	2.0	0.0
Someone else told them without my consent	9.8	8.5	9.3	48.3	15.7	3.9
They don't know my HIV status	60.1	62.8	61.2	26.4	37.3	81.8

Table 21: How employers were informed of respondents' HIV status

	OPC sample			Snowball sample		
	Men (n=257)	Women (n=168)	Total (n=425)	PWID (n=36)	FSW (n=38)	MSM (n=56)
I told them	28.8	24.4	27.1	30.6	34.2	10.7
Someone else told them with my consent	0.4	1.2	0.7	2.8	5.3	0.0
Someone else told them without my consent	5.4	8.9	6.8	11.0	5.3	5.4
They don't know my HIV status	65.4	65.5	65.4	55.6	55.2	83.9

Table 22: How religious leaders were informed of respondents' HIV status

	OPC sample			Snowball sample		
	Men (n=200)	Women (n=126)	Total (n=326)	PWID (n=19)	FSW (n=43)	MSM (n=44)
I told them	18.5	17.5	18.1	26.2	30.2	22.7
Someone else told them with my consent	1.5	4.0	2.5	0.0	7.0	0.0
Someone else told them without my consent	3.0	4.0	3.4	36.8	9.3	0.0
They don't know my HIV status	77.0	74.6	76.1	36.8	53.5	77.3

Table 23: How community leaders were informed of respondents' HIV status

	OPC sample			Snowball sample		
Know about HIV status	Men (n=349)	Women (n=229)	Total (n=578)	PWID (n=73)	FSW (n=78)	MSM (n=73)
I told them	22.9	26.6	24.4	19.2	43.6	8.2
Someone else told them with my consent	11.5	10.5	11.0	11.0	6.4	1.4
Someone else told them without my consent	17.5	15.7	16.8	52.1	25.6	11.0
They don't know my HIV status	48.1	47.2	47.8	17.8	24.4	79.4

Table 24: Violation of respondents' rights as people living with HIV

	OPC sample			Snowball sample		
	Men (n=744)	Women (n=451)	Total (n=1195)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Yes	17.5	21.1	18.8	35.3	42.0	11.3
No	80.4	77.6	79.3	56.7	62.7	81.7
Not sure	2.2	1.3	1.8	2.0	1.3	7.0

Table 25: Type of rights violations experienced by respondents (multiple-answer question)

	OPC sample			Snowball sample		
	Men (n=147)	Women (n=101)	Total (n=248)	PWID (n=56)	FSW (n=65)	MSM (n=27)
Right to study	2.0	5.9	3.6	1.8	0.0	0.0
Right to work	8.8	8.0	8.5	5.4	9.2	3.7
Right to privacy and confidentiality	65.3	69.3	66.9	32.1	53.9	44.4
Right to marry and have a family	1.4	1.0	1.2	0.0	0.0	7.4
Right to information and participation	1.4	2.0	1.6	0.0	0.0	3.7
Right to non-discrimination and	53.1	56.4	54.4	80.4	67.7	70.4

freedom from stigma						

Table 26: Events resulting from HIV-positive status in the past 12 months

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=451)	Total (n=1197)	PWID (n=150)	FSW (n=150)	MSM (n=142)
I was forced to follow medical or health -related procedures (including HIV test)	11.3	10.6	11.0	4.7	23.3	0.7
I was refused health insurance or life insurance	1.9	1.8	1.8	0.0	1.3	1.4
I had to disclose my HIV status in order to apply for a residence permit or nationality	0.3	0.2	0.3	0.0	0.0	0.7

Table 27: Incidence of seeking legal redress for any abuse of rights

	OPC sample			Snowball sample		
	Men (n=147)	Women (n=101)	Total (n=248)	PWID (n=56)	FSW (n=65)	MSM (n=27)
Yes	4.1	12.9	7.7	26.8	10.8	7.4
No	95.9	87.1	92.3	73.2	89.2	92.6

Table 28: Reason(s) for not trying to seek legal redress (multiple-answer question)

	OPC sample			Snowball sample		
	Men (n=141)	Women (n=88)	Total (n=229)	PWID (n=41)	FSW (n=58)	MSM (n=25)
Insufficient financial resources to take action	6.4	6.7	6.5	9.8	5.2	0.0
Process of addressing the problem appeared too bureaucratic	7.8	7.9	7.8	4.9	5.2	12.0
Felt intimidated or scared to take action	1.4	1.1	1.3	2.4	6.9	0.0
Advised against taking action by someone else	2.8	4.5	3.5	22.0	13.8	0.0
No/little confidence that the outcome would be successful	27.7	27.0	27.4	7.3	36.2	60.0
None of the above	63.1	65.2	63.9	56.1	34.5	44.0

Table 29: Reactions of husband/wife/partner when they first found out the respondent's HIV status *(not including people who responded "not applicable")*

	OPC sample			Snowball sample		
	Men (n=560)	Women (n=306)	Total (n=866)	PWID (n=113)	FSW (n=107)	MSM (n=93)
Discriminatory	7.7	11.8	9.1	27.4	8.4	12.9
No different	47.7	43.8	46.3	49.6	73.8	32.3

Supportive	44.6	44.4	44.6	23.0	17.8	54.8

Table 30: Reactions of other adult family members when they first found out the respondent's HIV status *(not including people who responded "not applicable")*

	OPC sample			Snowball sample		
	Men (n=665)	Women (n=411)	Total (n=1076)	PWID (n=145)	FSW (n=126)	MSM (n=121)
Discriminatory	10.4	12.2	11.1	24.1	16.7	9.9
No different	47.2	44.0	46.0	49.7	66.7	34.7
Supportive	42.4	43.8	42.9	26.2	16.6	55.4

Table 31: Reactions of colleagues when they first found out the respondent's HIV status *(not including people who responded "not applicable")*

	OPC sample			Snowball sample		
Reaction	Men (n=216)	Women (n=127)	Total (n=343)	PWID (n=81)	FSW (n=68)	MSM (n=28)
Discriminatory	13.9	17.3	15.2	23.5	10.3	42.9
No different	61.1	55.9	59.2	54.3	73.5	46.4
Supportive	25.0	26.8	25.6	22.2	16.2	10.7

Table 32: Reactions of friends/neighbours when they first found out the respondent's HIV status *(not including people who responded "not applicable")*

	OPC sample			Snowball sample		
Reaction	Men (n=455)	Women (n=285)	Total (n=740)	PWID (n=123)	FSW (n=87)	MSM (n=52)
Discriminatory	37.8	40.4	38.8	52.0	54.0	57.7
No different	52.5	49.8	51.5	30.9	46.0	40.4
Supportive	9.7	9.8	9.7	17.1	0.0	1.9

Table 33: Experiences of stigma and discrimination in the last 12 months[54]

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Aware of gossip about him/her	**30.8**	**35.3**	**32.5**	**36.7**	**49.3**	**52.2**
Verbally insulted	3.6	8.9	5.6	**22.0**	**31.3**	**20.4**
Physically harassed	0.8	1.8	1.2	1.3	**15.3**	**11.3**
Physically assaulted	1.3	4.9	2.7	1.3	**20.7**	3.5
Excluded, at least once, from social gatherings	3.7	4.5	4.0	4.0	**4.7**	2.2
Excluded, at least once, from religious events	2.2	2.8	2.4	0.0	**2.0**	0.0
Excluded, at least once, from	4.1	3.2	3.8	1.3	**6.1**	2.2

[54] Those who answered "one" or "a few times" or "often" were recorded as answering "yes – have at least one experience of stigma/discrimination".

family activities						

Table 34: Experiences of stigma and discrimination for reasons other than the respondent's HIV status

	OPC sample			Snowball sample		
	Men (n=589)	Women (n=266)	Total (n=855)	PWID (n=149)	FSW (n=148)	MSM (n=130)
Sexual orientation	1.0	0.4	0.8	0.0	1.4	89.2
Sex work	0.7	3.8	1.6	0.7	97.3	0.8
Injecting drug use	76.4	12.4	56.5	91.3	1.4	6.9
Refugee or asylum seeker status	0.3	0.0	0.2	0.0	0.0	0.0
Internally displaced person status	0.0	0.4	0.1	0.0	0.0	0.0
Member of an indigenous group	7.0	40.2	17.3	0.7	0.0	0.0
Migrant worker status	0.5	3.4	1.4	0.7	0.0	0.0
Prisoner status	1.0	0.0	0.7	0.7	0.0	0.0
None of the above - other reasons	13.1	39.5	21.3	6.0	0.0	3.1

Table 35: Experience of stigma and discrimination among OPC sample respondents (reporting at least one experience of stigma and/or discrimination)

		Crude OR	aOR
Time of living with HIV	0-4 years	1	1
	5-9 years	1.19 (0.93-1.54)	1.25 (0.97-1.63)
	≥ 10 years	1.51 (1.04-2.18)*	1.45 (0.97-2.13)
Current relationship status	Living with husband/wife or partner	1	1
	In a relationship but not living together	2.88 (1.63-5.09)*	2.52 (1.40-4.55)*
	Single	0.99 (0.74-1.33)	0.94 (0.69-1.27)
	Divorced/widow/widower	1.44 (1.07-1.95)*	1.33 (0.98-1.82)
PLHIV who reported undertaking sex work	Yes	3.20 (1.19-8.59)*	3.59 (1.29-10.0)*
	No	1	1
PLHIV who reported drug use	Yes	1.28 (1.01-1.62)*	1.50 (1.15-1.96)*
	No	1	1
PLHIV who reported being a member of indigenous population	Yes	1.53 (1.14-2.04)*	1.59 (1.15-2.19)*
	No	1	1
Current employment status	In full-time/part-time employment	0.86 (0.61-1.21)	0.87 (0.60-1.25)
	Self-employed	0.73 (0.54-0.98)*	0.76 (0.56-1.03)
	Unemployed	1	1
Residence	Rural area/village/small town	1.51 (1.17-1.93)*	1.60 (1.23-2.09)*
	Large town or city	1	1

Adjusted for sex, age, education, and yearly income; * p<0.05

Table 36: Respondents' feelings about themselves

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
I feel ashamed	44.4	43.8	44.2	**63.3**	**52.0**	**66.2**
I feel guilty	47.1	23.1	38.0	36.7	**68.0**	54.9
I blame myself	57.4	36.6	49.5	**74.7**	49.3	**73.9**
I blame others	3.9	20.0	9.9	0.7	18.0	12.7
I have low self-esteem	24.2	18.2	21.9	30.7	20.7	7.0
I feel I should be punished	34.7	9.1	25.1	52.0	28.7	35.9

I feel suicidal	10.1	13.8	11.5	10.7	17.3	15.5

Table 37: Decisions made or actions taken as a result of respondent's HIV status

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Decided not to attend social gatherings	16.4	12.4	14.9	28.0	9.3	22.5
Isolated myself from my family or friends	12.9	14.2	13.4	13.3	18.7	25.4
Decided to stop working	6.7	6.2	6.5	4.7	8.0	6.3
Decided not to apply for a job or promotion	11.8	15.7	13.3	19.3	12.7	9.2
Withdrew from education/training	9.1	7.3	8.4	15.4	7.4	23.2
Decided not to get married	46.6	51.8	48.5	66.7	70.0	78.0
Decided not to have (more) children	14.1	19.3	16.0	5.3	22.7	23.9
Avoided going to local clinic	4.4	5.8	4.9	2.7	8.0	6.3

Table 38: Associations between self-stigmatization and socio-economic factors (OPC sample respondents reporting at least one sign of self-stigmatization)

		Crude OR	aOR
Current relationship status	Living with husband/wife/ partner or in a relationship	1.11 (0.87-1.42)	1.51 (1.09-2.09)*
	Single	1	1
	Divorced/widow/widower	0.94 (0.69-1.28)	1.45 (0.97-2.15)
PLHIV who reported drug use	Yes	2.32 (1.78-3.02)	2.39 (1.81-3.16)*
	No	1	1
Education	Lower education (primary/secondary school)	1.35 (0.96-1.89)	1.89 (1.05-3.41)*
	Higher education	1	1
Current employment status	In full-time/part-time employment	0.54 (0.40-0.82)	0.59 (0.39-0.91)*
	Self-employed	0.45 (0.32-0.65)	0.51 (0.35-0.73)*
	Unemployed	1	1

- Adjusted for sex, age, time of living with HIV and place of living; * p<0.05

Table 39: Challenges when accessing work, health and education services (respondents experienced difficulties at least once in the previous 12 months)

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Forced to change residence or been unable to rent accommodation	4.2	8.0	5.7	2.7	20.7	8.4
Were refused employment or a job opportunity	7.3	7.6	7.4	8.7	14.1	4.4
Lost a job or source of income	11.5 (n=565)	8.8 (n=385)	10.4 (n=950)	6.1 (n=148)	16.2 (n=132)	9.7 (n=124)
Change in job description or nature of work or were refused a promotion/raise	4.8 (n=565)	5.7 (n=385)	5.2 (n=950)	1.5 (n=148)	14.2 (n=132)	2.4 (n=124)
Were kicked out, suspended or rejected from an educational institution	0.4 (n=540)	1.1 (n=382)	0.7 (n=922)	3.0 (n=99)	0.8 (n=130)	0.0
Children were dismissed or suspended from or prevented from attending an educational institution	0.8 (n=386)	3.8 (n=344)	2.5 (n=730)	4.0 (n=99)	4.0 (n=125)	0.0
Were refused health services	2.4 (n=669)	3.0 (n=434)	2.6 (n=1103)	1.5 (n=133)	7.9 (n=139)	4.0 (n=125)

Table 40: Challenges in accessing work, health and education services: comparison between disclosed/non-disclosed status (respondents experienced difficulties at least once in the previous 12 months) (OPC respondents only)

	Non-disclosed status (or within family) (n=945: OPC)	Disclosed status (outside family) (n=255: OPC)	Total (n=1200: OPC)
Forced to change residence or been unable to rent accommodation	5.5 (n=945)	6.3 (n=255)	5.7 (n=1200)
Were refused employment or a job opportunity	7.6 (n=945)	5.8 (n=255)	7.4 (n=1200)
Lost a job or source of income	10.9 (n=754)	8.7 (n=196)	10.4 (n=950)
Change in job description or nature of work or were refused a promotion	5.4 (n=754)	4.1 (n=196)	5.2 (n=950)
Were kicked out, suspended or rejected from an educational institution	0.7 (n=740)	0.6 (n=182)	0.6 (n=922)
Children were dismissed or suspended from or prevented from attending an educational institution	1.6 (n=569)	4.3 (n=161)	2.5 (n=730)
Were refused health services	3.1 (n=872)	0.9 (n=231)	2.6 (n=1103)
Were refused family planning services	0.9 (n=640)	2.2 (n=177)	1.2 (n=817)
Were refused sexual and reproductive health services	0.9 (n=667)	2.3 (n=176)	1.2 (n=843)

Table 41: Challenges in accessing work, health and education services: comparison between provinces (respondents experienced difficulties at least once in the previous 12 months) (OPC respondents only)

	Ha Noi (n=300:OPC)	Hai Phong (n=200:OPC)	Dien Bien (n=200:OPC)	Can Tho (n=200:OPC)	HCMC (n=300:OPC)	Total
Forced to change residence or been unable to rent accommodation	2.7	8.5	3.0	2.5	10.7	5.7
Were refused employment or a job opportunity	5.8	12.4	10.0	3.0	7.3	7.4
Lost a job or source of income	5.1 (n=254)	21.9 (n=146)	6.5 (n=154)	6.2 (n=162)	14.5 (n=234)	10.4 (n=950)
Change in job description or nature of work or were refused a promotion	1.6 (n=254)	8.9 (n=146)	5.2 (n=154)	1.9 (n=162)	9.0 (n=234)	5.2 (n=950)
Were kicked out, suspended or rejected from an educational institution	0.4 (n=284)	0.0	0.7 (n=150)	0.8 (n=122)	1.5 (n=197)	0.6 (n=922)
Children were dismissed or suspended from or prevented from attending an educational institution	0.9 (n=214)	7.4 (n=122)	0.0	0.9 (n=114)	3.0 (n=134)	2.5 (n=730)
Were refused health services	0.0	5.1 (n=197)	0.6 (n=182)	1.6 (n=184)	5.6 (n=267)	2.6 (n=1103)
Were refused family planning services	0.0	2.3 (n=133)	1.8 (n=163)	1.6 (n=126)	1.3 (n=152)	1.2 (n=817)
Were refused sexual and reproductive health services	0.0	0.7 (n=143)	2.5 (n=162)	0.8 (n=121)	2.4 (n=164)	1.2 (n=843)

Table 42: Respondent self-evaluation of current health status

	OPC sample			Snowball sample		
	Men (n=743)	Women (n=450)	Total (n=1193)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Excellent	0.1	0.9	0.4	0.0	0.0	0.0
Very good	4.2	3.3	3.9	1.3	1.3	2.1
Good	37.2	35.8	36.6	19.3	36.0	51.4
Fair	51.1	50.4	50.9	74.0	60.0	35.7
Poor	7.4	9.6	8.2	5.3	2.7	10.7

Table 43: Respondents currently taking antiretroviral therapy

	OPC sample			Snowball sample		
	Men (n=744)	Women (n=451)	Total (n=1195)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Yes	80.4	84.9	82.1	55.3	54.7	73.6
No	19.6	15.1	17.9	44.7	45.3	26.4

Table 44: Access to antiretroviral therapy, even if not currently taking it

	OPC sample			Snowball sample		
	Men (n=744)	Women (n=451)	Total (n=1195)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Yes	92.9	91.1	92.2	81.3	84.0	85.0
No	3.1	4.7	3.7	18.7	8.0	2.9
Do not know/no response	4.0	4.2	4.1	0.0	8.0	12.1

Table 45: Discussions with health care professionals in the past 12 months about HIV-related treatment

	OPC sample			Snowball sample		
	Men (n=598)	Women (n=383)	Total (n=981)	PWID (n=83)	FSW (n=82)	MSM (n=105)
Yes	65.1	63.5	64.4	59.1	85.4	43.4
No	34.9	36.5	35.6	40.9	14.6	56.6

Figure 46: Denial of family planning and sexual and reproductive health services

	OPC sample			Snowball sample		
	Men (n=746)	Women (n=454)	Total (n=1200)	PWID (n=150)	FSW (n=150)	MSM (n=142)
Were refused family planning services	1.6 (n=453)	0.8 (n=364)	1.2 (n=817)	3.9 (n=102)	0.2 (n=134)	0.0
Were refused sexual and reproductive health services	1.5 (n=482)	0.8 (n-361)	1.2 (n=843)	0.1 (n=97)	3.4 (n=144)	0.0

Table 46: Advice from health professionals on reproductive options
(not including people who responded "not applicable")

	OPC sample			Snowball sample		
	Men	Women	Total	PWID	FSW	MSM
Received counseling on reproductive options since being diagnosed HIV-positive	59.4 (n=614)	56.9 (n=362)	58.5 (n=976)	59.3 (n=123)	56.0 (n=134)	59.1 (n=93)
Advised by a health professional not to have children since being diagnosed HIV-positive	33.8 (n=646)	27.8 (n=381)	31.5 (n=1027)	34.2 (n=123)	31.2 (n=132)	27.2 (n=103)
Advised by a health professional to have sterilization since being diagnosed HIV-positive	2.7 (n=655)	1.8 (n=380)	2.4 (n=1035)	7.0 (n=114)	4.7 (n=128)	2.0 (n=101)
Forced to accept use a method of contraception in order to receive antiretroviral treatment	5.1 (n=713)	3.9 (n=432)	4.6 (n=1145)	5.2 (n=135)	0.8 (n=134)	2.4 (n=124)

ANNEX 3: Stigma Index Questionnaire

PEOPLE LIVING WITH HIV STIGMA INDEX
QUESTIONNAIRE

Before starting the interview you need to:

1. Give the interviewee a copy of information sheet and allow him/her time to read it. If he/she is unable to read, you should read it out loud to him/her.
2. Give the interviewee a copy of the informed consent form and read this through with them. If they agree to be interviewed for the study, ask to complete the two forms. The interviewee will then need to sign two copies of the consent form, give the interviewee one of the signed copies and you keep the other one.

At the end of the interview, please answer the following questions:

Referrals and Follow-up

1. Did the interviewee need the referral information?

☐ Yes
☐ No

2. If yes, what kind(s) of referrals were made?

☐ Legal aid
☐ Counselling
☐ Support groups
☐ Other

If the answer is "other", to where did you refer them?

_____
_____

3. **What steps have you taken to assist the interviewee with accessing the above referrals?** (Tick more than one option if appropriate)

☐ I provided the interviewee with sufficient information about the referrals
☐ I will send the necessary information to the interviewee
☐ Further follow-up is needed
☐ Please provide details about what you promised to assist the interviewee with regarding referrals after the interview:

_____
_____

4. Is this interviewee considered to be a potential candidate for a case study?

☐ Yes
☐ No

If yes, please explain why:

_____
_____

Quality control procedures
Fill out this table only after your tasks* have been completed

	Name	Signature	Date
Interviewer			
Team leader			
Data entry 1			
Data entry 2			

*Tasks:

- The interviewer must ensure that all sections of the questionnaire are completed fully and correctly, unless the interviewee does not want to answer certain questions – in this case it should be marked immediately alongside the relevant question(s).
- The team leader must check the questionnaire carefully and query any work that seems unclear with the interviewer. The quality check section on the last page of the questionnaire should be used to help the interviewer and team leader to complete these tasks.
- The two data-entry persons ("Data entry 1" and "Data entry 2") must enter all data from every questionnaire correctly and independently, following the procedures outlined in the User Guide.

II. **PEOPLE LIVING WITH HIV STIGMA INDEX: QUESTIONNAIRE**
(Please tick alongside the best answer)

Confidential and Anonymous

PART 1: INFORMATION ABOUT YOU (INTERVIEWEE)

1. Sex

Male	①
Female	②
Transgender	③

2. How old are you?

Youth aged from 18 to 19	①
Adult aged from 20 to 24	②
Adult aged from 25 to 29	③
Adult aged from 30 to 39	④
Adult aged from 40 to 49	⑤
Adult aged 50 years and above	⑥

3. How long have you been living with HIV? (Tick one option only)

0-1 year	①
1-4 years	②
5-9 years	③
10-14 years	④
15 years and above	⑤

4. Current relationship status (Tick one option only)

Married or living with an intimate partner and husband/wife/partner is currently living in household	①
Married or living with an intimate partner and husband/wife/partner is living/working temporarily away from the household	②
In an intimate relationship but not living together	③
Single (→ go to question 6)	④
Divorced/separated (→ go to question 6)	⑤
Widow/widower (→ go to question 6)	⑥

5. If you are currently in an intimate relationship, how long have you been involved with your husband/wife/partner?

0-1 year	①
1-4 years	②
5-9 years	③
10-14 years	④
15 years and above	⑤

6. At present, are you sexually active?

Yes	①
No	②

7. Are you a member of or have you been a member of any of the following key populations? (Tick at least one option. Tick more than one if appropriate)

Men who have sex with men	①
Gay or lesbian	②
Transgender	③
Sex worker	④
Injecting drug user	⑤
Refugee or asylum seeker	⑥
Internally displaced person	⑦
Member of indigenous population	⑧
Migrant worker	⑨
Prisoner	⑩
I am not, and I have never been, a member of one of these populations	⑪

8. Do you have any kind of physical disability? (excluding sickness related to HIV infections)

Yes	①
No	②

If yes, please describe this physical disability:

_____

_____

9. What is the highest level of formal education you have completed? (Tick one option only)

No formal education	①
Primary school	②
Secondary school	③
High school	④
Technical college/University/Post-graduate	⑤

10. Which one of these statements would best describe your current employment status?

Full-time employment (as an employee)	①
Part-time employment (as an employee)	②
Working full-time but not as an employee (self-employed)	③
Working part-time (self-employed)	④
Jobless and not working at all	⑤

11. How many people are currently living in your household in each of these age groups?

	Number of people
Children aged 0–14 years	
Youth aged 14–19 years	
Adults aged 20–24 years	
Adults aged 25–29 years	
Adults aged 30-39 years	
Adults aged 40-49 years	
Adults aged 50 years and above	

12. How many of the children and young people living in your household were orphaned by AIDS?

Number of children and young people orphaned by AIDS	

13. Where is your household? (Tick one option only)

A rural area	①
A village/small town	②
A large town or city	③

14. What was the average monthly income of your household in the last 12 months? (Provide figures in Vietnamese dong)

Average income of household over the last 12 months
For data capturers only: Annual income in local currency: _____ Current exchange rate from local currency to US dollars: _____ Annual income in US dollars: _____

15. In the last month, on how many days did any member of your household not have sufficient food to eat?

Number of days	

PART 2A: YOUR EXPERIENCES OF STIGMA AND DSCRIMINATION CREATED BY OTHER PEOPLE

1a. Within the last 12 months, how often have you been excluded from social events or activities (e.g. weddings, funerals, parties, clubs)? (Tick one option only)

Never (→ go to question 2a)	①
Once	②
A few times	③
Often	④

1b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

2a. Within the last 12 months, how often have you been excluded from religious events or places of worship? (Tick one option only)

Never (→ go to question 3a)	①
Once	②
A few times	③
Often	④

2b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

3a. Within the last 12 months, how often have you been excluded from family activities (such as cooking, eating together, and sleeping in the same room)? (Tick one option only)

Never (→ go to question 4a)	①
Once	②
A few times	③
Often	④

3b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

4a. Within the last 12 months, how often have you been aware of being gossiped about? (Tick one option only)

Never	①
(→ go to question 5a)	
Once	②
A few times	③
Often	④

4b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

5a. Within the last 12 months, how often have you been verbally insulted, harassed and/or threatened? (Tick one option only)

Never	①
(→ go to question 6a)	
Once	②
A few times	③
Often	④

5b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

6a. Within the last 12 months, how often have you been physically harassed and/or threatened? (Tick one option only)

Never	①
(→ go to question 7a)	
Once	②
A few times	③
Often	④

6b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

7a. In the last 12 months, how often have you been physically assaulted? (Tick one option only)

Never (→ go to question 8)	①
Once	②
A few times	③
Often	④

7b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

7c. If yes, who physically assaulted you? (Tick one option only)

My husband/wife/partner	①
Another member of the household	②
A person or people outside the household whom I know	③
A stranger	④

8. In questions 1–7, if you experienced stigma and/or discrimination for any reasons other than your HIV status, please choose ONE of the reasons below that best explains why you felt you were stigmatized and/or discriminated against: (Tick one option only)

Sexual orientation (MSM, gay or lesbian, transgender)	①
Sex worker	②
Injecting drug user	③
Refugee or asylum seeker	④
Internally displaced person	⑤
Member of an ethnic minority group	⑥
Migrant worker	⑦
Prisoner	⑧
None of the above – other reasons	⑨

If your answer is “None of the above”, please explain why you think you were stigmatized or discriminated against:

_____
_____
_____
_____

9. Within the last 12 months, how often have you been subjected to psychological pressure or manipulation by your husband/wife or partner in which your HIV-positive status was used against you? (Tick one option only)

Never	①
Once	②
A few times	③
Often	④

10. Within the last 12 months, how often have you experienced sexual rejection because of your HIV-positive status? (Tick one option only)

Never	①
Once	②
A few times	③
Often	④

11. Within the last 12 months, how often have you been discriminated against by other people living with HIV? (Tick one option only)

Never	①
Once	②
A few times	③
Often	④

12. Within the last 12 months, how often has your wife/husband or partner, or any member(s) of your household, experienced discrimination because of your HIV-positive status? (Tick one option only)

Never	①
Once	②
A few times	③
Often	④

13. If, within the last 12 months, you have experienced any forms of stigma and/or discrimination related to HIV, what are the reasons? (Tick more than one option if there are multiple reasons)

People are afraid of being infected by me	①
People don't understand how HIV is transmitted	②
People are afraid of getting HIV from me through casual contact	③
People think that having HIV is disgraceful and they should not be associated with me	④
Religious beliefs or "moral" judgements	⑤
People disapprove of my lifestyle or behaviour	⑥
I look sick with HIV-associated symptoms	⑦
I don't know why/I am not sure of the reason(s)	⑧

PART 2B: ACCESS TO WORK, HEALTH AND EDUCATION SERVICES

1a. In the last 12 months, how often have you been forced to change your place of residence or been unable to rent accommodation? (Tick one option only)

Never (→ go to question 2a)	①
Once	②
A few times	③
Often	④

1b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

If the interviewee has not had any income (from either formal employment or casual or part-time work) or has not been self-employed during the last 12 months, please go to question 5.

2a. Within the last 12 months, how often have you lost a job (if employed) or another source of income (if self-employed or an informal/casual worker)? (Tick one option only)

Never (→ go to question 3)	①
Once	②
A few times	③
Often	④

2b. If yes, what was the reason? (Tick one option only)

Because of your HIV status	①
For other reasons	②
Both because of your HIV status and other reasons	③
Not sure why	④

2c. If it was because of your HIV status (totally or partially), did you lose your work/income? (Tick one option only)

Because of discrimination from your employer or co-workers	①
Because you felt you had to stop working due to poor health	②
Because of a combination of both discrimination and poor health	③
Because of another reason	④

3. Within the last 12 months, have you been refused employment or a job opportunity because of your HIV status?

Yes	①
No	②

4a. Within the last 12 months, how often has your job description or the nature of your work changed, or how often have you been refused a promotion due to your HIV status?

Never (→ go to question 5)	①
Once	②
A few times	③
Often	④

4b. If yes, why did it happen? (Tick one option only)

Because of discrimination from your employer or co-workers	①
Because poor health prevented you from doing certain things	②
Because of a combination of both discrimination and poor health	③
Because of other reasons	④

5. Within the last 12 months, how often have you been dismissed, suspended or prevented from attending an educational institution because of your HIV status? (Tick one option only)

Never	①
Once	②
A few times	③
Often	④

6. In the last 12 months, how often has your child/children been dismissed, suspended or prevented from attending an educational institution because of your HIV status? (Tick one option only)

Never	①
Once	②
A few times	③
Often	④

7. Within the last 12 months, how often have you been denied health care services, including dental care, because of your HIV status? (Tick one option only)

Never	①
Once	②
A few times	③
Often	④
Not applicable	⑤

8. In the last 12 months, have you been denied family planning services because of your HIV status? (Tick one option only)

Yes	①
No	②
Not applicable	③

9. In the last 12 months, have you been denied sexual and reproductive health services because of your HIV status?

Yes	①
No	②
Not applicable	③

PART 2C. SELF STIGMA (THE WAY YOU FEEL ABOUT YOURSELF) AND YOUR FEARS

1. Within the last 12 months, have you experienced with any of the following feelings because of your HIV status? (Tick one option for each category)

I feel ashamed	Yes ☐ No ☐
I feel guilty	Yes ☐ No ☐
I blame myself	Yes ☐ No ☐
I blame others	Yes ☐ No ☐
I have low self-esteem	Yes ☐ No ☐
I feel I should be punished	Yes ☐ No ☐
I feel suicidal	Yes ☐ No ☐

2. In the last 12 months, have you done any of the following things because of your HIV status? (Tick one option for each category)

I took the decision not to attend social activities/events	Yes ☐ No ☐
I have isolated myself from my family and/or friends	Yes ☐ No ☐
I took the decision to stop working	Yes ☐ No ☐
I decided not to apply for a job/work or for a promotion	Yes ☐ No ☐
I withdrew from education/training or did not take up an opportunity for education/training	Yes ☐ No ☐
I decided not to get married	Yes ☐ No ☐
I decided not to have sex	Yes ☐ No ☐
I decided not to have (more) children	Yes ☐ No ☐
I avoided going to a local clinic when I needed to	Yes ☐ No ☐
I avoided going to a hospital when I needed to	Yes ☐ No ☐

3. In the last 12 months, have you been worried about the following things happening to you – whether or not they have happened actually to you?

Being gossiped about	Yes ☐ No ☐
Being verbally affronted, harrassed and/or threated	Yes ☐ No ☐
Being physically harrassed and/or threatened	Yes ☐ No ☐
Being physically assaulted	Yes ☐ No ☐

4. Within the last 12 months, have you been afraid that someone would not want to become your sexual partner because of your HIV-positive status?

Yes ☐ No ☐

PART 2D: RIGHTS, LAWS AND POLICIES

1a. Have you ever heard of the *Declaration of Commitment on HIV/AIDS,* which protects the rights of people living with HIV?

Yes	①
No	②
(→ go to question 2a)	

1b. If yes, have you ever read this document or discussed its contents?

Yes	①
No	②

2a. Have you ever heard of the *Law on HIV Prevention and Control*, which protects the rights of people living with HIV?

Yes	①
No	②
(→ go to question 3)	

2b. If yes, have you ever read or discussed the contents of the *Law on HIV Prevention and Control*?

Yes	①
No	②

3. In the last 12 months, have any of the following things happened to you because you are living with HIV? (Tick more than one option if appropriate)

I was forced to submite to a medical/health procedure (including HIV testing)	①
I was denied health insurance or life insurance because I am living with HIV	②
I was arrested or taken to the court on a charge related to my HIV status	③
I had to disclose my HIV status in order to enter another country	④
I had to disclose my HIV status in order to apply for a residence permit or nationality	⑤
I was detained, quarantined, isolated or segregated	⑥
None of these things happened to me	⑦

4a. Within the last 12 months, have any of your rights as a person living with HIV been violated?

Yes	①
No	②
(→ go to PART 2E)	
Not sure	③
(→ go to PART 2E)	

4a(i). If yes, which right(s) have been violated/abused? (Tick more than one option if appropriate)

Right to education	①
Right to work	②
Right to privacy and confidentiality	③
Right to marry and have a family	④
Right to information and participation	⑤
Right to non-discrimination and freedom from stigma	⑥
Other	⑦

If other, please specify

_____

_____

4b. If yes, have you tried to get legal redress for any abuse of your rights as a person living with HIV?

Yes	①
No	②
(→ go to question 4e)	
Not sure	③
(→ go to question 4e)	

4c. Has this process begun in the last 12 months?

Yes	①
No	②

4d. What was the result?

The matter has been dealt with	①
The matter is still in the process of being dealt with	②
Nothing happened/the matter was not dealt with	③

4.d(i). While seeking legal redress, did you contact a lawyer?

Yes	①
No	②

4d(ii). If yes, who did you contact for legal assistance? (Tick more than one option if appropriate)

HIV/AIDS legal clinic	①
Provincial legal aid centre (Provincial Department of Justice)	②
Centre for legal consultancy (Viet Nam Lawyers Association)	③
Legal consultancy unit under social unions/associations (e.g. Women's/Labour Union)	④
Private lawyer	⑤
Other	⑥

4d(iii). What kind of assistance did the lawyer provide to you? (Tick more than one option if appropriate)

Legal advice	①
Support in court proceedings	②
Support in negotiations with authorities (in the form of representation)	③
Other assistance	④
I did not receive any services (→ go to question 4d(vi))	⑤

4d(iv). How would you describe the quality of the legal assistance you received?

Very helpful	①
Somewhat helpful	②
Not helpful	③

4d(v). How much were you charged by the lawyer?

Free service	①
Less than 500,000 VND	②
Between 500,000 and 5,000,000 VND	③
More than 5,000,000 VND	④

4d(vi). What difficulties did you face in the process of seeking redress? (Tick more than one option if appropriate)

Difficulties in collecting evidence	①
Limited access to authorities/court	②
Limited collaboration from lawyers	③
Costs were too high	④
No collaboration from the community (e.g. witnesses)	⑤

4e. If the response to question 4b was NO or NOT SURE, what was the reason for not trying to get legal redress?

Insufficient financial resources to take action	①
Process of addressing the problem appeared too bureaucratic	②
Felt intimidated or scared to take action	③
Advised against taking action by someone else	④
No/little confidence that the outcome would be successful	⑤
None of the above	⑥

If “none of the above”, please specify

_____

_____

5a. Have you tried to get a government employee(s) to take action against an abuse of your rights as a person living with HIV?

Yes	①
No	②
(→ go to question 6a)	

5b. Did this happen within the last 12 months?

Yes	①
No	②

5c. What were the results?

The problem has been resolved	①
The problem is still in the process of being dealt with	②
Nothing happened/the problem is not resolved	③

6a. Have you tried to get a local or national party official to take action against an abuse of your rights as person living with HIV?

Yes	①
No	②
(→ go to PART 2E)	

6b. Did this happen within the last 12 months?

Yes	①
No	②

6c. What were the results?

The problem has been resolved	①
The problem is still in the process of being dealt with	②
Nothing happened/the problem has not been resolved	③

7. To your knowledge, are any of the following legal services available to PLHIV in your district? (answer yes/no for each)

HIV/AIDS legal clinics	①
Provincial legal aid centre (Provincial Department of Justice)	②
Centre for legal consultancy (Viet Nam Lawyers Association)	③
Legal consultancy unit under social unions/associations (e.g. Women's/Labour Union)	④
Private lawyers	⑤

8. How would you rate the accessibility of PLHIV to lawyers?

Very accessible	①
Accessible	②
Limited accessibility	③
Inaccessible	④

9. What are the main barriers to PLHIV accessing legal services? (Tick more than one option if appropriate)

Cost	①
Distance	②
Lack of awareness/information about the service(s)	③
Lack of trust of the support the service(s) can provide	④
Fear of stigma and/or discrimination from lawyers	⑤
Fear that your HIV status may be revealed to others	⑥
Fear of stigma and/or discrimination from the community	⑦

PART 2E: EFFECTING CHANGE

1. Within the last 12 months, have you confronted, challenged or educated somebody who stigmatized or discriminated against you?

Yes	①
No	②

2a. Are you aware of any organizations and/or groups that you can ask for help if you experience stigma or discrimination?

Yes	①
No	②
(→ go to question 3)	

2b.If yes, which organizations or groups are you aware of? (Tick more than one option if appropriate)

Support group for people living with HIV	①
Network of people living with HIV	②
Local non-governmental organization	③
Faith-based organization	④
A lawyer	⑤
A human rights group	⑥
National non-governmental organization (NGO)	⑦
National AIDS committee or council	⑧
International non-governmental organization (NGO)	⑨
United Nations agencies	⑩
Other	⑪

2c. If the answer is “Other”, please describe the organization or group you are referring to:

_____
_____
_____

3. Have you ever asked for help from these organizations to resolve an issue of stigma and discrimination?

Yes	①
No	②

4. If you have tried to resolve issues of stigma and discrimination by yourself or with help from others, please describe what the problem was and how you or others have tried to resolve it.

4a. What was the issue of stigma and discrimination?

_____
_____

4b.If you were assisted by somebody else, who was it?

_____
_____

4c. How did you (or others) try to resolve the issue of stigma and discrimination?
(i.e. what were the specific activities that you and others tried to do?)

_____
_____
_____

5a. During the last 12 months, have you helped and supported other people living with HIV?

Yes	①
No	②

5b. If yes, what types of support did you provide to them? (Tick more than one option if appropriate)

Emotional support (e.g. counselling, sharing individual stories and experiences)	①
Physical support (e.g. providing money or food, doing small jobs for them)	②
Referring them to other services	③

6. Are you currently a member of a support group or network of people living with HIV?

Yes	①
No	②

7. During the last 12 months, have you served as a volunteer or employee in any support programmes or projects for people living with HIV (either government or NGO)?

Yes	①
No	②

8. During the last 12 months, have you participated in any process of developing legislation, policies or guidelines related to HIV?

Yes	①
No	②

9. Do you feel that you have the power to influence decisions in any of the following aspects: (Tick at least one option. You can tick more than one, if relevant)

Legal and rights matters affecting people living with HIV	①
Local government policies affecting people living with HIV	②
Local projects intended to benefit people living with HIV	③
National policies affecting people living with HIV	④
National programmes/projects intended to benefit people living with HIV	⑤
International agreement/treaties	⑥
None of the above	⑦

10. There are several organizations of people living with HIV working against stigma and discrimination. If one of these organizations asked you “What is the most important thing we need to do in order to address stigma and discrimination?” what would you recommend? (Tick one option only)

Advocating for the rights of people living with HIV	①
Emotional, physical and referral support for people living with HIV	②
Advocating for the rights of and/or providing support for marginalized groups (men who have sex with men, injecting drug users, sex workers)	③
Educating people living with HIV on living with HIV (including treatment literacy)	④
Raising the awareness and knowledge of society about AIDS	⑤

PART 3A: TESTING/DIAGNOSIS

1. Why were you tested for HIV? (Tick one or more option(s) as appropriate)

Employment	①
Pregnancy	②
Preparation for a marriage/sexual relationship	③
Referred by a clinic for sexually transmitted infections	④
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	⑤
Wife/husband/partner/family member tested HIV-positive	⑥
Wife/husband/partner/family member got sick or died	⑦
I just wanted to know	⑧
Other reasons	⑨

If "Other reasons", please specify the reason

_____

_____

2. Was the decision to be tested up to you? (Tick one option only)

Yes, I decided myself to have an HIV test (i.e. it was voluntary)	①
I decided to go for the test, but under pressure from others	②
I was forced to take an HIV test (coercion)	③
I was tested without my knowledge. I only found out after the test had been done	④

3. Did you receive counselling when you were tested for HIV? (Tick one option only)

I received pre- and post-test counselling	①
I only received pre-test counselling	②
I only received post-test counselling	③
I did not receive any counselling when I had an HIV test	④

PART 3B: DISCLOSURE AND CONFIDENTIALITY

1. For each of the following people or groups of people, please, describe how they were told about your HIV status for the first time, if they were told:
(Tick your answer(s). Only tick more than one option in each line if your answer is different for different individuals)

	I told them	Someone told them WITH my consent	Someone told them WITHOUT my consent	They do not know my status	Not applicable
Your husband/wife/partner	1	2	3	4	5
Other adult family members	1	2	3	4	5
Children in your family	1	2	3	4	5
Your neighbours/friends	1	2	3	4	5
Other people living with HIV	1	2	3	4	5
Your co-workers (colleagues)	1	2	3	4	5
Your employer(s)/ boss(es)	1	2	3	4	5
Your clients	1	2	3	4	5
Injecting drug partners	1	2	3	4	5
Religious leaders	1	2	3	4	5
Community leaders	1	2	3	4	5
Health care workers	1	2	3	4	5
Social workers/counsellors	1	2	3	4	5
Teachers	1	2	3	4	5
Government officials	1	2	3	4	5
The media	1	2	3	4	5

2a.How often have you felt pressure from other people living with HIV or groups/networks of people living with HIV to disclose your HIV status?

Often ①
A few times ②
Once ③
Never ⑤

2b. How often have you felt pressure from people **not** living with HIV (e.g. family members, social workers, staff of non-governmental organizations) to disclose your HIV status?

Often	①
A few times	②
Once	③
Never	④

3. Has a professional health worker (e.g. medical doctor, nurse, counsellor, laboratory technician) told others about your HIV status without your consent?

Yes	①
No	②
Not sure	③

4. How confidential do you think your medical records relating to your HIV status are? (Tick one option only)

I am sure that my medical records will be kept completely confidential.	①
I do not know if my medical records are confidential	②
It is clear to me that my medical records are not being kept confidential	③

5. How would you describe the reactions of the following people (in **general**) when they were first knew about your HIV status ? (Tick one option only for each category of people)

	Very discriminatory	Discriminatory	No different	Supportive	Very Supportive	Not applicable
Your husband/wife/partner	1	2	3	4	5	6
Other adult family members	1	2	3	4	5	6
Children in your family	1	2	3	4	5	6
Your neighbours/friends	1	2	3	4	5	6
Other people living with HIV	1	2	3	4	5	6
Your co-workers (colleagues)	1	2	3	4	5	6
Your employer(s)/ boss(es)	1	2	3	4	5	6
Your clients	1	2	3	4	5	6
Injecting drug partners	1	2	3	4	5	6
Religious leaders	1	2	3	4	5	6
Community leaders	1	2	3	4	5	6
Health care workers	1	2	3	4	5	6
Social workers/counsellors	1	2	3	4	5	6
Teachers	1	2	3	4	5	6
Government officials	1	2	3	4	5	6
The media	1	2	3	4	5	6

6. Did you find that the disclosure of your HIV status was an empowering experience? (Tick "not applicable" if you have not disclosed your HIV status)

Yes ①
No ②
Not applicable ③

PART 3C: TREATMENT

1. In general, how would you describe about your health status at this moment? (Tick one option only)

Excellent	①
Very good	②
Good	③
Fair	④
Poor	⑤

2a. Are you currently taking antiretroviral treatment? (Tick one option only)

Yes	①
No	②

2b. Are you able to access* antiretroviral treatment services, even if you are not on treatment at the moment ? (Tick one option only)

Yes	①
No	②
Do not know	③

*Access in this question means that antiretroviral treatment services are available and free, or available and affordable for you.

3a. Are you taking any medication prevent or treat opportunistic infections? (Tick one option only)

Yes	①
No	②

3b. Have you been able to access* medication for opportunistic infections, even if you are currently not taking any of these medications?

Yes	①
No	②
Don't know	③

*Access in this question means the treatment is available and free, or available and affordable for you.

4. Within the last 12 months, have you had a constructive discussion with a health care professional on the topic of your HIV-treatment options?

Yes	①
No	②

5. Within the last 12 months, have you had any constructive discussions with a health care professional on other subjects such as sexual health and reproductive health, sexual relationships, mental health, well-being and drug use etc.?

Yes	①
No	②

PART 3D: HAVING CHILDREN

Questions 1-5 can be completed by both male and female interviewees

1a. Have you got a child/children?

Yes	①
No	②

1b. If yes, are any of your children HIV-positive?

Yes	①
No	②

2. Since being diagnosed HIV-positive, have you ever had counselling about your reproductive options?

Yes	①
No	②
Not applicable	③

3. Has a health professional advised you not to have a child since you were diagnosed HIV-positive?

Yes	①
No	②
Not applicable	③

4. Has a health professional advised you to be sterilized since you were diagnosed HIV-positive?

Yes	①
No	②
Not applicable	③

5. Have you been forced to accept the use of a method of contraception in order to be given antiretroviral treatment?

Yes	①
No	②
Not applicable	③
Do not know	④

Questions 6 and 7 are only completed by female respondents.

6. Within the last 12 months, has a health professional forced you to do anything related to the following because you are living with HIV?

	Yes	No	Not applicable
Termination of pregnancy (abortion)	1	2	3
Method of giving birth	1	2	3
Newborn baby feeding practices	1	2	3

7a. Have you ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV? (Tick one option only)

Yes, I have received this treatment	①
No, I do not know about this treatment	②
No, I was refused this treatment	③
No, I did not access this treatment	④
No, I was not HIV-positive when pregnant	⑤

7b. If yes, have you been provided with information about healthy pregnancy and safe motherhood as a component of the programme to prevent mother-to-child transmission of HIV?

Yes	1
No	2

PART 3E: PROBLEMS AND CHALLENGES

In your opinion, what are the MAIN PROBLEMS & CHALLENGES related to:

1. Testing and diagnosis

_____
_____
_____

2. Disclosure and confidentiality about being HIV-positive

_____
_____
_____

3. Antiretroviral treatment

_____
_____
_____

4. Having children when you are HIV-positive

_____
_____
_____

The interview ends here. Before completing the information on the quality check section with the interviewee, thank the inteviewees for their time working on the interview. After completing the quality check section, provide information for the referral and follow-up section at the beginning of the questionnaire and confirm any follow-up arrangements. Give the honorarium to the interviewees and thank them again.

After the interview, take some time to review the results of the interview that has just been completed: check again your notes taken during the interview to ensure that you had taken all the details you wanted and added any information if needed to your notes. Write down things that you want to discuss with or consult the team leader about.

Quality Checks

This section is designed to help the interviewers and team leader to check the quality of the completed questionnaire to ensure that it was done properly and completely.

However, you also need to use your own judgement to ensure that good work has been done. The team leader will check the answers of the interviewees when you return to the office.

The interviewer should answer the following points before the interview is closed, so that the interviewee can help you in answering the questions.

1. Has the interviewee fully answered all the questions from Parts 1-3 of the questionnaire?

☐ Yes
☐ No

If No, specify which questions have not been answered and give the reasons why.

2. Are the answers to the question 7 in Part 1 and question 8 in Part 2a (groups the interviewee has belonged to or does belong to) consistent?

☐ Yes
☐ No

If No, please explain why.

3. Does the information provided in Part 1 (questions 14 and 15) seem credible? (e.g. is the level of household poverty consistent with the realities that the household did not have sufficient money to buy food, given the fact that some poor households could farm their own food?)

☐ Yes
☐ No

If there are differences, have you explored the reasons for them with the interviewee and written down these reasons in your notes?

☐ Yes
☐ No

_____
_____

4. Has the front page of the questionnaire been completed?

☐ Yes
☐ No

The final part of the quality check can be completed by the interviewer after the interviewee has left, but before the interviewer leaves the interview location.

5. Has the code of the questionnaire been written in the top right hand corner of each page?

☐ Yes
☐ No