

United Nations Country Team
on HIV/AIDS Malaysia
PAF Project



Study on the
Impact of HIV
on People Living with HIV,
their Families and
Community in Malaysia
Project Report

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Glossary

APN+	Asia Pacific Network of People Living with HIV/AIDS
ARV	Anti-Retroviral therapy
DIC	Drop-In Centre
DU	Drug User
EPF	Employees Provident Fund
FGD	Focus Group Discussion
FFPAM	Federation of Family Planning Associations of Malaysia
FPA	Family Planning Association
GIPA	Greater Involvement of Persons with AIDS
HAART	Highly Active Acute Retroviral Therapy
ID	Infectious Disease
IDIs	In-Depth Interviews
IDU	Injecting Drug Use/User
IEC	Information, Education and Communication
KWSP	Kumpulan Wang Simpanan Pekerja
M&E	Monitoring and Evaluation
MAC	Malaysian AIDS Council
MDGs	Millennium Development Goals
MoH	Ministry of Health
MSM	Men having Sex with Men
NACA	National Advisory Committee on AIDS
NGO	Non-Government Organisation
NSP	National Strategic Plan
OVC	Orphaned and Vulnerable Children
PLHIV	People Living With HIV ¹
PMR	<i>Penilaian Menengah Rendah</i> (Lower Secondary Assessment)
SOSCO	Social Security Organization
SPM	<i>Sijil Pelajaran Malaysia</i> (Malaysian Certificate of Education)
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
STPM	<i>Sijil Tinggi Pelajaran Malaysia</i> (Malaysian Higher Certificate of Education)
SW(s)	Sex Worker(s)
TB	Tuberculosis
TCA	Technical Committee on AIDS
SW	Transgender Sex Worker
UNAIDS	The Joint United Nations Programme on AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Fund for Population Activities
UNGASS	United Nations General Assembly Special Session
UNHCR	United Nations High Commissioner for Refugees

¹UNAIDS Editors' Notes for Authors (May 2006)

Executive Summary

The main objective of this project is to strengthen the national policy and programmes on HIV/AIDS in Malaysia by assessing the impact of HIV/AIDS on people infected by the disease to provide an information base on PLHIV (People Living with HIV) and the families/communities affected. The specific objectives are to:

1. construct a unique policy-relevant information base on PLHIV and their families;
2. promote an understanding of the processes and consequences for PLHIV and how these impact on their families and communities in which they live;
3. identify the unmet needs of PLHIV and their immediate families/communities;
4. document the treatment, care and support services (such as health, welfare and counselling) PLHIV and their families are accessing and identify service gaps.

Three main activities were planned under this project:

- a) a qualitative study to elicit personal perspectives from PLHIV on the processes and consequences of HIV/AIDS on their lives and that of their families/communities, including the role of public policy;
- b) a rapid needs assessment survey among PLHIV communities; and
- c) a national dialogue with key stakeholders, including PLHIV, to disseminate the findings and promote the formulation of evidence-based policies/programmes with increased participation of PLHIV.

Members of the PLHIV community were included in all stages of this project up to analysis and report writing.

Both qualitative and quantitative methodologies were applied for the study component of this project. Specifically, Focus Group Discussions (FGDs) were carried out for the qualitative study on the social, psychological, health and economic impact of HIV and AIDS on HIV-infected persons and their families, and community. In addition, a survey to assess the needs of PLHIV was undertaken on the FGD participants.

This study gathered information from seven categories of participants, six of which were men and women living with HIV:

1. DU – HIV-infected person who is/was an injecting drug user or drug user
2. Infected Partner – HIV-infected person who was infected by a spouse or partner in a steady relationship
3. MSM – HIV-infected man who has sex with men
4. HM – HIV-infected heterosexual man
5. SW – HIV-infected sex worker (female or transgender)
6. Refugee – HIV-infected person with refugee status
7. Community – community member or lay-person (HIV status unknown)

While there was much interest, it was decided not to include children with HIV as a group for ethical reasons.

The total FGD participants were 130 participants with 94 of whom were PLHIV and 36 were members from the community. Of the 36 community participants, 18 were women and 18 were men. This report describes the findings from the FGDs and the needs assessment survey of these study participants.

The main findings from the qualitative study are summarised as follows:

- Whilst there is now drug treatment for the physical health impact of HIV, there is insufficient attention paid to its psychological effects, especially for the newly diagnosed; at the very least, pre- and post-test counselling should be available and accessible so as to cushion the initial trauma.
- Although current practices related to HIV testing, namely, routine testing in prison and rehabilitation centres, are deemed necessary for HIV control, complementary programmes, such as intensive counselling, outreach, after-care or follow-up, or peer support, are vital to support inmates/residents after release to prevent transmission and enable positive living
- There is clear evidence of stigmatization and discrimination of PLHIV from healthcare providers, employers, aid agencies, community and within the family
- Although moral judgements on associated behaviours may play a part, the stigma on HIV is rooted in the fear of contagion which has persisted despite past IEC campaigns, i.e., that HIV cannot be spread by casual contact, through sharing utensils and so forth.
- The economic impact of HIV, through death of the family breadwinner or resignation due to coercion or ill health, or by limiting career options, affects women disproportionately than men, especially those who are single parents, and, regardless of gender, those of lower education and income-earning capacity
- NGOs and other HIV-related resources play a critical role in the lives of PLHIV, especially the key populations such as refugees, sex workers and transgender, and enabling their access to treatment, care and support
- Condom use is poor among men, even among clients of sex workers who may be exposed to high risk of HIV and STIs
- This resistance to condom use, despite awareness of potential exposure to STIs, involves a denial of risk and is rooted in the lack of male responsibility
- The current hospital practice of sealing up the body of an HIV-related death denies the deceased a dignified burial or cremation, denies loved ones the chance of performing last rites, and discloses the deceased's HIV status to others; this, in turn, stigmatizes the surviving family

It was clear from the FGDs in this study that several factors influence how HIV-infected people cope with the disease and its consequences. These are:

- Contribution of competent and compassionate care in motivating adherence to HIV treatment and preventive practices, as well as physical and psychological healing
- Importance of security in income sources/employment after HIV diagnosis
- Protection from stigmatization and discrimination
- Benefits of counselling in gaining acceptance of HIV status by self and by family
- Importance of HIV support groups in accepting HIV, coping with consequences and motivating preventive practices
- Role of support groups and after-care programmes in ending drug dependence and maintaining drug-free status
- Critical role of community-based organizations or resources in assisting SWs and transgender, e.g, to access treatment, welfare and aid

- Benefits of support from faith-based organisations for spiritual and other basic needs

It should be pointed out that the above findings on PLHIV from this qualitative study are based on participants with the following common features:

1. Willing to participate in a group discussion, i.e., involving disclosure
2. Sufficiently healthy to travel to the venue and participate
3. Able to give time attend a meeting at a selected time and venue
4. Associated with a HIV resource, namely, NGO or hospital

While the findings from a qualitative enquiry cannot be generalised, it may be argued that the impact of HIV may be worse for those PLHIV who are unwilling to disclose their status and participate, who are not healthy enough to attend and who do not have access to, or association with, a HIV resource.

In terms of policy, the spirit and conditions of the Patient's Charter needs to be internalized into healthcare providers as part of their training and its principles strictly enforced. PLHIV communities have access to healthcare and medication. The professionalism of healthcare staff needs to be improved based on the many cases of complaints voiced in this study. Particular attention should be given to the training of nurses as they are the front-liner and they interact most with patients in the healthcare setting. Negative experiences with healthcare providers contribute to poor healthcare-seeking behaviour and poor compliance with treatment. This is a recognised barrier to HIV prevention.

Similarly, the Code of Practice for the Prevention and Management of HIV/AIDS in the Workplace needs to be strengthened with a legal mandate to prevent discrimination of PLHIV. The loss of employment and income understandably adds to the burden of HIV to the individual, to their families, and ultimately, to the Nation.

The role of drug dependence in HIV transmission is well-recognised with prevention and control strategies already in place, including, Harm Reduction. At the same time, programmes towards the healthy development of youth, such as *Rakan Muda*² and *PROSTAR*³ (Programme for Healthy Youth without AIDS), need to be popularised and strengthened with a focus on promoting responsible citizenship and reducing the demand for drugs.

Behaviour Change Communication (BCC) programmes for sex workers and drug users have also been implemented by MOH. However, since SWs are not likely to have negotiating power over the use of condoms by their clients, the continued preference for unprotected sex among men, despite years of IEC on exposure to risk, needs to be addressed. The primal nature and urgency of sexual needs combined with denial of risk tends to over-ride any consciousness of risk of exposure to HIV and other STIs. The availability of treatment for HIV, i.e., knowledge that HIV is no longer a death sentence, may also induce some complacency with regards to practising protected sex. Men with

² The Rakan Muda programme was launched in 1995 by the Ministry of Youth and Sports under one of six major thrusts – Healthy Lifestyle Programmes – of the Government's Youth Development Policy; http://www.epu.jpm.my/new%20folder/development%20plan/RM8/c21_cont.pdf

³ PROSTAR (Program Sihat Tanpa AIDS untuk Remaja) was launched in 1995 by the Ministry of Health; http://www.infosihat.gov.my/Projek_Khas_Prostar.html

multiple partners and clients of sex workers are harder to identify as a target audience for BCC strategies. Hence, in addition to focussed approaches, control measures must be attempted through wider ranging social policies, in particular, increasing gender-awareness and sensitivity among boys and increasing male responsibility in family life and in reproductive health. Such education programmes through schools, however, must be reinforced at home to be effective; in other words, parents should be sensitized as well. These policies should parallel HIV-specific policies and laws to prevent discrimination and promote positive living among PLHIV. Measurable outcomes should be formulated and monitored in relation to HIV trends.

In addition to affective behaviour change strategies to prevent HIV/AIDS transmission through protected sex, there is a great need for interventions that empower those HIV-infected who are particularly vulnerable and disproportionately impacted such as women infected by their husbands/partners and the destitute transgender sex workers. Instead of dependency on welfare and aid, they prefer gaining skills and access to credit towards independent means of earning a living.

The focus on reducing stigmatization and discrimination of PLHIV is explicitly stated as a key point in the National Strategic Plan on HIV/AIDS towards increasing access to treatment, care and support (NSP 2006). Past IEC approaches have contributed to this association of HIV infection with socially unacceptable or immoral behaviours (and people), and with death. Furthermore, some practices dealing with PLHIV, such as segregation and hospital procedures for the body of AIDS-related death, reinforce the stigma and, in particular, the fear of contagion. More than the moral judgements branded on PLHIV, the core of the stigma on HIV is this basic fear of becoming infected. Years of IEC educating the public on how HIV can and cannot be transmitted, yet the information has not been universally believed.

One of the ways to reverse this image of HIV is to present PLHIV as human beings with specific challenges and responsibilities in light of their HIV status, and to show them in their daily lives alongside non-infected people. PLHIV are not willing to disclose their status because of its negative repercussions; the ones who do step into the public eye tend to be the ones who have no fear of the consequences of disclosure, perhaps because they have already faced it. Hence, there must first be assurances that negative consequences, such as those described in this study, will not occur. At the same time, measures to “normalise” PLHIV must not have the unintended effect of diminishing the seriousness of the disease.

The moral judgements on PLHIV arising from their behaviour or sexual identity will be far more difficult to overcome in a conservative society as Malaysia. Prejudice and judgemental attitudes are barriers to effective implementation of policies. Further, they exclude PLHIV from participating as equal partners in formulating policy or implementing programmes. Existing rights-based laws must be invoked and enforced to limit discrimination.

Overall, the findings from this study reinforce the need for coordinated multi-sectoral actions in the national response to HIV as delineated in the National Strategic Plan 2006. With the number of HIV infections emerging daily, it is timely to invest and deliver on the strategies identified within. Without the effective implementation of relevant multi-

sectoral policies, there remains little hope in halting and reversing the spread of HIV in Malaysia.

Introduction

Since 1986 when the first cases were diagnosed up to December 2005, 70,559 people have been diagnosed with HIV (including AIDS and AIDS deaths) (MOH 2006a). The number of cases detected has increased steadily with the expansion of testing capabilities throughout the country and comprise in large part the results of routine testing of selected groups, as shown below:

Table A: Routine HIV Testing – List of Groups

1. Women receiving antenatal care in government facilities (private practitioners are encouraged to screen their antenatal patients)
2. Blood donors
3. Inmates of drug rehabilitation centres
4. High-risk prison inmates (drug users, drug dealers and sex workers)
5. Confirmed tuberculosis cases
6. STD cases
7. Patients with suspected clinical symptoms
8. Traced contacts of infected persons.

Source: Ministry of Health Malaysia

There have been over 6,000 new HIV infections per year since 2002 (Ministry of Health 2005). Among men, and overall, the likely mode of transmission in the majority of cases is related to injecting drug use (IDU) (75.1%), followed by heterosexual (13.6%) transmission. A very small proportion of infections are characterised as via “homo/bi-sexual” (1.3%) and via vertical transmission routes (0.7%) (Ministry of Health 2005). Clearly, more effort needs to be focussed on the drug-using, and in particular, injecting drug-using, group.

Thus, since HIV/AIDS is relatively confined to certain population sub-groups, Malaysia is described currently as a country with a concentrated epidemic. However, the rising trend of sexual transmission from 5.3% in 1990 to 22.15% in 2005 (Ministry of Health AIDS/STD Section) indicates that the situation could expand into a general epidemic. Moreover, the proportion of women infected has risen from 1.4% in 1990 to 14.5% in 2005 (Ministry of Health AIDS/STD Section). Indeed, the female to male ratio of new infections has narrowed substantially (Reid et al 2005). In sharp contrast to men, 64% of HIV infections in women were sexually transmitted (Reid et al 2005). This evident “feminization” of the HIV situation in Malaysia adds impetus to the need for a gender-sensitive national response.

As is the pattern worldwide, HIV affects Malaysians in their prime productive years, hence, represents a drain in human capital investment and productive resources. It is a national development issue affecting youths, in particular, young Malay men. The cost of medical care alone, estimated at RM66-RM240 per month (NST 2005) for the remaining lifetime of those with HIV constitutes a significant burden to the national healthcare budget as well as individual and family finances. National expenditures on HIV-related patient care and support for the period 1993 to 2003 was USD36.8 million (Ministry of Health 2005). In addition, there are other costs, such as, sick days from

school or work, transport costs for medical care, loss of income, school withdrawal, psychological/emotional trauma, for the individual, his/her family, the work place, and, ultimately, for the nation's economy. HIV/AIDS has a multi-dimensional impact on a country affecting social, demographic, economic and structural factors, not least, the health sector, family welfare and households, the education sector, business enterprises and workplaces, and manpower resources. This wide spectrum of impact has been documented for Africa¹ but less so for affected countries in Asia. The recent United Nations Millennium Development Goals report commended Malaysia on its record towards achieving all MDG targets by 2015 except in halting and reversing the spread of HIV/AIDS (UNDP 2005). An escalation of the HIV epidemic would seriously undermine the pace of socio-economic progress and the Nation's Vision towards developed status by 2020.

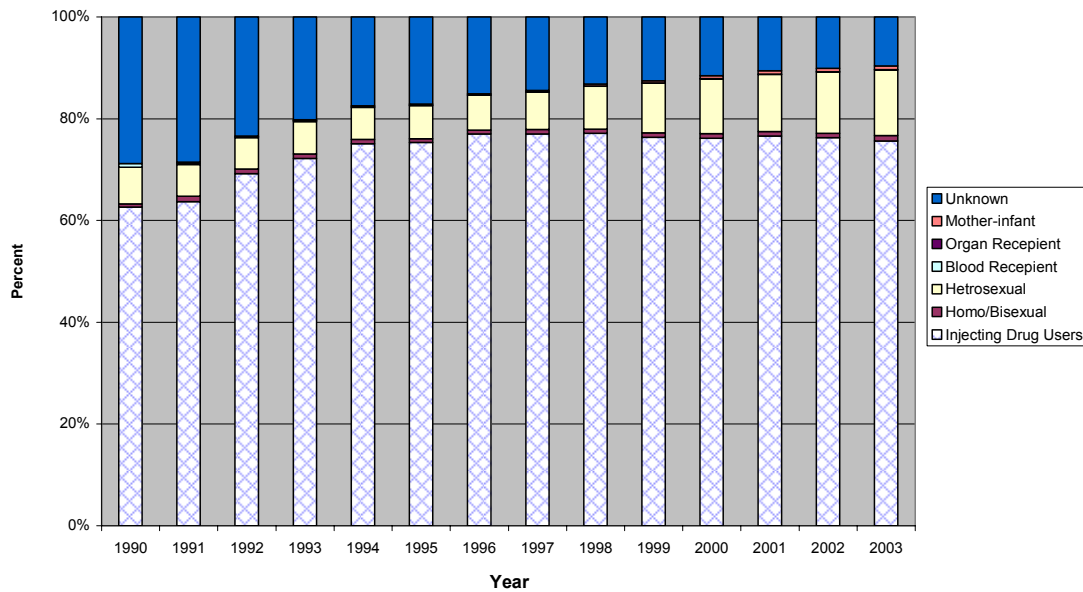
Profile of HIV in Malaysia

Since the disease emerged in the mid-Eighties, the profile of reported HIV infections has remained consistent, i.e., predominantly substance abusers (IDUs), male, 20-39 years of age, Malaysian Malay ethnicity and heterosexual (Figure 1). The relatively young age-group affected implicates losses in human capital investments and productive resources.

Furthermore, despite the preventive measures thus far, the persistence of the substance abuse and dependence problem in Malaysia provides a continuous human pool of potential HIV infections. To reduce this risk, the Ministry of Health (MOH) and Malaysian AIDS Council (MAC) initiated the Harm Reduction programme in December 2005 which will be expanded under the 2006-2010 National Strategic Plan on HIV/AIDS (MOH 2006b).

Despite the preponderance of infected men, there is serious concern over the rising numbers of women infected with HIV. Women with HIV bear the added risk of vertical transmission to infants. In addition, although the present numbers and proportion are small, there also appears to be a rising trend in new HIV infections classified as MSM transmission.

Figure 1: % cumulative HIV cases by year and mode of transmission



As shown in Figure 1, the majority of infections are related to IDU. As testing, diagnoses and reporting improve over time, the proportion of infections classified under unknown causation has narrowed. Over the same period, the proportion of infections classified as heterosexual has risen, particularly after 1995 when the Ministry of Health, as the lead agency in the country's prevention and control strategy, expanded its screening programme, including through government antenatal clinics, prisons and drug rehabilitation centres.

In fact, heterosexual transmission contributes a significant proportion of infections among Chinese Malaysians, in contrast to Malay and Indian Malaysians for whom IDU transmission predominates by far. Heterosexual transmission is also prominent in certain locations, e.g., Sabah.

With regards to the preponderance of IDU in Malaysia, it is recognised that this situation is partly due to reporting bias. Substance abusers are routinely tested for HIV when they opt for treatment and rehabilitation or when they enter the criminal justice system. Although the direct route of disease transmission among this group is most likely through contaminated needles or other objects involved with injecting drugs, it is recognised that unprotected sex may also be a risk factor. Furthermore, most of the substance abusers are heterosexual and risk infecting women partners and offspring. Other issues pertinent to substance dependence and the ensuing life circumstances, hamper prevention efforts, such as, fear of criminal prosecution, marginalisation, apathy and poverty. Hence, this group remains a priority in controlling the HIV epidemic.

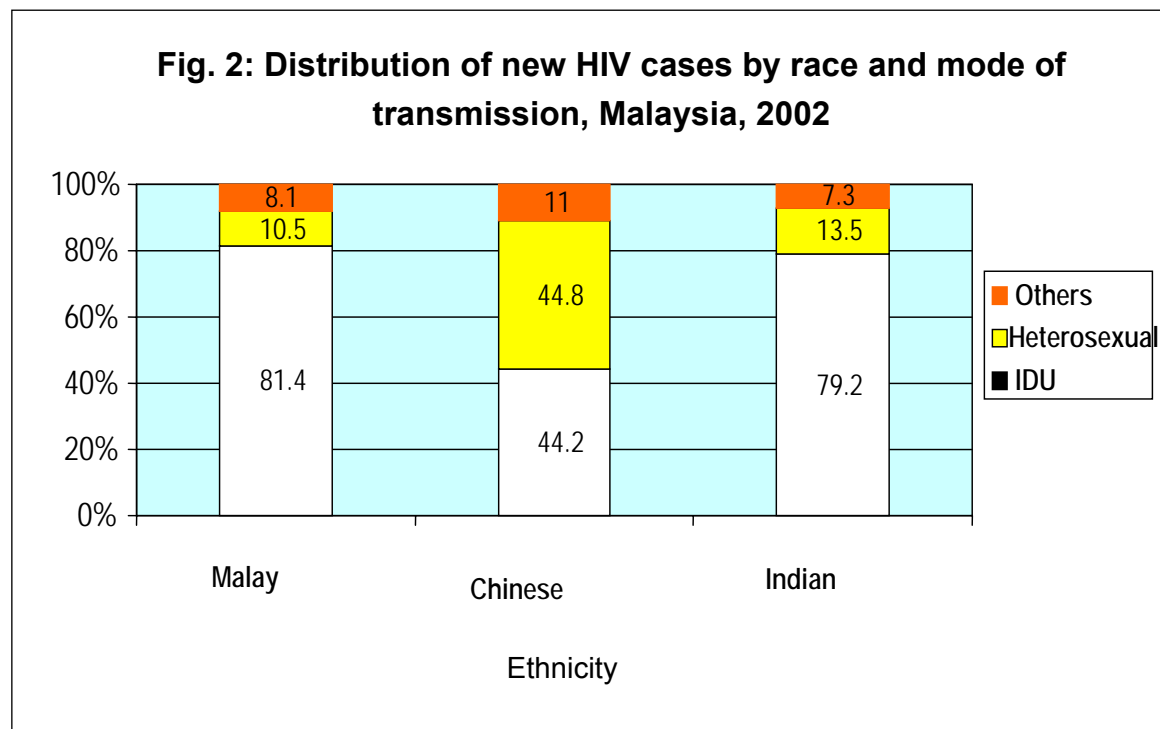
The rise in diagnosed infections via heterosexual transmission raises concerns for women. While HIV cases have continued to be overwhelmingly male, the percentage of women has increased from 1.4% in 1990 to nearly seven percent (3,781 cases) in 2003. In terms of AIDS, the number of women diagnosed increased from two in 1991 to 700 in 2003, representing about eight percent of all AIDS cases. Again, increased detection has followed expanded HIV testing among women through mandatory testing in antenatal care. The unequivocal difference between infections among men and women in Malaysia

is that the large majority of women are infected through sex with an infected male partner, rather than substance use. As Figure 2 shows, the number of HIV infected persons classified as housewives is similar to that of sex workers, a group considered high-risk. Entrenched gender inequalities, and gender-based violence in its varied forms, confer upon women unique vulnerabilities with regards to reproductive health problems, including HIV and AIDS (Sen et al 2002; Heisse et al 1999).

In terms of sexually transmitted HIV infections, heterosexual transmission predominates over other sexual routes, notably, men having sex with men (MSM). In 2003, however, the number of HIV infections transmitted via bi-/homosexual activities nearly tripled from 51 cases to 151, a percent that far exceeded increases in other modes of transmission. Although the percentage contribution of HIV cases attributed to MSM is relatively low at present, the potential for HIV to spread rapidly is a reality, more so because the moral climate in Malaysia hampers prevention efforts that may be effective for this group. At the same time, it should be noted that, if the Malaysian population could be disaggregated by sexual orientation, calculated rates of HIV prevalence within the MSM or homosexual male sub-group may suggest a very different profile of risk.

Furthermore, by ethnicity, the data show that Chinese Malaysian males are at higher risk of infection through sexual activity compared to Malay and Indian men, among whom the majority of HIV infections are associated with drug use (Fig. 3). This suggests that different approaches should be targeted at various sub-groups in the population.

It is also postulated that the breakdown by mode of transmission among Chinese Malaysians may better reflect the distribution of risk among the general population as detections are less biased towards drug users among this group. In other words, the data suggests the potential significance of heterosexual transmission of HIV in this country.



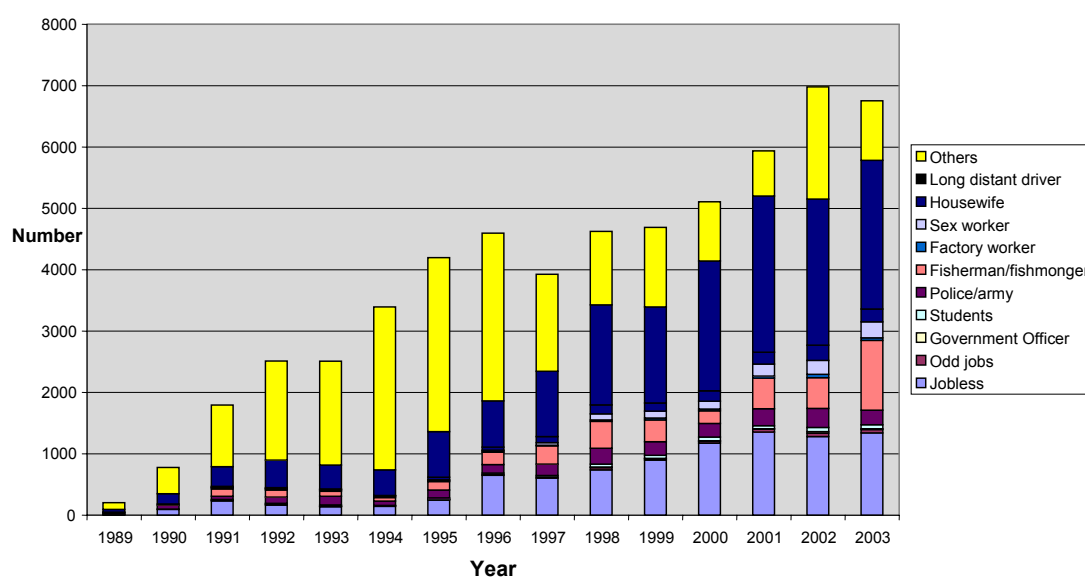
Source: UNDP (2005)

Exposure to HIV among the heterosexual population implicates risks to children. In this regard, there is no documentation on the number of infected and affected children in Malaysia. The Malaysian AIDS Foundation has on record 246 HIV-infected children below 12 years who are receiving its support⁴. Furthermore, estimates for Malaysia from the UNAIDS and WHO global surveillance of HIV/AIDS and sexually transmitted infections report as many as 14,000 children who have lost one or both parents to AIDS (UNDP 2005). Without doubt, the number of orphaned and vulnerable children (OVC) in this country will rise as HIV spreads among the heterosexual population. At the same time, being in the MSM category does not preclude having children. The 2006 National Strategic Plan on HIV/AIDS stipulates improving support to this group through the following strategies (MOH 2006b):

- ❖ The provision of appropriate counselling and psychosocial support to orphans and other vulnerable children, and to their carers;
- ❖ The provision of HIV/AIDS treatment and care for HIV-infected children;
- ❖ Their enrolment in school; ensuring their access to shelter, good nutrition, health and social services on an equal basis with other children;
- ❖ Non-discrimination through the promotion of an active and visible policy of destigmatisation of children orphaned and made vulnerable by HIV/AIDS.

Contrary to the widely held perception that sex workers are a high risk group, it appears that, by occupation, the majority of infected persons are categorised as long-distance drivers, followed by the unemployed or with temporary employment (odd job labour) and fishermen/fishmongers (Figure 3). At the same time, however, a study on fishermen in Terengganu found an association between substance abuse and HIV infection among them (MOH 1999). Similarly, odd job labour, unemployment, and, possibly long-distance driving, also may be job categories correlated with substance abuse/dependence.

Figure 3: New HIV cases by year and occupation group



⁴ Source: Malaysian AIDS Foundation (November 2006)

In fact, special surveys conducted by the Ministry of Health among selected risk groups shows highest prevalence rates among drug users, followed by sex workers, and other groups with high exposure (Table B). In contrast, the MOH's Voluntary Screening Programme, piloted in Johor in 2001 and expanded nation-wide since 2003, found HIV-positive rates ranging from none in Sabah and Kuala Lumpur to a high of 4.31% in Kelantan, followed by 2.26% in Johor (MOH 2004b). Although the figures based on this programme may be biased since testing is voluntary and only 5,314 people have volunteered to be tested over a two-year period, it nevertheless indicates much lower infection rates in the general population.

Although injecting drug use is the main concern at present, it is recognised that sexual activity may also be a source of risk among this group. Moreover, drug use and the sale of sexual services are often associated. Hence, the life circumstances and marginalisation of sex workers necessitates specific prevention strategies, particularly, if they are also drug users.

Table B: HIV Prevalence Rates Among High-Risk Groups				
Survey group	Source	Year	N	% HIV-positive
Drug users and prison inmates	National Screening Programme in 27 drug rehabilitation centres and 33 prisons	1996	-	14.3
		1997	-	16.4
		1998	-	13.2
		1999	-	17.9
		2000	9,500	19.6
		2001	35,763	13.2
		2002	50,351	10.3
Drug users	National Screening Programme in rehabilitation centres in 11 states	2002	12,532	16.8
SWs	HIV Sentinel Surveillance Ad-hoc survey in Kuala Lumpur (65% transsexuals, 35% female)	1996	2000	6.3
		2000	208	11.5
Fishermen	Survey in Pahang, Perlis, Kedah (northern region)	1998	542	1.7
Long distance drivers	Survey in Pahang, Kelantan, Terengganu (east coast)	2000	906	3.7
Factory workers	Survey in Selangor, Negeri Sembilan, Melaka (west-central region)	2001	3,000	0.0
Sources: MOH (2004b), Ahamad (2004)				

By the same token, refugees and migrant workers are also considered population groups with special vulnerabilities and needs for treatment, care and prevention. Very little information is available on refugees and migrant workers in the context of HIV at present

although there are millions in Malaysia, a significant proportion of whom remain undocumented.

Rationale for project

There has been no published study on the impact of HIV/AIDS in Malaysia. The impact of HIV/AIDS manifests at both micro- and macro-levels. At the micro-level, impact includes the social, psychological, health and economic consequences for PLHIV and their families/care-givers. At the macro-level, HIV/AIDS can be positioned within a development context that has potential impact on various sectors, such as Education, Healthcare, Social Welfare, Population/Demography, Labour, Industry and Business Enterprise.

At the micro-level, the personal experiences of PLHIV related to their HIV and AIDS have been reported (e.g., Sam 2002; Zaiton 2002; MAC 1999). However, although these provide interesting and useful narratives, they have not focussed on the impact of the disease in a framework with policy considerations. The present study proposes a qualitative approach to systematically document and analyse the impact of the disease on infected and affected people's lives from various perspectives based on the different backgrounds of HIV transmission. In particular, the study will document the consequences of being HIV-infected in the context of individual, family and societal factors, including public policy.

Furthermore, a recent consultative report on obstacles in scaling-up the national response to HIV/AIDS identified, among others, continued stigmatization and discrimination, low participation of PLHIV in planning, implementing and utilising prevention and treatment programmes, and poor programme monitoring and evaluation (MOH 2006c). A study to document the various dimensions of the impact of HIV/AIDS on the personal lives and of affected families will provide the baseline information to strengthen and enhance strategies in the national response to HIV/AIDS. Similarly, a monitoring and evaluation (M&E) system is predicated on rational programme planning, which in turn, should be based on assessment of needs.

Within the rationale of this project are the underlying principles of:

- ❖ greater involvement of PLHIVs (GIPA) – to assess information from the target population in order to frame policies that can better address their needs;
- ❖ the growing feminization of the epidemic – to better understand the specific vulnerability of women to HIV and how they are infected from their partners and enable a gender-focussed perspective to the debates on HIV in Malaysia;
- ❖ Increasing access to HIV prevention, treatment, care and support – to comprehend the realities and barriers in the lives of PLHIV community and how policies affect them;
- ❖ the Three Ones approach - One comprehensive HIV/AIDS framework; One national HIV/AIDS authority with broad multisectoral support; One monitoring and evaluation (M&E) system integrated into the AIDS framework with a set of standardised indicators - by strengthening the information base towards a greater understanding of the processes and consequences of HIV/AIDS, beyond mere numbers.

Objectives

The specific objectives of this project are to:

1. construct a unique policy relevant information base on PLHIV and their families with their participation in all stages of the project;
2. promote an understanding of the processes and consequences for PLHIV and how these impact on their families and communities in which they live;
3. identify the unmet need of PLHIV and their immediate families/communities; and
4. document the treatment, care and support services (health, welfare, counselling, etc.) PLHIVs and their families are accessing and identify service gaps.

Three main activities will be undertaken towards the stated objectives:

1. A qualitative study to elicit personal perspectives from PLHIV on the processes and consequences of HIV/AIDS on their lives and that of their families/communities;
2. A rapid needs assessment survey of the needs of PLHIV;
3. A national dialogue with key stakeholders to disseminate the findings and promote the formulation of evidence-based policies/programmes with increased participation of PLHIV.

The UN Country Team organised an Inception meeting with relevant Government and non-Government agencies and groups on 10th March 2006 to inform, and gain input from, service providers, policy-makers and the PLHIV community. The research team gained critical input on study locations and potential sources of respondents at this meeting.

Methodology

Both qualitative (Focus Group Discussion and In-Depth Interview) and quantitative methods (survey) will be used for the two study components of this project. The study on impact of HIV/AIDS will be the qualitative component whilst the needs assessment will utilise a quantitative methodology. The quantitative component comprises a survey using a structured questionnaire in the appropriate language that is self-administered, or where necessary, by face-to-face interview. The studies will be subjected to an ethical review committee and informed consent obtained from all participants.

With regards to methodology, the basis for undertaking qualitative research for the study on impact of HIV/AIDS are as follows: First, a quantitative survey has the advantage of a bigger sample size, resources permitting, for drawing inferences to the larger population. However, in the Malaysian case, surveys on PLHIV will have constraints on their generalizability because of sampling issues. A random sample of known surviving persons with HIV could, theoretically, be selected from the existing MOH database of PLHIV. However, this is not possible because of confidentiality as well as availability of contact addresses or phone numbers. Secondly, a population-based survey (household survey) is unlikely to capture a random sample of infected persons since HIV status is most probably unknown for the majority as testing is routine only for certain groups. In

addition, the stigmatization associated with HIV promotes secrecy, hence many, if not most, HIV-positive persons will likely not disclose their status for a survey. Thirdly, Malaysia has a concentrated epidemic with relatively low prevalence in the general population; hence, very large numbers have to be canvassed to capture a random selection of infected persons. The anticipated problems, and resources required, in selecting a generalizable sample for a survey of PLHIV, and the absence of in-depth baseline information, suggest a qualitative approach to this study on the impact of HIV/AIDS. The advantages of a qualitative enquiry are the following (Ulin et al 2002; Sacket & Weinberg 1997; Dickerson 1997; Allen-Meures & Lane 1990):

1. elicits in-depth information from respondents that may uncover unanticipated causal factors, and reveal new research questions (exploratory, emergent and iterative processes)
2. provides the opportunity for respondents to speak about and discuss issues pertaining to the study with less constraint than a structured questionnaire, i.e., respondents are active participants rather than subjects
3. adds to the content and quality of data collected via a quantitative (survey) approach via a more in-depth understanding of actions and behaviours.

Among various qualitative methods, this study will utilise focus group discussions (FGDs) and in-depth interviews (IDIs) (face-to-face interviews), where preferred. The FGD will comprise 8 to 10 participants with one trained facilitator whereas the IDIs are conducted individually. Each FGD or IDI will take between one and a half to two hours.

Focus groups are a form of group in-depth interview that capitalises on communication among research participants in order to generate data (Kitzinger 1995). Focus group discussions or group in-depth interviews are among the most widely used research tool to examine people's experiences, and attitudes, with disease and of health services (Murray et al. 1994; Morgan 1988). A focus group takes advantage of the interaction within a small group of people as they express their own and respond to other's views in the group. A moderator or group facilitator stimulates and guides the discussion along the specific research issues or questions. In addition, a focus group discussion may have a note-taker who observes and reports on the proceedings, e.g., levels of interaction, participation and enthusiasm, group dynamics, dominant members, sensitivities, and non-response.

Defining impact

Impact is broadly defined as the constellation of events or situations arising after diagnosis and in the process of living with HIV. As mentioned, HIV/AIDS has a multi-dimensional impact at the individual, community and country levels. For the individual, the consequences of HIV include illnesses, long-term healthcare costs, income and opportunity losses from sick days, or forced withdrawal, from work/school and consequent unemployment, transport costs for medical and/or supportive care, psychological or emotional trauma, fear and anxieties, stigmatization and marginalisation, changes in inter-personal relationships and household structures (Krishna et al 2005; Mehta & Gupta 2005; AVERT 2005).

These aspects of consequences affect family members/caregivers as well, and in other ways, notably, fears of contagion, stigmatization, loss of the main breadwinner and/or family head, and changes in family dynamics and relationships. There are PLHIV who

have been rejected by their immediate families, in which case, a primary non-family member care-giver will be eligible as respondent in the Family group.

The issue of children infected or affected by HIV/AIDS is recognised. In this study, aspects relevant to children were explored in the FGDs from the perspectives of the HIV+ parent (all PLHIV groups) and care-giver (Family group). This issue will also be raised for the community respondents. Infected or affected children were not recruited as respondents in this study because of methodological and ethical reasons, e.g., need for parental/guardian’s consent, varying chronological and developmental ages, and problems of disclosure.

The various dimensions of impact for PLHIV and their families explored in this study are summarised below:

Table C: Dimensions of impact for PLHIV and their affected families	
Social	<ul style="list-style-type: none"> • Stigmatization and discrimination • Changes in family structure and relations – e.g., divorce/separation/death; children fostered or sent to other care-providers • Marital relations and/or marriage/remarriage • Friendship networks • Fear of contagion • Fear of disclosure • Spirituality/religiosity • Behaviour modifications • Resources accessed • Awareness of HIV-related policies and laws
Health – physical and mental	<ul style="list-style-type: none"> • Type and frequency of illnesses • Side-effects of HIV therapy • Anxieties over HIV drug treatment and associated costs • Guilt, depression, isolation, anger, retribution, rejection by loved ones • Concerns about opportunities for marriage and family life (if unmarried people) • Stress about infecting spouse and children (if married), and concern for their welfare • Psychological stress from having a chronic and fatal ailment (anxiety, insecurity, emotional trauma) • Loss of self-esteem and self-confidence
Economic	<ul style="list-style-type: none"> • Education (change in status and future opportunities) • Employment (change in status and future opportunities) • Income-generating potential • Career track/mobility • Cost of medical care (drugs, hospitalisation) • Financial aid/support (monetary or others) • Housing/shelter

The impact of HIV for the community differs from those directly involved or affected by it. As such, the content of enquiry for this group was focussed on their knowledge on and attitudes towards PLHIV, related HIV policies and programmes, expressions of stigmatization and discrimination, and issues related to prevention strategies. The FGD Guides used in this study are appended in Annexes III to V.

Defining needs

The needs of PLHIV may be organised at three levels towards the purpose of designing or targeting programmes (WHO 2003):

- ❖ Individual level, e.g.,
 - individual's social, economic, physical and psychological profile
 - Knowledge, attitudes and behaviours
 - Access to treatment (and other resources)

- ❖ Community level, e.g.,
 - characteristics of environment
 - community resources
 - social and family networks
 - traditional beliefs and cultural practices

- ❖ Structural or macro level, e.g.,
 - Socio-economic and political conditions
 - Laws and their enforcement
 - Religions and their influences
 - Health systems

At the individual level, there are various concepts of need, e.g., physiological, emotional, economic, security/safety, certainty/assurance, sense of belonging, contentment, self-actualisation, etc., that contribute to a state of well-being. A recent extensive survey of the needs of people living with HIV in the UK defined 18 areas of personal need (Weatherburn et al 2002) as shown in the Table below:

Table D: Areas of need	
1. Sex	11. Discrimination
2. Anxiety/depression	12. Mobility
3. Sleep	13. Dealing with health professionals
4. Self-confidence	14. Drugs and alcohol
5. Money	15. Relationships
6. Job opportunities	16. Taking treatments regularly
7. Chores and self-care	17. HIV treatment knowledge
8. Housing and living conditions	18. Looking after children
9. Eating and drinking	
10. Friendships	

A “need” can be defined as the gap between a person's current and desired states (Weatherburn et al 2003). However, Weatherburn et al (2003) caution that the measurement of this gap is not always clear-cut. A person's needs may increase or decline when (1) his/her current state changes *vis a vis* the same desired state, or (2) the current state is unchanged but the desired state changes. Thus, a person may feel (and

report) that his/her healthcare (or other service) needs are satisfactory not because the service is good (current state) but because his/her expectations of that service (desired state) have declined. This measurement issue has to be considered in interpreting findings from an enquiry into needs.

Focus Group Discussions on impact

Selection process

For the qualitative study, eight groups of infected and affected communities were identified as focal points of enquiry. These can be classified under three categories – (1) PLHIV, (2) Care-givers, (3) Community. Six are PLHIV communities and the latter two are affected communities. This selection is based on the profile of HIV in Malaysia, special interest groups (refugees and community), and family care-givers group as a proxy to gain perspectives on infected children and also to elicit their perspectives. Although HIV+ children are a rising concern in Malaysia, ethical and social (e.g., young age) factors preclude their direct participation in this research.

The list of FGD groups are summarised diagrammatically below:

FGD groups

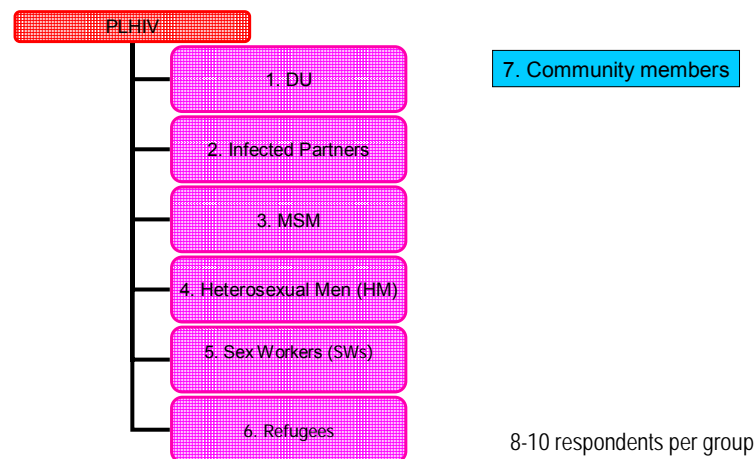


Table E: Definition of focal groups in study	
1. DU	HIV-infected person who is/was an injecting drug user or drug user
2. Infected Partners	HIV-infected person who was infected by a spouse or partner in a steady relationship
3. MSM	HIV-infected man who has sex with men
4. HM	HIV-infected heterosexual man
5. SW	HIV-infected sex worker - female or transgender (TG)

6. Refugee	HIV-infected person with refugee status
7. Community members	Lay-persons from the community (non-HIV infected or status unknown)

The eligibility criteria for the FGD participants were:

1. HIV infection diagnosed at least six months ago to allow for the experiences of coping, disclosing, seeking resources, and possible emotional trauma associated with these processes
2. Age range 20 and above for DU men
3. Age range 18 years and above for infected women partners and sex workers
4. Ability to hear and speak, hence, participate in a discussion

Participants were recruited through NGOs in the locations selected for this study. As such, all participants are clients/patrons/patients of these centres. This method of selection has its drawbacks but offered the only viable access to PLHIV communities. Each NGO source was given an honorarium for the use of their space and for recruiting participants.

FGD guide

Areas of impact that were explored in the focus group discussions were:

1. Health and healthcare issues
2. Social issues
3. Economic issues
4. Stigmatisation and discrimination
5. Experiences related to HIV policies and programmes, including desire to participate

At the same time, attempts were made to elucidate strategies of coping with HIV at the individual, community and structural levels. In summary, the specific topics explored on the impact of HIV for each group are shown in the Table below:

Category of FGD Group	Issues of impact
PLHIV (DU, MSM, SWs, heterosexual men, infected women partners, refugees)	<p>Physical health – including change in health status, side-effects of medications, health-promotive behaviour changes, alternative therapies, attitudes of and experiences with healthcare providers;</p> <p>Psycho-social – including changes in family and other relationships, emotional/mental health, sources of social support, family's or children's well-being, life concerns;</p> <p>Economic consequences – sources of income and financial support, access to resources, changes in household or personal expenses;</p> <p>Experiences with or perceptions of stigmatization and discrimination;</p> <p>Experiences related to HIV policies and programmes - HIV testing, ethical issues, awareness of policies, desire to participate in HIV/AIDS policy and programmes</p>

Community	<p>Knowledge/awareness of HIV and AIDS – sources of information;</p> <p>Perspectives on prevention and control strategies;</p> <p>Attitudes and perceptions towards PLHIVs - as neighbours, friends, co-workers;</p> <p>Expressions of stigmatization and discrimination towards PLHIV - attitudes to Government subsidized support</p> <p>Involvement with PLHIV</p>
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A flow chart was devised to assist moderators in conducting each FGD (Annex II). There are slight variations in the Guide for the Refugees to accommodate their specific circumstances in a host country. The FGD Guides are shown in Annex III to V. The FGD guide for PLHIV was pilot-tested and revised

For each FGD, confidentiality was assured by not collecting names or identification and disposing of the audio-taped discussions after transcribing and checking. All participants were informed of the purpose of the study, the measures to maintain confidentiality. Consent to take part in the study was elicited verbally and by participants' agreement to take part in the discussion.

FGD tapes were transcribed, checked, and additional notes from note-takers inserted, where relevant. Thereafter, each transcript was perused and codings, based on the research issues, applied using NVIVO Edition 3 (QSR 2002).

At the same time, each FGD participant completed the questionnaire to assess their needs. This questionnaire also collected their background socio-demographic data. The data were analysed using SPSS 14.0.

Framework of analysis

The analytical framework consists of:

A. Describing the consequences of HIV/AIDS on PLHIV and their families lives in the following areas:

- ❖ Physical and health consequences
- ❖ Social and psychological consequences
- ❖ Economic consequences

In terms of consequences, a specific focus was given to forms of stigmatization and discrimination in all the above areas. These were analysed in terms of perceived and experienced stigmatization and discrimination. This distinction has been otherwise described in the literature as 'felt stigma' and 'enacted stigma':

- Felt stigma - defined as feelings that individuals harbour about their condition and the likely reactions of others
- Enacted stigma - defined as the actual experiences of stigmatization and discrimination (Scambler & Hopkins, 1986; Jacoby, 1994 cited in UNAIDS 2000).

B. Analysing the above dimensions of impact by the following cross-cutting issues:

- ❖ Factors/situations that assist or hinder coping mechanisms
- ❖ Factors/situations that motivate self-help, and positive behavioural and attitudinal changes
- ❖ Awareness of policies, resources related to HIV/AIDS, and desire to participate in HIV/AIDS prevention, treatment and/or support programmes in line with GIPA initiatives

Survey on needs

Selection process

The same focal groups of PLHIV were targeted as respondents for this survey. As mentioned earlier, FGD participants completed the survey questionnaire to complement findings from a qualitative approach.

The eligibility criteria were similar to the FGD participants:

1. HIV infection diagnosed at least six months ago to allow for the experiences of coping, disclosing, seeking resources, and possible emotional trauma associated with these processes
2. Age range 20 to 50 years for DU men
3. Age range 18 years and above for infected women partners and sex workers
4. Ability to read and write (if possible)

In addition, additional questionnaires were distributed to NGOs which were willing to administer them to their clients. These NGOs were solicited through the Malaysian AIDS Council. Since most NGOs have limited time and manpower, only a few NGOs participated in this survey. Nonetheless, the additional data served as a means to substantiate the data from the FGD participants.

Questionnaire

In summary, the questionnaire for the survey focussed on individual needs from the following perspectives:

1. What are the respondents' current problems (health, social, economic)?
2. Are they receiving help/assistance for these problems?
3. For which problems would they like help or assistance (or further assistance)?
4. What are their major concerns?
5. Have they experienced stigmatisation and discrimination, and in what forms?
6. How have they coped with these forms of stigmatisation and discrimination?
7. Are they aware of resources for PLHIV?
8. Would they like to be involved with efforts related to HIV?

The survey questionnaire also includes a section on socio-demographic background (Annex V).

The questionnaire was designed to be self-administered, and was pre-tested and revised. Non-literate respondents were assisted by research members or NGO staff.

Data were checked and coded for analysis using SPSS 14.0 (SPSS Inc. 2005).

Framework of analysis

A descriptive analysis was carried out on the data from the survey to assess the needs of PLHIV communities as a whole, and to determine any specific needs of focal groups, namely, DU, SWs, infected women partners, MSM and heterosexual men.

Ethical review

The study project proposal was submitted to the University Malaya Medical Centre Ethical Review Board for review. Ethical approval was obtained prior to commencing the study (Annex VI). Prior to starting each FGD, participants were:

1. informed of the background and purpose of the research
2. reminded that participation was voluntary
3. assured that data from the discussions and questionnaires would be kept strictly private and confidential for use only by the research team
4. assured that participants' identities would not be recorded (anonymous)
5. explained that discussions would be audio-taped and that tapes would be destroyed after transcribing
6. explained that there were no right or no answers and that each had the right not to respond or discuss issues with which they were not comfortable

When participants had affirmed that they understood, consent was obtained from them verbally at the outset of each FGD. For the needs assessment questionnaire, a cover letter was attached explaining the background and purpose of the survey. No names or personal identifiers were obtained from participants.

Problems and constraints

Except for DU men, a major problem in the qualitative study was getting participants especially among sex workers, MSM and heterosexual men groups. Without exception, all the NGOs that were approached to recruit participants and facilitate the organising of venue and refreshments were extremely helpful, for which the project team would like to record their sincere acknowledgement of thanks.

Overall, IDU men proved to be the easiest to recruit and the most vocal during discussions. The reasons for this can only be speculated. A possible factor is that their involvement with the specific NGO (PENGASIH) has nurtured a sense of empowerment and coping with the infection, resulting in a willingness to talk and share. It may also be related to their drug-using history and consequent acceptance of self-blame for being infected. Another factor may be that they are male, who may be more easily forgiven, or excused, than women for undesirable social behaviours, such as drug use. In contrast, women partners were less vocal in the FGDs compared to men. In fact, for one group in Kita Baru, the feelings of shock and dismay, arising from their being infected by their own husbands whom they loved and trusted, were still palpable with most women breaking down emotionally regardless of how long ago they were diagnosed.

In Kuching, there were logistic problems in recruitment as some patients who were contacted to participate in this study lived long distances away from the FGD venue. Sex workers in Sabah also needed a lot of persuasion to come forward as they were no longer doing commercial sex work and wanted to leave that past behind.

At the outset, a Family care-givers group was included for the FGDs. The criterion for this group was a main care-provider for a HIV-positive person (or child) who is not HIV-positive. The premise was that HIV-positive persons who are care-givers to other HIV-positive family members, notably children, would be captured in one of the other groups. This was intended to recruit family members, including grandparents or adoptive parents, or friends who have taken on the care of one or more HIV-positive person(s) whose usual care-giver has, or care-givers have, died or abandoned them. It was particularly aimed at care-givers of HIV-positive children. Since such participants may not be clients of NGOs which provide services to PLHIV, the approach was through doctors of HIV patients. However, despite trying for several weeks, there were no participants who fit the criterion and who were willing to take part in a discussion.

Another problem that arose for the FGDs was the selection criteria. Despite specifying the criteria to contact recruiters, a few participants who turned up did not meet all the criteria, e.g., duration since diagnosis and age. It was desirable to have an age ceiling of 50 years so as to minimise the confounding effects of age on the various dimensions of impact, notably, physical health. However, several who turned up for the FGDs were slightly above this age-group. Possibly, this older group is the one who has more free time or more flexible hours. The criterion of more than six months since diagnosis, as mentioned earlier, was to avoid those in the early stages of HIV diagnosis and its associated experiences and emotional state. In terms of eligibility, the research team also met with two participants who had speech impediments; one due to stroke and another due to a problem with her tongue. Since the team relied upon contact persons to recruit participants, and in turn, since contact persons do not have full control over who finally attends, these situations were difficult to control.

There were frequent problems of literacy and, in particular, the ability of participants to complete the short needs assessment questionnaire. Although initially designed to be self-administered, many PLHIV could not fill out the questionnaire on their needs without assistance from project team members.

The survey on needs was intended to be disseminated to all the organisations which provide services to PLHIV communities. The Malaysian AIDS Council was contacted to gain access to their partner organisations for which they were very helpful. However, while there was interest in carrying out the survey, manpower limitations prevented many organisations from participating. Although the survey was intended to be self-administered, service providers found that they had to assist respondents. Hence, the survey did not capture as many respondents as planned, i.e., all clients at participating service providers for a one month period.

Summary profile of study participants

By end of September, a total of 19 FGDs were conducted with 93 participants from PLHIV communities. The FGD participants also filled out a needs assessment questionnaire. In addition, four FGDs were conducted with men and women from an

urban and a rural community. In all cases, the assistance of relevant NGOs was solicited in recruiting participants. A summary profile of the FGDs by focal group are summarised in the Table below. More detailed background characteristics are described in the section on the needs assessment survey:

Summary profile of FGDs (June-September 2006)				
Focal group	Locations* (n)	N	Age Range (yrs)	Ethnicity
DU men	KL (8) K Baru (10) B Arang (10)	28	25-51	17 Malay 6 Chinese 4 Indian 1 Eurasian
Infected women partners	KL (3) K Baru (5) Kuching (8) K Kinabalu (6)	22	23-46	7 Malay 3 Chinese 3 Indian 5 ethnic Sarawakian (3 Bidayuh; 1 Iban) 4 ethnic Sabahan (2 Kadazan; 2 Dusun; 1 Rungus)
Sex workers: Transgender	KL (1) KL (7)	8	29-53	6 Malays 2 Indians
Sex workers: Women	Kuching (5) KL (8)	13	23-54	1 Malay 6 Indian 5 ethnic Sarawakian (4 Bidayuh; 1 Iban) 1 Orang Asli
MSM	KL (8)	8	24-48	8 Chinese
Heterosexual men	KL (8)	8		8 Chinese
Refugees	KL (7)	7	24-40	7 Myanmar Chin
Total PLHIV		94	24-54	32 Malay 25 Chinese 14 Indian 1 Eurasian 1 Orang Asli 9 ethnic Sarawakian 5 ethnic Sabahan 7 Myanmar Chin
Community - Women	Penang (10) Johor Baru (8)	36		14 Malay women 2 Chinese women 2 Indian women
- Men	Penang ((10) Johor Baru (8)			15 Malay men 2 Chinese men 1 Indian men
TOTAL		130		

* B Arang – Batu Arang, Selangor; KL – Kuala Lumpur; K Baru – Kota Baru, Kelantan; K Kinabalu – Kota Kinabalu, Sabah

** na – not applicable

Findings from the FGDs: “How HIV affects our lives”

Health impact

Physical health

The FGD participants varied in the length of time since their diagnosis from less than a year to more than 10 years. Hence, some have not sensed any difference in their physical health since diagnosis. In addition, except for one FGD among DU men, all the discussions were convened in a convenient and appropriate venue at which participants gathered. Thus, participation was relatively confined to those who were mobile and had the means to get to the venue. Contact persons from NGOs and hospitals who assisted in recruitment were very helpful in assisting participants with transport arrangements.

In fact, several of the participants, men particularly, could cite their CD4 count and provide this as the basis for their relatively good or unchanged health status thus far. However, for one person there is an expectation that his health could decline in the future. Others ascribed HIV drug therapy for considerable improvements in their health.

Some participants were tested following their spouse's or partner's diagnosis upon advice by doctors, or were tested in prison or a rehabilitation centre, while others were tested by their doctors based on symptoms, during antenatal care or medical check-up. Only one DU man and one infected wife volunteered to be tested because of their perceived exposure through drug use and husband's drug use, respectively. Those tested because of their symptoms more often than not had severe illness involving weeks in hospital. They suffered severe weight loss, extreme weakness, high recurring fevers, profuse night sweats, loss of consciousness, severe headaches, white (fungal) growth on the tongue and skin rash. Prior to her husband's diagnosis and death shortly after, one woman (Infected Partner) spoke of the crippling headache he suffered for several weeks. Despite several clinic and hospital visits, doctors were not able to provide any treatment or even a diagnosis.

In summary, many of the participants reported a range of health complaints currently or at some time after their diagnosis, namely:

- Fatigue
- Weight loss or loss of appetite
- Feeling hot
- Sleeplessness
- Need/desire to sleep more
- Frequent headaches
- Poor recall (memory)
- Reduced ability to concentrate/focus on a task
- Depression
- Tuberculosis (TB)
- Diabetes
- Stroke
- Ovarian cancer

Indeed, sleeping and eating problems were also the most commonly cited in the Needs Assessment questionnaire filled out by each participant. For many currently on HIV

medication, the physical health complaints they suffered reduced considerably after starting treatment. It is noteworthy that women infected by their husbands voiced a wider range of complaints than those in other groups, including, ovarian cancer, stroke, diabetes, thyroid dysfunction, severe headaches and depression.

By far, the most common health complaint was fatigue, tiring easily or having much lower energy levels than before. Sleep disturbances – either needing a lot more sleep or, in contrast, difficulty sleeping - were also relatively common and may be associated with the problem of fatigue. This physical effect was voiced by several men and women:

“The energy is not there. I don’t know how.... I don’t know how to put my energy forward [raise energy levels] already. But when I was not infected that time... in games... the exercise anyhow also, I don’t feel tired.”

(Male, 49yrs, University education, DU)

“Macam saya dulu, sebelum dapat ini sakit macam... ok je. Macam kuat...tidak cepat lelah, naik bukit pun tidak lenguh, mahu angkat barang pun..... tidak rasa sangat. Tapi sekarang, naik bukit sikit - rumah saya naik bukit - naik sikit pun macam putus saya punya nafas.”

“Previously, before I got this illness... I was OK. Like strong.... Not easily breathless, don’t get sore muscles from walking uphill, lifting any thing....don’t feel it much but now, going uphill - my house is up a hill - even a little way, like I get breathless.”)

(Female, 46yrs, Upper secondary education, Infected Partner)

“I also got the same experience like howdifficult toto tell the doctor what is the problem. Something is going wrong....but cannot tell in a word....you know. Feel very weak....very weak. Sometimes sleep so many hours.....but sometimes cannot sleep. By the time we go to work, then the performance is not good....but not the emotion make the trouble but, physically....cannot handle it.”

(Male, 31yrs, Upper secondary education, MSM)

A few specifically mentioned problems concentrating or focussing their thoughts or drifting off:

“Sebelum tu memang I... kalau I baca satu cerita tu, besoknya 90% I boleh cerita dengan orang... but now 50/50.”

“Previously, it’s true if I read a story, tomorrow I can relate 90% of it to peoplebut now 50/50”)

(Transgender, 27yrs, Primary education, Infected Partner)

“I’m sitting right in front of the computer and typing. My mind is shut off but my hand still typing...and by the time I...I...realise what I’m doing, right? On the computer screen is all garbage.....and I’m just typing garbage.”

(Male, University education, MSM)

However, one male respondent suggested that this symptom may be psychosomatic since most do not know when they were infected; merely when they were diagnosed. He postulated that, if HIV caused such a physical effect, it should have been apparent even before diagnosis. While this could be the case, it is also possible that duration since onset of infection plays a part in the physical impact of HIV.

Several of the participants are on HIV medication. As mentioned earlier, they noted how much better they felt after starting their drug therapy. Only one (Infected Partner) said she did not feel any different, although she understood that she needed to continue taking it. However, some suffered, or continue to suffer, side-effects. For one, a refugee, this necessitated up to four changes in the drug regimen, for another, the addition of pills to aid sleep. These side-effects included gastric pain after taking the pills, quick temper, skin redness, loss of appetite and weight loss:

“....didn’t have time to prepare.....the moment I went to see the doctor in UH [Universiti Hospital], they said my CD4 was already 149.....have to start the medication. So....no time to do anything, just start the medication....but over the period of recovering, the CD4 was going up, there would be lots of things happening within body – rashes and high fever....sweating at night....things like that. So, basically, I just handle things as it comes alongface each thing when it presents itself. We just manage it...with fever, then, I will use Panadol, when it is night sweat then I change my t-shirt or I put a towel around my neck.”

(Male, 46yrs, University education, MSM)

For one woman (Infected Partner), Stockrane made her dizzy – a feeling of being “high”. Some of these effects are documented in the literature (Aidsmeds.com 2006). Another woman (Infected Partner) suffered an unusual side-effect which, in itself, was traumatic for her and her family:

“Orang lain makan ubat putih... saya makan ubat semakin hari semakin gelap... hingga dua bulan, saya tak keluar daripada rumah... tak keluar.... Kerja pun saya berhenti. Sekarang saya tak buat apa apap....pasal wajah saya hitam, bukan sebab lain. Wajah tersangat hitam; cuma gigi sahaja yang putih.”

(“Others take the medication become paler... I took it and got darker by the day.... Up to two months, I didn’t go out of the house....didn’t go. I even stopped working. Now I don’t do anything.....because my face turned black, not for any other reason. Face too black; only my teeth were white.”)

(Female, 39yrs. Lower secondary education, Infected Partner)

Most of the side-effects, however, were not lasting ones as they became accustomed to the drugs or changed their regimen.

When probed, some of the participants who currently have a regular partner, notably spouse, reported reduced sexual activity following HIV diagnosis. Reduced frequency of sexual relations appears to affect women more than men. Many of the infected wives who are still with their HIV-positive husband either no longer have sexual relations with him or only occasionally. For some, this situation preceded HIV diagnosis because of

husbands working in other places whilst for others, it was specifically due to HIV diagnosis:

“After diagnosis, aaah....sexual activity also slower.”

(Male, 40yrs, University education, DU)

“I was very long time have not slept with him....because....almost two to three years.... He was in Kuching”

(Female, 37yrs, Primary education, Infected Partner)

“Seldom....not feeling [after HIV diagnosis]”

(Female, 43yrs, Primary education, Infected Partner)

One DU, however, reported improved sexual activity because he now was no longer on drugs and has recently married; his drug dependence caused him to lose interest in sex. In fact, it was evident that HIV-infection does not deter marriage prospects entirely. One woman among the participants had remarried a HIV-uninfected man after the death of her HIV-infected husband and two HIV-infected male participants had married HIV-infected women. In all cases, the prospective spouse had knowledge of the partner’s HIV status.

Healthcare issues

All the FGD participants have access to regular healthcare, primarily in Government hospitals, including the refugees. Not all of the participants are on medication, however. As mentioned previously, the FGD participants were all recruited via NGOs, and the UNHCR (United Nations High Commissioner for Refugees) in the case of refugees, hence, they have assistance in obtaining healthcare. The majority receive medical care from Government hospitals; either under the Ministry of Health or University hospitals, either fully or partially subsidised.

With regards to the quality of care, most participants were very happy, and even moved by, the care they have received, or are receiving, from the medical specialists in hospitals:

“The doctors in GH, I really salute them! They know how to be sensitive, even to your feelings. They will come and look around but they’ll never disinfect their hands in front of you.....to avoid you feeling ostracised.”

(Male, 44yrs, Upper secondary education, DU)

“*Sejak saya jumpa Kak M [Registered Nurse in Infectious Diseases] and Doktor M [Infectious Disease specialist].....mereka ini lah yang beri semangat.*”

(“Since I met Sister M, Doctor M...they are the ones who give me courage.”)

(Female, 39yrs, Lower secondary education, Infected partner)

“*I pergi hospital dekat [mentions hospital location], I get counselling from...[mentions name] ahh....then from there I masuk balik hospital. Dia bagi I ubat...tak....ahhh....bagi I penerangan yang lebih tentang benda ini. And then, the doctor yang...yang merawat saya, doctor yang bagi banyak*”

semangat, macam [mentions doctors' names].....ahhh doktor doktor tu, dia bagi semangat.”

“I went to hospital at [mentions hospital location], I got counselling from...[mentions name] ahh...then, from there, I was re-admitted into hospital. He/she gave me drugs.....not...ahhh....give me more information about this thing. And then, the doctors....who treated me, doctors who gave me lots of courage, like [mentions doctors' names]....ahhh....those doctors gave me courage.”)

(Transgender, 53yrs, Upper secondary education, SW)

“Dia [doctors] akan cakap banyak kali lah....suruh kita.....nasihat kita makan ubat betul betul.....jaga pemakanan. Kalau tidak, dulu sekejap je buat pemeriksaan.....sekarang OK.”

“They [doctors] will say many times....tell us.....advise us to eat medicine properly.....take care of nutrition. Before, they would only make a quick examination, now OK.”)

(Transgender, 32yrs, Lower secondary education, Infected Partner)

“When I was first...when my doctor first saw me, he was a very decent doctor, you know - Doctor [mentions name). So, he was telling me....straight to conclusion....said, don't take this as a punishment from God.”

(Female, 54yrs, Lower secondary education, SW)

In Kuching, participants appeared to be happy with both doctors and nurses as their healthcare providers:

“Dari dulu sampai sekarang,,,misi [nurses] bertukar tukar pun semua bagus.”

“From before till now.....even the nurses keep changing, all are good.”)

(Female, 39yrs, Lower secondary education, Infected Partner)

“They are very good, they give us support. Only the people here know about us, not the people outside.”

(Female, 34yrs, Primary education, Infected Partner)

There were a few participants who had grievances. Two participants spoke of doctors who shattered them emotionally by estimating their survival:

“Lepas tu, seorang doctor tu, dia sahkan saya boleh hidup dalam tiga bulan. Mulalah saya fikiran ni....betul ke Mak? Boleh dalam masa.... .oooh... .beritahu hidup tiga bulan. Tak sempat nak membersarkan anak anak! Tapi saya fikir juga...sampai sekarang ni...saya jumpa doctor tu.....saya lagi terkilanlah – takut.yang ada semangat, tak ada semangat terus.”

“And then, this doctor, he/she verified I would live up to three months. I started to think.....could it be true, Mother? In that time....tell me [I have] three months to live. No time to raise my children! But, at the same time, I thought....until today...I meet that doctor....I’m still not content – afraid.what courage I had was totally gone.”

(Female, 39yrs, Lower secondary education, Infected Partner)

“I ada dua kawan daripada Kedah, seorang daripada Merbok dekat Gurun. Seorang lagi dekat Sungai Petani, aaah.....so, dia orang kat sana....macam doctor bagi tau dia....I rasa you ada enam bulan lagi.”

“I have two friends from Kedah, one from Merbok near Gurun. Another near Sungai Petani, aaah...so, over there, there....like their doctor told them....I think you have six more months.”

(Transgender, 27yrs, Primary education, Infected Partner)

A few others complained about insensitivity on the part of doctors while providing treatment, notably, explicitly demonstrating their fear of contagion by avoiding contact or reluctance to treat. These are described in the section on stigmatization and discrimination. However, there was one experience that not only was humiliating but also exposed the patient’s HIV status to other patients with negative consequences:

“The doctor came with his practical students to make a routine morning check, and look at patients’ medical reports [charts]. When he came to my bed, he shouted out when he looked at my medical report. He said, loudly, in Cantonese, ‘Do you know you are diagnosed with AIDS? Do you feel like dying? If you don’t feel like dying, ask your relatives and your family members to pay for your medicine; about RM706 each month!’ The medicines at that time were TTD and D40 and cost about RM706. Then, the other patients started looking at me strangely and never gave me help any more. None came to visit me and none buy me fruit.”

(Male, 36yrs, Primary education, Heterosexual)

One participant talked about the tiresome and frustrating process she and her husband experienced before HIV diagnosis was finally made. During this time, her husband endured much pain and discomfort, and his family the consequences of it:

“Lepas tu, saya pergi Hospital USM. Lepas tu, USM hantar saya....Hospital Kota Baru. Doktor check semua....doktor kata tak ada penyakit. Doktor suruh balik..... Lepas tu, makin hari, makin teruk, kita bawa lagi ke....ke Kubang Kerian [Hospital USM].....sama juga. Doktor suruh balik. Lepas tu, di kampung saya ada seorang doctor. Saya pergi klinik dia lah....masa tu juga dia suruh saya pergi hospital. Tiga kali saya ke Kubang Kerian.....doktor kata tidak ada penyakit. Lepas tu, hee, dia semakin teruk lah....sampai tahap dia tidak boleh bangun. Saya panggil lagi doctor di kampung saya tu.....mmm....dia tanya saya masa saya pergi Klinik Kubang Kerian tu. Dia [doctor Kubang Kerian] kata macam ni....dua minggu lagi awak pergi jumpa dengan doctor kaunselling - doktor sakit jiwa dia kata. Kemungkinan suami awak ni....aaaa....macam nakarah.... macam ke arah tak siuman.”

“Then, I went to USM Hospital. Then, USM Hospital sent me to...Kota Baru Hospital. Doctor checked everything....doctor said there is no illness. Doctor told us to go home. Then, day by day, he got worse. We took him to....to...Kubang Kerian.....same thing. Doctor told us to go home. Then, in my area there is a doctor. I went to his clinic....he immediately told me to go the hospital. Three times I went to Kubang Kerian.....doctor said there is no illness. Then, hey, he deteriorated.....to the extent that he could not get up. I called the local doctor again.....mmm....he asked me about the time I went to Kubang Kerian. He [the doctor] told me like this....in two weeks time, you go and see a counselling doctor – a psychiatrist he said. It’s possible your husband.....aaaa.....he’s like....heading towards....like, towards insanity.”)

(Female, 46yrs, Upper secondary education, Infected Partner)

Her local doctor then prescribed anti-depressants on the suspicion that her husband may be worried about personal debts. However, she did not give her husband the anti-depressants as she was convinced that depression was not his problem as she knew he had no debts. She felt it may be an infection in his brain. She went again to Kubang Kerian and, after being told yet again, to go home as there was nothing wrong with her husband she finally broke down in tears and begged the doctor to admit him. Only then did doctors do a more thorough examination and, thereafter, suspected HIV and confirmed the diagnosis. Her husband died shortly after. She was tested after HIV infection was confirmed in her husband, as was their youngest child when he became ill and hospitalised for a week. Fortunately, her child was not HIV-infected. The experience caused her much anguish then and, although her husband passed away a few years ago, it was evident during the FGD that recalling it still distressed her.

It is possible that if a patient is not suspected to be in one of the high-exposure categories to HIV, i.e., drug user, sex worker or MSM, then HIV testing is not included in the battery of routine diagnostic tests. This brings to question how many such patients with HIV may be missed if they, knowingly or unknowingly, decline to disclose their potential risk of exposure. For example, those with multiple sex partners may not perceive themselves at high risk of any sexually transmitted infection on the assumption that their sex partners are not sex workers or drug users or have other casual sex partners.

While many participants tended to be complimentary, and appreciative, of the care they receive from their doctors, several participants complained about the treatment they have received from nurses:

“They [their doctors] really understand, you know, about....the....the difficulty that we are going through with the disease but the nursesare.....terrible!”

(Male, 36yrs, Upper secondary education, DU)

“They [nurses] only see the HIV....when....when we are there. They only see the HIV inside us but they don’t see the human. We can see patients lying on the bed, you know, with the....diapers, you know, because they are bed-ridden cases. They cannot move. We thought [they’ve] not [been] changed for a few days, you know, one day, two days. And even like now,

their food. Nurses and their attendants are never bothered to see whether they have eaten their food, taken their medication. That part [of] treatment is considered very important. But, even that, it's....for them, is nothing. Everything - they are not bothered to check and the patient dying there. He cannot eat by himself. He cannot drink by himself and he'll be dying there and it's only because he is HIV positive."

(Male, 36yrs, Upper education education, DU)

"Dekat hospital, apa yang saya lihat.....orang pun aaah.....nurse atau attendant atau masyarakat lain lah. Dia ini....aaahh....tahu tentang AIDS dan HIV. Dia tahu tapi dia tak yakin. Dia tak yakin apa yang dia belajar."

("In hospital, what I can see....people....nurse or attendant or other members of society. They know about AIDS and HIV. They know but they are not convinced. They are not convinced about what they have learned.")

(Male, 32yrs, Lower secondary education, DU)

One participant was admonished by a nurse for getting pregnant by her HIV-infected husband. More importantly, she felt that the Army, with whom her husband was serving, knew of her husband's HIV status but did not inform her that he was HIV-positive and neither did he:

"Lepas tu, nurse dekat situ [hospital] cakap – apahal you mengandung? Kamu tak tahu kah suami kamu HIV? - dia cakap kan. Masa itu, suami saya masih army lagi, kan, dekat Johor sana. Aaah..masa tu kan, saya terus....dia orang belum check darah saya lagilah, cuma memang dari suami. Sebab tentera ni....army – dia memang tidak berapa bagi tahu, kan. Aaah...masa saya mengandung, saya tahu."

("After that, the nurse there said – for what reason did you get pregnant? Didn't you know your husband has HIV? – she said. At that time, [my] husband was still in the army, there in Johor. At that moment, I immediately....they hadn't checked my blood yet, only certain [it was] from [my] husband. Because the army....army – they actually don't tell much, right. When I got pregnant, I found out.")

(Female, 36yrs, Upper secondary education, Infected Partner)

There were concerns about breach of confidentiality by nurses and other healthcare staff as well:

"When we go to the registration, you know, the card....'Oh, HIV patient', he said out loud, you know.....and there are people around."

(Male, 44yrs, Upper secondary education, DU)

"Sebab saya.....aaah....pernah dimasuk di wad hospital Kota Baru dalam tiga minggu, rasanya, situ ada masalah sikit dari segi jururawat. Dia suka suka bercerita tentang kita ni kepada orang."

“As I’ve been admitted to the ward in Kota Baru Hospital [for] about three weeks, I think, there was a little problem there on the part of the nurses. They like to tell stories [talk] about us to others.”)

(Male, 39yrs, University education, DU)

“Yeah, private hospital. So my boss sent me to the hospital and everything and aaah.....when I was diagnosed for HIV ah..... my surprise is ah..... my doctor told my boss and that I was HIV positive. After one week I went to work, you know, my boss call me inside and then wrote two cheques and then he said, “This is your salary and this.....this is you know, something I want to give to you”. And then he said ah.... “I give you a choice lah since you having HIV all the other staff are not comfortable working with you. So, maybe you can write a resignation letter”. Then I told him, “Boss, this is not a choice!” I wrote the resignation letter and finish.....”

(Male, 36yrs, Upper secondary education, DU)

In fact, there are administrative practices that have the effect of subverting any policy or law on confidentiality with regards to HIV. In this study, participants complained about the differentiation of their hospital record files by colour at the clinic they attend – one colour for HIV patients and another colour for all others. It goes, literally, without saying, that this reveals their HIV status. The same applies to the segregation of HIV-infected patients in the ward and, and in prison following inmates’ diagnoses. The sex workers in this study who have been in prison said that, at that time, their food trays were marked with the words “HIV”. The segregation itself discloses their status to other prisoners. While this may protect them from other prisoners, particularly for men, the problem trails them when they are released because fellow inmates know of their status and tell others outside about their HIV status.

Health behaviour

Since all of the participants were recruited through NGOs, most have access to healthcare services and regular medical check-up. Healthcare services are obtained at Government hospitals for the most part. Men, in particular, seem to regularly monitor their status and are aware of their CD4 count. This includes refugees who obtain medical care from the General Hospital Kuala Lumpur (GHKL).

The exceptions are sex workers and active drug users. Although they use facilities (drop-in centre or shelter) provided by NGOs, it was evident that SWs and DUs do not seek healthcare regularly. Some of the SWs are active drug users as well. They tend to seek healthcare only when they fall ill:

“Kalau saya sakit, saya pergi Ikhlas [NGO] je lah – ambil ubat.”

(“If I’m sick, I’ll go to Ikhlas – pick up medicine.”)

(Female, 40yrs, Primary education, SW)

“Sebab kita hisap dadah mah....tak ada masa nak pergi hospital!”

“Because we take drugs...no time to go to hospital!”)

(Male, 36yrs, Upper secondary education, DU)

There were very few complaints about adhering to the strict drug-taking schedule, even during fasting month with the necessary adjustments. In fact, only one woman experienced a problem remembering to take her medication on time, and this was while she was working.

Infected women and children are provided with fully subsidized HIV drugs, as per national policy. However, there were accounts of people in other groups, for whom medication is only partially subsidized, who stopped taking their medication because they could not afford it. Prices they paid ranged from RM90 or RM140 per month to RM250 for three months' supply. One mentioned a drug treatment price of RM706 per month. One or two DU men had access to HIV drugs that were given free on a clinical trial basis but this free “trial” supply has continued for more than five years. A participant in Kelantan noted that, in the past few months, the hospital in Kuala Trengganu provided all drugs free to HIV patients, regardless of mode of transmission. In fact, a few participants reported that all drugs are now provided free where before they had to pay for one or more.

Not many participants used traditional medicines or alternative therapies. A small number mentioned that they heard of traditional therapies but none were taking any at present. One mentioned knowledge of someone taking a herbal medicine which cost RM1000 a bottle from Terengganu. How much quantity this bought or how long it lasts for was not known. Another DU participant said he tried a traditional drug for three months but, after finding no benefit, went back to modern drug therapy. Although spiritual healing is known to be popular in Malaysia, only one woman in Kuching drank water blessed by a spiritual/religious healer.

In terms of supplements and diet, a few participants, mainly women, expressed conscious efforts to take supplements or make dietary changes in light of their HIV status. A few said they tried to consume more vegetables, especially green vegetables. One young woman, with tertiary education, said she looked out for food supplements specifically to boost her immunity. Such food supplements, she added, are not cheap. Another concurred by noting the price of one supplement as RM500 a bottle (Elken?). Two others, respectively, took spirulina and a blood tonic. A few others, including from other groups obtained vitamins from the hospital where they get treated. None of the women SWs who are still doing business consume vitamins or other health supplements.

None of the Chin refugees are aware of any traditional therapy or supplements. Only one refugee was prescribed vitamins by his doctor but, at that point, had not started taking it since his doctor did not tell him when to begin. Whether this was a result of a language barrier between a doctor and a foreigner, or simply an oversight on the doctor's part, it is a useful reminder of the importance of clear communication by healthcare staff as patients follow instructions on their medications implicitly.

In terms of other health and lifestyle behaviour, a few of the participants were active drug users; primarily women sex workers followed by DUs. It is interesting to note that all the sex workers who are drug users or drug dependent were introduced to drugs by their husband or boyfriend. While alcohol consumption was not common among the

participants, one woman sex worker admitted that she had a problem with alcohol abuse. This was the reason her children (all adults) ended their relationship with her years ago, and how she began doing commercial sex work.

Condom use

Use of condoms was specifically probed in the discussions based on its protective function in sexually transmitted infections. Among the women participants, none of the infected women partners, who are currently without a partner due to death or separation, claimed to be sexually active. Hence, the question of condom use does not arise. Among those who are sexually active, there is awareness of the need to use condoms for protection. With no exception, all the men with a regular partner, notably, spouse, reported using condoms every time they have sex:

“For sex....is only condom. No other way of protection.”

(Male, 42yrs, Primary education, Heterosexual)

“This is for protecting our partner from being infected....because we have been told by those doctors and counsellors.”

(Mae, 36yrs, Primary education, Heterosexual)

“*Kena ada....kena ada. Kena pakai kondom....mesti pakai.*”

(“Must have....must have. Must use condoms....must use.”)

(Male, 39yrs, University education, DU)

One woman (Infected Partner), however, remarried after the death of her husband. She said she informed her new fiancé, who is not infected, prior to marriage but he was willing to marry her any way. However, despite knowing the risks of infection, and advised by their doctor each time he went for a screening test, he did not use condoms until after their child was born. Both husband and infant, presently, are not infected:

“*Kalau macam saya.....saya memang honest. Memang saya bagi tahu sama ada dia terima kah atau tidak. Kekadang tu.....actually kan, mula mula tu kan, saya ada perjanjian dengan dia. Saya harap perjanjian kami kan.....sex protection.....pakai kondom itu kan? Tapi last-last, sebelah suami ni tidak mahu pakai kondom. Rupa rupanya kan....motif nya tidak pakai kondom pada awal tahun 2001. Lepas sekarang baru dia mahu pakai kondom. Tapi...skrin, skrin, skrin....masa negatif tu kan, doctor cakap mesti pakai kondom. Bila dapat anak satu kan, terus dia [pakai].*”

(“Like me....I’m actually honest. In fact, I asked him whether or not he can accept. Sometimes....actually, initially, I made an agreement with him. I hoped we agree to....protected sex....use condoms right? However, in the end, my husband did not want to use condoms. It turned out...his motive was not to use condoms beginning of 2001. Now, he wants to use condoms. But....screen, screen, screen....at that time. Negative, doctor said we must use condoms. After we had one child, he immediately [started using condoms]”)

(Female, 30yrs, University education, Infected Partner)

The same claim to 100% condom use was not echoed by women, however. A few have husbands who still refuse to use condoms every time they have sex:

“Tapi tidak selalu. Kadang kadang.....dalam satu bulan ada dua kali, macam tu lah.”

(“But not often. Sometimes....in a month, may be two times, like that.”)
(Female, 35yrs, Primary education, Infected Partner)

“Dia tak mau pakai....itu celaka tak mau pakai!” [laughs] “Ya, saya tak mau bagi....dia gaduh sama saya. Saya malu! Dia punya mak ada, dia bapak ada....dia tanya apa lu dua orang bilik dalam gaduh. Macam masa saya boleh kasi tau dia orang? Saya malu. Aaah.... Saya cakap kalau lu.....lu....gatal, lu cari lain lah! Pergilah! Pergi Chow Kit lah....jangan kacau sama saya!” [All laugh]

(“He doesn’t want to use....that damned [one] doesn’t want to use! [laughs] “Yes, I don’t want to give [have sex].....he fights with me. I’m embarrassed! His mother is there, his father is there.....they ask, why are you two fighting in the room. How can I tell them? I’m embarrassed. I told him if he is aroused, go look for someone else! Go! Go to Chow Kit [a red light district in KL]... don’t disturb me!”)

(Female, 44yrs, No formal education, Infected Partner)

“Sebab lelaki ni memberi.....kita yang menerima. Apa? Lelaki juga yang puncanya.”

(“Because the man gives....we receive. What? Man is still the source.”)
(Transgender, 32yrs, Lower secondary education, Infected Partner)

Sex workers, on the other hand, reported poor use of condoms despite their HIV status and awareness of the need for protected sex. The SWs recruited in this study were all direct sex workers⁵ who primarily are/were street walkers. However, their usual place of business is in a rented room where condoms commonly are placed in a bedside drawer. It should also be pointed out that the sex workers who were vocal about condom use in this study are above 30 years of age with low education. Other characteristics of the sex worker, e.g., younger age, higher education or higher-priced sex, or characteristics of the customer base, may influence condom use. In addition, some of the sex workers in this study are also drug users. While drug addiction adds to the problem of having unprotected sex, it is clear that the primary reason for not using condoms is reluctance or refusal on the part of their clients:

“Saya bukan nak cakap apalah, doktor....dulu saya kerja itu kan? Kebanyakan lelaki tak nak pakai. Ada customer kadang kadang, terus cabutlah....apa lah...”

⁵ Direct sex workers defined as brother-based or formal sex workers (UNAIDS Editor’s Notes for Authors).

“I don’t want to say much, doctor....previously, I did that work [sex work] right? Most men don’t want to use [condoms]. There are customers who, sometimes, pull it off...”

(Transgender, 32yrs, Lower secondary education, Infected Partner)

“Tak mau pakai! Saya cakap mau pakai? Dia kata tak mau pakai.”

“Don’t want to use! I ask him to use; he says he doesn’t want to use.”

(Female, 48yrs, No formal education, SW)

“Macam mana tu? Kalau kita mahu – suruh dia pakai kan? Kalau kita suruh, ‘Bang, pakai kondom’, dia tak nak....macam mana tu?”

“What [to do] about that? If we want – we ask him to use, right? If we ask, ‘Mister⁶, use a condom’, and he doesn’t want to....what [can we do] about that?”

(Female, 38yrs, No formal education, SW)

“Kalau kita masuk bilik - ‘Bang, pakai kondom?’. ‘Tak nak, kondom buat apa? Kau dah sakit ke?’ Tak rugi ke - kita cakap kita sakit?”

“If we go in the room - “Brother, use a condom?” ‘No – what for use condoms? Are you sick?’ Don’t we lose [if] we admit we are sick?”

(Female 38yrs, No formal education, SW)

“So, masa kita sudah addict....kita tak boleh pikir benda tu [about infecting others], tau? Dia kena, tak boleh kesian orang. Kita pentingkan diri sendiri, pentingkan diri sendiri. I want the money! So, kita nak duit! Kita gian punya orang, bila customer layan, kita tanya berapa. Kalau boleh, kita mau tarik itu customer. Bila tanya customer, customer sendiri tanya kondom, kita kasi. Bila customer tak mau, cakap pakailah, Bang, dua dua orang selamat. Kita tak boleh cakap....saya ada HIV! Bila kita cakap HIV, I lose my business!”

“So, when we are addicted...we don’t think of such things [infecting others], you know? He gets it, [we] can’t feel sorry for him. We place our self above all others, we are the most important. I want the money! So, we want money. We need our fix – when a customer calls, we say how much. If possible, we want to attract that customer. If we ask the customer, and he himself asks for a condom, we give him. If the customer doesn’t want, we’ll say, ‘Wear one, Mister; both of us will be safe.’ We can’t say....I have HIV! If I say HIV, I lose my business!”

(Female, 36yrs, Lower secondary education, SW)

It is likely, and understandable, that sex workers make no attempt to persuade their clients to use condoms as this may involve divulging their health status and losing their potential clients. There was one transgender who said she was forthright with her clients

⁶ Literal translation of the word “Abang” or “Bang” is older brother but the term is also used as a respectful generic name for a man”.

in asking them to use condoms, even mentioning HIV, as she was conscious of infecting others. Yet, most clients still refused to use condoms. That clients of sex workers still do not, or prefer not to, use condoms is highly regrettable despite the resources spent on Information, Education and Communication campaigns in the country. Clearly, the message on protected sex is not reaching the appropriate target group or is not succeeding in promoting a change in attitudes and behaviour towards condom use.

Counselling, care and support

There is no doubt from discussions with PLHIV communities that they receive support from a limited number of sources. The first source, which some are lucky to receive, is the love, care and support from their own families. The acceptance by family members is evident for those who were infected by their husbands. In Sarawak, this family support is extended to infected sex workers as well.

In this regard, participants spoke of how much better their families understood and accepted their situation after they received counselling with their families from their doctors or counsellors at the hospital:

“At that time, they have a person in charge to talk to my father and let him know about my situation....and so on....so that now, my father is not afraid of it now.”

(Male, 42yrs, Primary education, Heterosexual)

“First is through hospital. They are very professional counsellors. They will meet your family and close relatives first before you get to them. It helps a lot. Like us - we just directly tell our relatives and friends, sure, they will be afraid of us....because they haven't been educated yet, so they don't know how to prevent and avoid be [becoming] infected. No matter, their wife, girlfriend or their mother, family....once they meet the counsellor - the second time when they bring them along to the counsellor - 95% of them will be able to accept it.”

(Male, 36yrs, Primary education, Heterosexual)

“I have to accept the fact because the result is there. And then, I went through one counselling programme in Singapore. They gave me – explanation. Then, I understand what is the danger of HIV, how to prevent or going to AIDS.”

(Male, 49yrs, University education, DU)

“Sebab saya koma. Saya koma, dia orang trace saya punya address last. Dia orang [keluarga] dapat tahu sebab saya kira 80% dah tak boleh hidup, tinggal 20%. Jadi, sebelum apa terjadi, dia mencari saya punya address - dapat. Jadi, famili saya pun datang. Dia pun tidak sangka yang saya ini.....aaah....jadi macam ini. Doktor telah memberitahu yang saya ini positive HIV. Dan permulaan sekali apa yang kaunselor saya memberitahu saya, aaah...semasa you koma, keluarga you tak nak sentuh you, tak nak lap you punya badan, tak nak tukar you punya pampers. Jadi, di situ gunanya kita ada kaunselor tolong. Dia akan memberitahu kepada

keluarga you as....orang HIV positif dan penagih; ini life dia begini, begini, begini....”

“Because I was comatose. I was comatose, [so] they traced my last address. They [family] got to know because I was about 80% near death, left 20% [chance to survive]. So, before anything happened, they looked for my address – found it. So, my family came. They didn’t suspect that I could become like this. The doctor told them I am HIV positive. And the first thing the counsellor told me....when you were in a coma, your family didn’t want to touch you, didn’t want to wipe your body, didn’t want to change your pampers. So, there’s where a counsellor is useful. He/she will tell your family you are....a HIV positive person and an addict; his life is like this, this, this.....”

(Male, 32yrs, Lower secondary education, DU)

“Bagi saya....bagi saya....keluarga sayakeluarga saya mengetahui saya ada HIV. Tapi peringkat permulaan tu, keluarga saya tak boleh nak terima lah. So, setelah sayadaripada pergi ke hospital, dia dapat penerangan daripada pakar pakar. So, keluarga saya boleh terima....boleh terima dengan apa yang saya alami lah – HIV ni.”

“For me....for me....my family....my family knows I have HIV. But at first, my family could not accept [me]. So, after...from going to the hospital, they got information from specialists. So, my family can accept [me]..... can accept what I am experiencing – this HIV.”

(Male, 34yrs, Upper secondary education, DU)

The above testifies to the importance of counselling services delivered in the appropriate way. However, participants who were tested in prison reported that they did not receive any counselling before or after testing when they are informed of its outcome. Blood testing is carried out routinely for all inmates and the result of the test given to them as a matter of course. After testing, inmates who are confirmed HIV-positive are then segregated. With regards to Pusat Serenti, the Government drug rehabilitation centres, one participant said that whether or not counselling is given depends on the counsellor assigned to that person. However, according to procedure, every Pusat Serenti resident should receive it:

“Dalam pusat, kalau nak kaunseling tu, bergantung kepada kaunselor. Kaunselor dia yang jaga dia lah. Itu terpulang pada dia – dia nak kaunseling, kaunseling lah. Kalau dia tak nak..... Kalau ikut prosedur dia punya perkhidmatan, memang sepatutnya lah.”

“In the centre [drug rehabilitation], if you want counselling, it depends on the counsellor. The counsellor assigned to take care of him. It depends on him – if he wants to counsel, he counsels. If he doesn’t..... If service procedures were followed, it should be [provided].”

(Male, 34yrs, Upper secondary education, DU)

“Normally.....normally, memang macam tu lah. Kalau pusat atau penjara kan – memang dia orang....dia orang just.....just inform you macam tu lah.”

“Normally.....normally, it’s that way. If it’s a centre or prison, it’s true that they....they just....just inform you like that.”

(Male, 34yrs, Upper secondary education, DU)

In fact, one participant doubted that counselling was a service that was easily available even in a large Government hospital setting:

“Kalau....kalau tak percaya, kita boleh telefon HKL [General Hospital Kuala Lumpur].....tanya dekat kat....kat mana kita nak dapat kaunseling. Dia orang tak tau nak pergi mana....”

“If....if you don’t believe, we can call HKL.....ask where to....where we can get counselling. They don’t know where to go....”

(Male, 32yrs, Upper secondary education, DU)

“...Counselling for newly diagnosed aaah....positive people. You have to go to the peer group. The number of peer support group is limited in Malaysia, so....aaah....and this is a problem of reference [referral] lah. A lot of patients in hospital are still....living, like, lonely and out of....what you call....community and feel isolated and so on. It can be said.....seventy thousand reported cases, our group couldn’t reach out... Kalau [If] reach out, less than five percent...you see.”

(Male, 40yrs, University education, DU)

“Ya....the doctors handle very well...but one thing I think not enough is....they didn’t get some, maybe, brochures or some contact for us....to have maybe some help or counselling.....or.....what....they didn’t do that. They just quiet and let you cool down first...they will tell you the truth....then they tell you do another testto confirm – that’s all.”

(Male, 31yrs, Upper secondary education, MSM)

“I go and do the HIV...and of course no pre-test counselling and they did the test and they came back, they told me the results. So you have to find out everything like that – make sure all food....contact...and even go [which] hospital I also don’t know....which hospital treat this type of thing? All I have is this letter, that kind of refer [referral] letter lah....that’s about it!”

(Male, 46yrs, University education, MSM)

“Saya kena HIV masa saya masuk Kajang. Saya kena tangkap, masuk Kajang. Saya ada check dengan Kajang punya doctor lah. Macam tu je [beri keputusan]. Ada bagi surat.”

“I got HIV [diagnosed] when I was in Kajang [prison]. I was caught, imprisoned in Kajang. I was checked by a doctor in Kajang. Just like that [test result was given]. [The prison authority] gave a letter.”

(Female, 40yrs, Primary education, SW)

“Masa dia orang [banduan] bebas, dia ada bagi surat. So, itu surat kita, kalau kita punya, kita care lah. Boleh pergi GH, nanti boleh buat medical check up.”

(“When they [inmates] are released, they [prison authority] give you a letter. So, that’s our letter, if it’s ours, we take care. [We] can go to GH [General Hospital], then, we can have the medical check up.”)

(Female, 36yrs, Lower secondary education, SW)

In contrast, all the refugees in this study received counselling at UNHCR before and after HIV testing. These refugees were all registered with, and recruited through, UNHCR (United Nations High Commissioner for Refugees) and were under their purview, including for regular healthcare.

Several participants commended the services provided by non-Government organisations which they patronised. The services provided by NGOs in Malaysia range from information, counselling, basic medical care and shelter through outreach activities, drop-in centre facilities (DIC) and shelter homes. Some participants in Kuala Lumpur and Kuching mentioned Tzu Chi (Buddhist Tzu Chi Merit Society), a Taiwan-based charitable organisation with centres in several urban centres in Malaysia, as their source of financial assistance for HIV drugs. Other NGOs that were mentioned were MS (?), Pelangi, Prihatin. Clearly, these resources are much appreciated sources of support:

“After that, they sent me to Pelangi for around eight to nine months. I started to recover from sitting at wheelchair, then using a walking stick. After that, not using it any more....then, how to say, from thin become a bit fat, then become handsome like this, now!”

(Male, 42yrs, Primary education, Heterosexual)

“Tzu Chi.....dia bayar sikit. Dia bagi sana farmasi. Saya peri bagi surat....sain satu buku ambil ubat. Dia pun satu bulan dua kali....satu bulan dua kali...dia mari jumpa saya. Mari jumpa saya....ada sihat ke? Kalau apa apa sakit, dia panggil hospital....pergi dia....appointment kasi....dia telefon, saya pergi hospital.”

(“Tzu Chi....they pay a little. They give [pay] that pharmacy. I go with letter....sign a book, pick up medicine. They also, one month twice....one month two times.....they come and see me. Come see me....am I healthy? If any illness, they call the hospital....they go.....get appointment....they call....I go to the hospital.”)

(Female, 44yrs, No formal education, Infected Partner)

“Tapi saya terus gunalah dalam masa tu....dapatdapat....dapat support daripada sana...tapi dia orang....risau sebab saya masih guna lagi....dan last sekali dia orang hantar saya masuk rehab lah dekat Pengasih. Dan...dekat Pengasih tu...baru saya.....dapat belajar lah, kan....dapat apa....saya dapat saya punya life balik lah.... daripada emotional support, saya dapat.....dengan support group.”

“But I continued using at that time....got....got....got support from there....but they were.....worried because I was still using....and finally they sent me into rehab at PENGASIH. And....at PENGASIH...there I started....to learn.....I got my life back...from the emotional support I got....with the support group”)

(Male, 32yrs, Upper secondary education, DU)

A few specifically drew attention to the benefits of having service providers who were also HIV-positive:

“.....as a HIV volunteer, they will help you according to your situation and your needs – living....aaah.....medication...aaah..... or look at the things that you really need. If they are capable and do connect to this kind of people....they will help us as [much as] they could.”

(Male, 42yrs, Primary education, Heterosexual)

“Because when you first find out....when you [are] first diagnosed with HIV and AIDS, of course, there is gonna to be denial. There’s gonna be denial....there’s gonna be isolation.....there’s gonna be blame. There’s gonna be all these things, you know. And how is this person gonna overcome all these - everything at once?! So....the....the first thing a person [who] is diagnosed with HIV and AIDS should.....should come to terms with is....to live with HIV AIDS. It is not that....it’s about living – what you gonna do, there is medication and then all this kind of information and the best will come from a peer who already has a support group [like the one] I’m in.”

(Male, 50yrs, Upper secondary education, DU)

It was clear that an important source of support for their healthcare is friendship, more so in the absence of family relations. In the same way as support groups, friends provide understanding and accepting relationships. The importance of friends applies in particular to marginalised groups, such as, SWs, DUs and TG communities who may have been abandoned by or have lost contact with their families for one or other reason. Most likely, family estrangement stem from behaviours deemed unacceptable by family members, often preceding HIV infection. At the same time, it may also be the case that a drug user, or sex worker or transgender him/herself decides to distance themselves or cut off family ties on the perception that he/she is not accepted. In responding to the moderator’s query on how she managed to recover after a year of illness and hospital treatment, one participant ascribed her survival to the support of her friends:

“Sebab.....sebab saya ada kawan kawan datang melawat. Kalau tak ada kawan kawan, doctor, saya dah macam tak ada keyakinan.”

“Because.....because I had friends visiting me. If I did not have friends, doctor, I would have lost faith.”)

(Transgender, 32yrs, Lower secondary education, Infected Partner)

At the same time, personality characteristics or psychological features may also play a part in how the physical body copes with the disease. Speaking of a friend (another participant) who was so sick in the past, and who recovered:

“No hope already because dia dah tinggal tulang dengan kulit je. Dia ini sebagai orang kata - dia punya will power. Everybody say that.”

(“No hope already because she was nothing but skin and bones. She’s like, what they say – has will power. Everybody says that.”)

(Transgender, 53 yrs, Upper secondary education, SW)

“When we really talk about HIV AIDS.....to me.....I’m not that stressed..... I’ve seen friends.... I’ve seen lots of friends of mine coming from stress to depression and, after a couple of days, they die. So, I recognise stress and depression as one of the things that will kill me. And a lot of NGOs....err....like home care. I don’t know what they do about this..... Basically, I mean, I’ve been living with HIV now for 14 years. I’m not on meds. My CD4 is 470 which I’m very happy about. My viral load is 1300, so I look at my life and I know I got to take care of myself because I’m not on meds. One day maybe I will but for now, I make sure I have proper meals and proper rest.”

(Male, 50yrs, Upper secondary education, DU)

On the contrary, although affordable healthcare is available through public hospitals, apathy, fatalism or other negative attitudes may exacerbate health through irregular or insufficient healthcare monitoring or failing to take drug treatments properly or not at all. In particular, active DUs tend not to have regular visits or maintain their medication because of the nature of substance dependence. In fact, a few of the participants mentioned what little difference HIV made to their own life, not to mention others that they might infect, as the only thing they care about is their continuing drug supply. They will go to a clinic or hospital only when they are sick. This apathy extends to seeking HIV-related services, including counselling following diagnosis. This negative attitude is illustrated in the following comments:

“And then, she asked me to go down to P2 [floor level in hospital where counselling service is located]. Go there and find out, they will tell you how to take care....counselling. What’s your CD4 and all....I just couldn’t take it! I didn’t go there!”

(Male, 38yrs, Lower secondary education, DU)

“Same thing with me - I couldn’t be bothered!”

(Male, 36yrs, Upper secondary education, DU)

“Most of us can’t be bothered.”

(Male, 44yrs, Upper secondary education, DU)

However, it is evident that access to the appropriate resource enables DUs, and other HIV communities, to cope with various issues, such as overcoming denial, gaining acceptance by their families, and learning to accept it themselves and live with HIV:

“Buat pada permulaannya, saya memang tak dapat accept lah....saya....HIV positif kan. Denial pada diri saya tu masih tinggi lagi lah. Lepas saya....aaah....berjumpa dengan [a name], iaitu, pengurus projek motivasi, saya telah dapat kaunseling daripada dia tentang HIV, kan, dan saya dapat acceptlah sebab saya.....saya....yang buatkan diri saya berisiko untuk dapat kan. Maknanya, saya.....saya menagih dadah, saya menggunakan jarum suntikan. Outcome daripada jarum suntikan tu - saya kena acceptlah apa yang berlaku pada diri saya tu kan. So, hari ini saya dapat menerima diri saya seadanya bahawa saya HIV positif.”

“In the beginning, I really could not accept....[that] I am HIV positive, right? For me, denial was still high. After I.....met with [a name], that is, motivational project manager, I received counselling from him about HIV, right, and I could accept because I...I...am the one who put myself at risk to get it, right? Meaning, I...I was drug dependent, I used injecting needles. The outcome from those injecting needles - I just have to accept what happened to me, right. So, today I can accept myself as being HIV positive.”)

(Male, 32yrs, Upper secondary education, DU)

Psycho-social impact

Social impact

Several questions were posed as to how being HIV positive has affected participant's relationships with people close to them. Issues such as disclosure, stigma, prejudices and discriminations, social relationships and interactions with family members, friends, colleagues and community, as well as religious participation and/or spirituality were explored.

Disclosure

Experiences of disclosure, and to whom, were also explored. Some choose to disclose and only to certain people, such as their loved ones or significant others, such as spouses, parents, brothers and sisters. Others choose not to disclose their status for fear of repercussions, such as ostracism by family members, stigma and the fear of being discriminated, and this well kept secret render them more stress. Some participants kept the secret for a while before deciding to disclose their status. The FDGs revealed both good and bad experiences of disclosure.

“How should I say...When I was diagnosed...I told my girlfriend, then my father, relatives and friends. All ran away from me. Nowadays, I am only with my father”

(Male, 36yrs, Primary education, Heterosexual)

“When I was diagnosed, my parents couldn't accept it and asked me to move out from the house. I thought by letting my parents know...letting my family know that I would have..arr..family support but I was wrong because at that time, there was no information about HIV and AIDS”

(Male, 50yrs, Upper secondary education)

“Pada pendapat saya, kalau kita nak berkawan lebih baik..ah...kita merahsiakan identiti kita, kita ada HIV. Sebab kita tak kenal. Kita tak kenal you. Lebih lebih dalam. Sebab apa saya nak terangkan you, itu akan jadi satu tanggapan..ah....individu yang ada HIV. Jadi pada saya, tak semua orang kita boleh..ah..memberitahu”

(“In my opinion, if we want to make friend it is better...ah...we keep our identity a secret, we have HIV. Because we don't know (you). We don't know you. Know you well. Because what i'm going to tell you, it will be an impression...individual with HIV. So to me, not everyone we can...ah...tell”)

(Male, 44yrs, Upper secondary education, DU)

“Susah juga. Saya sebenarnya di diagnosed pada bulan Ogos tahun lepas 2005. Jadi, masa tu saya keep secret sampai bulan dua 2006. Saya pengsan kat rumah. Sakit...hantar hospital, baru saya punya isteri tahu. Bila tahu, saudara saya semua tahu. Jadi, benda ini memang secret pada saya. Yang tahu cuma my immediate family dengan keluarga mertua. My mother pun tak tahu lagi I positif. Sampai sekarang, I keep it confidential. Tetapi dia orang pun masih belum tahu lagi. Saya keep it confidential jugak. Stigma dia memang lah. Kita rasa memang tekanan lah sebab kita nak kena behave properly, kan? Jangan bagi nampak kita HIV positif”

(“It's difficult. Actually i'm diagnosed in the month of August last year, 2005. During that time I keep secret until the second month of year 2006. I fainted at home. Sick...was sent to hospital, then my wife knows. When (my wife) knows, all my relatives know. So, this thing (HIV status) is a secret for me. [People] that know, are my immediate family and my in laws family. My mother also doesn't know that i'm positive. Until now I keep it confidential. But they don't know yet. I keep it confidential also. No doubt there is stigma. We really felt the pressure because we have to behave properly, right? Don't let other people see (that) we are HIV positive”)

(Male, 39yrs, University education, DU)

“It's no point for me to tell them. Its like a story. Everyone will keep passing it around and said how serious it is. We have no choices, but I will tell only when I need my partner's understanding or else I will choose not to tell. My family, the same situation. My father and mother will feel sad and worry if they know about my status. They are in their old age now, so, I don't feel like make them worry. Sometimes, they couldn't help me also. They are both quite conservative and believe in religion. May be they will feel cheated when looking treatment for me. So, what I want to do now is be more filial, accompanying them, get them out, although I don't know how long am I suppose to live but at least I saved them some memory”

(Male, 31yrs, Upper secondary education, MSM)

However, not all experiences with disclosure are bad. There are also happy stories when HIV status is disclosed.

“I did not immediately come back and tell my parents. It took me one year to prepare that...before I actually said anything about my status. I guess they, they can....they can accept. Cause it took me one year together with my fiancée to prepare them, you know, we kind of educate them, exposing them to right information. My relationship with them, I think much better compared to before. Friends they do not know”

(Male, 40yrs, Upper secondary education)

“Doktor bagi letter, dia beritahu saya. Doktor tak beritahu family. Saya sendiri beritahu mak bapak. My family all know. Sayang. Bila kena sakit, lebih sayang”

(“Doctor gave letter, he/she informed me. Doctor didn’t tell family. I told my parents by myself. My family all know. Loving/caring. When [I] fall sick, more loving/caring”)

(Female, 36yrs, Lower secondary education, SW)

Some chose not to disclose their HIV status for fear of shame, neglect or disown by the family and also the lack of courage to disclose.

“I’m scared. My family don’t know that I have. I’m scared that they will hate me. Nobody knows. My friends also don’t know”

(Female, 40yrs, Lower secondary education, SW)

“Saya punya mak bapak tak nak bagi tau dia orang. Sampai sekarang adik-beradik tak tau. Kawan saya tak tau. Sebab rasa malu pun ada”

(“I don’t want to let my parents know. Until now, my siblings don’t know. My friends don’t know. Because feel ashamed”)

(Female, 22yrs, Lower secondary education, SW)

“Saya berfikiran keluarga, saya berfikiran saya, dan saya berfikir kawan-kawan saya. Macam-macam saya fikir, tapi almost saya fikirkan keluarga saya. Saya tak berani nak bagi tahu keluarga saya. Sebab apa, keluarga saya ini dari kampong dan tak tahu apa-apa tentang benda-benda ini semua. May be satu hari nanti saya akan bagi tahu tapi now saya tak yakin. Kita tak boleh terus tiba-tiba saya ada penyakit macam ini”

(“I thought of my family, myself and my friends. I ponder on all sorts of things, but mostly I think of my family. I don’t dare to let my family know. Because my family came from rural area and do not know anything about this things. Maybe one day I will let (them) know but now i’m not confident. We can’t suddenly (tell) that I have this illness”)

(Transgender, 40yrs, Lower secondary education, SW)

The participants seemed to be at a lost in deciding whether and how to disclose their status. The difficulties in disclosing their status could perhaps be minimized if people living with HIV/AIDS can be taught how to disclose the matter to their loved ones. Once this is disclosed at the appropriate time, they have to bear the consequences of this disclosure. Perhaps, following disclosure, their mental health would be better.

Relationships

The effect of being a person living with HIV/AIDS does affect one's relationships, be it with family members, relatives or friends. Some do not want to further burden the family, and thus has to leave home and be on their own. Some who have been out for sometime crave for family love and relationship.

“My father speaks to me like that. Because HIV doesn't die faster than drugs. I don't want to see you smoke. See you smoking drug every, everyday and then you turn yourself into a ghost. At least, HIV there is still lot of prevention. I still can support lah what kind of good food and what kind of good health you want. I support you, I don't mind but I cannot support you on drug. So, at last, I don't want to put my family into so much trouble. I left the town and I stay on my own”

(Male, 49yrs, University education, DU)

“Dengan keluarga, saya permulaan dulu, memang saya dah tahu saya ada HIV dan saya penagih tapi keluarga saya tak tahu saya ada HIV. Jadi, saya penagih. Tapi, keluarga saya tak tahu saya ada HIV. Jadi, saya melari, melarikan diri daripada dia, selama hamper 10 tahun. Saya tidak berhubung dengan dia, saya tak nak dia. Bermasalah saya dengan masyarakat. Saya punya jiran semua, tak nak dia...ada masalah. Disebabkan oleh saya seorang penagih dan saya pembawa HIV, saya keluar daripada keluarga saya”

“With my family, I at the very beginning, really, I know that I have HIV and i'm a drug addict. But my family doesn't know that I have HIV. So i ran away, ran away from my family, for almost 10 years. I didn't contact them, I don't want them. I'm having problem with the society. All my neighbours, (I) don't want them...have problems. Because of me as a drug addict and a HIV carrier, I come out from my family”

(Male, 32yrs, Lower secondary education, DU)

“My family didn't like that I have HIV. Because I think I fail myself, sad. And also my family members may not accept me, they try to avoid every part of my life when I was at home. Many scare to use knives and spoons, plates and spoons. So, I just don't want to bluff them anymore”

(Male, 51yrs, Lower secondary education, DU)

“Ok, I'm a Muslim. But since I got to know that I have this disease, my life change, totally change. My relationship with friends, with family totally out. Ok, they people can say they care but in actual fact, they are not. Especially those who have more knowledge about HIV/AIDS. So, I feel now I am out of the family. *Even sekarang ni I rasa hidup I susah,*

yang amat sangat. Tak pernah I rasa hidup macam tu, walaupun family I orang kaya, tapi, dia orang tak ada ambil berat tentang I. Apabila dia sisihkan kita dah keadaan kita memerlukan kecil hati itu akan berpanjangan kan. I run my own life alone. Jadi, I bawa diri. Duduk menyewa bilik. I rather stay with my friends at Chow Kit there in a room. Kawan ok”

“Ok, I’m a Muslim. But since I got to know that I have this disease, my life change, totally change. My relationship with my friends, with family totally out. OK, the people can say they care but in actual fact, they are not. Especially those who have more knowledge about HIV/AIDS. So, I feel now I am out of the family. Even now, I felt that life is hard, extremely difficult. Never have I experienced this before, although my family is rich, they are not concerned about me. When they cut us off and we are really in need, the hurt remains and runs deep. So, I isolate myself. Stay in a rented room. I rather stay with my friends in a room at Chow Kit. Friends [are] ok”

(Transgender, 53yrs, Upper secondary education, SW)

Some do get support (moral and physical) from family members in their struggle against HIV.

“Semangat saya, saya tidak pernah putus asa dengan keluarga saya. Mereka tidak asingkan saya. Pergaulan sama sahaja....orang sihat dengan tidak sihat. Mak lah tempat mengadu”

“My will power, I never give up with my family. They didn’t isolate me. Our relationship is still the same...healthy people with the sick people. My mum is my pillar of strength”

(Female, 39yrs, Lower secondary education, Infected Partner)

“My family they all knew about it. After they send me to Pelangi for around 8-9 months, I started to recover from sitting at wheelchair, then using walking stick, after not using it anymore. I become fatter and then become handsome like this now. They talked to my father and let him know of my situation. My family helped me a lot”

(Male, 42yrs, Primary education, Heterosexual)

“My mum cried. My father like a man lah, keep quiet. He never said anything lah until today. Only my mum will ask. Have you done the check-up? How long do you do your check-up? Have you taken the medication? Any medication can cure this disease or not? How come no medication can cure this disease, she is still asking. Initially I feel pressured lah, but now not really. They just treat me like normal”

(Male, 36yrs, University education, MSM)

“My wife and my parents knew about it. They told me to come back to Myanmar, but I refused it”

(Male, 30yrs, No formal education, Refugee)

“They told me that they still love me, they pray for me. I always encourage to my wife”

(Male, 29yrs, Primary education, Refugee)

Among friends, particularly those who have the same problem, they are easily acceptable. However, being honest with one’s HIV status also render problem, for example, rejection from friends and colleagues.

“People that we mix with are drug addicts and they are our only friends. It doesn’t affect our relationship and I think most of them also HIV positive. Sometimes, we tend to think that drug addicts are more acceptable. They accept you openly. In fact, prison mates and the Serenti inmates...ah...they can accept you even you are HIV positive. Even you are AIDS. Because if you go to these centre, you don’t see them ostracizing. The HIV/AIDS patient, they have got no prejudice around these things. They are the birds of the same feather”

(Male, 44yrs, Upper secondary education, DU)

“You know like my case, when I was isolated, you know, when I was rejected by my colleagues, working colleagues because I was working and everything now for me tell people who, you know, normal people who are not HIV and everything to tell them I am HIV and everything is I have to think 2-3 times. The painful experience that we have gone through by being honest by telling that I’m HIV and everything”

(Male, 36yrs, Upper secondary education, DU)

Some of the participants will shy away from social relationships and interactions, for fear of exposing their status or being asked too many questions about themselves or their health status. Thus, social relationships are avoided.

“I seldom meet my friends...worried they will spread and tell others. I go out with them if they look for me, or else I won’t take initiative to find them. They said why I’m so thin, do I do diet and take weight loss medicine. But, I tell them I am not. I never go anywhere since have this disease because friends always keep asking why I look thin”

(Female, 34yrs, Primary education, Infected Partner)

“When we meet friends, ask how are you...they ask many, many questions, so, we don’t like give them the answer. We don’t know how to give them an answer. I moved back to kampong. I hide from others, from the town people. Lebih baik jangan berkawan (better not make any friends)”

(Female, 40yrs, Lower secondary education, SW)

Psychological and emotional impact

People living with HIV/AIDS faced significant impact on their psychological well-being. This psychological impact comes from various sources, from disclosure and its consequences, from silencing themselves, from stigma and discrimination that they experienced, worries about their health, impending death and from their own personal

long term fears and anxieties. The initial period of adjustment following diagnoses is extremely difficult and challenging. Some go through a denial stage and some mourning and grieving. Some faced a sense of shame and guilt in them. All these emotional turmoil subsequently affect the mental health and the coping skills and strategies of the participants.

“Orang saya ini dihantui oleh HIV. Kadang-kala, saya biasanya saya akan cakap pada diri saya, saya tak ada HIV. Bila orang cakap..eh...engkau datang ini apa problem sakit ke...ada HIV? Simple saya nafikan sebab apa benda itu menghantui, jadi kita tidak perlu jadi tertekan pada diri kita sendiri. Kita tidak boleh asyik memikirkan tentang yang saya ini ada HIV. Memikirkan sangat tentang tu akan jadi gila macam ini. Saya tak mau macam itu”

(“People like me is haunted by HIV. Sometimes I, usually I’ll tell myself that I don’t have HIV. When people come to me and ask...eh...you come here because of illness problem...have HIV? Simple, I denied because whatever that is haunting us, we don’t have to pressure ourselves. We cannot constantly think myself have HIV. If we think too much about that, we’ll go crazy. I don’t want to be like that”)

(Male, 32yrs, Lower secondary education, DU)

”Saya cuba mahu kerja. Macam tidak tenang saya punya fikiran kalau saya kerja. Habis saya kadang-kadang ambil ubat, kadang-kadang check darah. Itulah saya jadi bingung. Bagus lagi saya diam-diam di rumah”

(“I tried to work. I felt restless, my thoughts, if i don’t work. I’m done if occasionally I take medicine or check blood. That’s why I’m stunned. It’s better if I sit quietly at home”)

(Female, 29yrs, Upper secondary education, Infected Partner)

Some of the participants had a more positive outlook in life and have gathered courage to move on with their lives.

“Walaupun saya tahu yang saya sakit saya tidak mau lemah semangat. Saya mesti meneruskan kerja saya. Still meneruskan hidup saya”

(“Although I am aware that I’m sick, I don’t want to give in. I want to continue with my work. I want to move on in my life”)

(Female, 30yrs, University education, Infected Partner)

Emotional status following diagnosis

Following diagnosis, participants are swamped with all sorts of worries, anxieties, fears, anger, frustration and even suicide. They find themselves suddenly at a loss. Some gave up hope and see the future as dim. The FGDs found that it was initially very hard for one to accept the fact that they are HIV positive.

“Was really uncomfortable at that time and felt hurt when all friends and relatives ran away from me. What else to do other than just feel sad. I was feeling like I have come to the end of my life. I was extremely sad because you don’t know why all your friends ran away from you even though you honestly told them your situation. Everything changed after they knew about my status”

(Male, 36yrs, Primary education, Heterosexual)

“When I was admitted to the hospital, doctor told me I have HIV and everything lah. Eventually I disagree with the doctor lah, make a mistake. I felt angry. At that moment, I couldn’t accept I have HIV and everything. I don’t know anything about HIV or AIDS...but I know the disease can kill you. Then, I was thinking I am going to die, what the heck, you know. Physically nothing lah, only mentally and emotionally I was affected lah”

(Male, 36yrs, Upper secondary education, DU)

“When my father sent me to Pelangi, I was thinking of why my father left me here. Why he doesn’t want me. During the first two days, I’m alone there with all other race of people like Malays and Indians. Most of them in Pelangi are drug addicts. They treated me badly because I’m not one of them”

(Male, 42yrs, Primary education, Heterosexual)

“You will worry and think of the existing medicine can cure your sickness or not. That’s the first thing come into my mind. Medicine treatment aspects. Will there any method to cure my disease? Never think of die. Just fear of the money problem. Fear of no treatment can cure this disease. We have to personally learn how to face this kind of problem and other problems as well”

(Male, 42yrs, Primary education, Heterosexual)

“Buat pada permulaannya, saya memang tak dapat acceptlah, saya HIV positif kan. Denial pada diri saya tu masih tinggi lagi lah”

(“At the beginning, I cannot accept, I’m HIV positive. Denial in me is still high”)

(Male, 32yrs, Upper secondary education, DU)

“I was losing a lot of weight. I just wanted to know what was wrong with me and they did the test. They told me that I was HIV positive. Ok, and at that time when they told me, I was like...devastated. I was devastated. The question was...Why me? It felt like a time bomb just dropping into my lap and when I asked the doctor how many more years I had to live. The doctor told me and said that you only got seven years. So, that made me worst. That made me becomes very self-destructive. I mean, in that seven years, I tried to destroy myself. I have tried four times to commit suicide and things like that because I was thinking, I mean what’s the point of living with the disease that you gonna die very soon”

(Male, 50yrs, Upper secondary education)

“The first time I heard from the doctor that I was HIV positive, I feel so sad. It seemed to me that there is no future. I just want to die, but I came to senses that one will die one day”

(Male, 29yrs, Primary education, Refugee)

“They told me myself....HIV positive. Then, I went in to see the doctor, he broke the news. That was the time when I really feel a bombshell. I feel so depressed right after I knew about the news. I was very depressed, very suicidal, you know and then I got angry with my son, angry with my daughter for getting pregnant without a husband”

(Female, 54yrs, Lower secondary education, SW)

“Ya, saya disahkan HIV positif. Masa tu saya tak tahu macam mana saya buat. Yang cuma tahu saya fikir nak mati dan saya taka da semangat nak hidup lagi. Nak hidup lagi and then saperti mana kawan-kawan yang duduk dengan saya mula menjauhkan diri daripada saya. Tak apa. Dia orang taka da pengetahuan tentang HIV. Yang dia orang tahu HIV boleh merebak. Itu saja. Kemudian, saya berpindah ke tempat lain. Lagi makin lama, kesihatan badan saya down”

“Yes, I am diagnosed with HIV positive. At that time, I don't know what to do. All I know is, I thought of wanting to die and I don't have the will to live anymore. When I'm resolved to live and then...like my friends who sit next to me begin to stay away from me. Never mind. They don't have knowledge on HIV. All they know is HIV can spread. That's all. Then I moved to other place. As time passes by, my health goes down”

(Transgender, 40yrs, Lower secondary education, SW)

Among women who are infected by their spouse or partner, they feel betrayed and cheated. Some of the women found out of their HIV status only when they went for their pregnancy check up.

“Apabila saya tahu yang saya ada penyakit, saya sangat susah. Macam tidak boleh terima apa dia buat. Hari itu, saya sudah tanya dari mana laki saya dapat penyakit ini kan. Dia ada seksual dengan perempuan luar. Start hari itu, kita punya kasih sayang pun tidak macam dulu. Sepatutnya, kita sebagai isteri kita harap laki kita jujur dengan kita. Tapi sebaliknya, dengan tiba-tiba saja kita tahu yang laki kita tidak jujur sama saya. Kalau tidak melibatkan isteri tak apa. Ini, isteri pun kena dengan perbuatan yang dia buat. Itu yang paling sedih sekali”

“When i found put that i have illness, I'm very sad. Like...cannot accept what he has done to me. The other day, I asked where did my spouse get this illness from. He has sexual relationship with other women. From that day onwards, our love for one another has change, unlike before. By right, as a wife, we hope that our husband is honest with us. On the contrary..., suddenly we found out that our husbands are not honest with us. If it has got nothing to do with us, never mind. But this..., as wife, got it due to his deed. This is the most upsetting”

(Female, 46yrs, Upper secondary education, Infected Partner)

”At first, I cannot take it, until I want to kill myself. I am pregnant. I think about my baby. I think why I so stupid. Then I think how to grow my children up”

(Female, 23yrs, Lower secondary education, Infected Partner)

“Nurse dekat situ cakap...apahal kamu mengandung. Kamu tak tahu kah suami kamu HIV, dia cakapkan. Masa tu, suami saya masih army lagi kan, dekat Johor sana. Sebab tentera, army dia macam tidak berapa bagi taukan. Ah..masa mengandung saya tahu. Mula-mula saya rasa marah lah”

(“The nurse over there said...“Why did you get yourself pregnant. Don’t you know that your husband has HIV” she said. During that time, my husband is still in the army, in Johor. Because as soldier, his army (he) doesn’t really want (them) to know. Ah...I found out when I was pregnant. At the beginning, I was angry lah”)

(Female, 36yrs, Upper secondary education, Infected Partner)

Current psychological and emotional status

The FGDs revealed that there is a difference in terms of psychological and emotional state between the period of diagnosis and their current psychological state. Most of the participants have more or less accepted their disease and some have now learnt to cope with it and move on.

“After you know you have this disease, you know how precious life is. That’s where they start to change. Change emotionally. Usually you get to know, no doubt still like you are in sort of denial. When you, you know, you don’t take to know about the disease itself. But, it changes in a positive way. You want to go on living, you want to do something. But the disease itself, we push aside. You consider yourself normal, able to work, able to look for help. No doubt you got the disease, the change comes in the sense...ah...now we are struggling to survive to live instead of not caring about a thing”

(Male, 44yrs, Upper secondary education, DU)

“Apa orang ada, saya pun ada. Bukan lah orang ada rumah tiga tingkat, saya ada rumah empat tingkat. Tak ada lah. Saya biasa juga. Ada orang ada ni handset, saya ada handset. Ada orang ada kereta, saya ada kereta sendiri. Dulu saya tak ada. Saya main kat Lorong Haji Taib. Hidup bersepah-sepah. Tidur atas kotak. Daripada situlah saya...kalau saya tak perbaik diri saya, saya ingat saya tak ada lagi lah. Mungkin saya dah tidur lama lah. Rileks for ...untuk selama-lama kan. Daripada situ, saya sedar, sedar, sedar, sedar sampai lah ke sini...sampai ke hari ini. Saya pun merasa gembira juga lah”

(“What others have, I have also. Not like, others have three storey houses, I have four storey houses. No lah. I’m normal also. Some of them have

handset, I too, have handset. Some have car, I have my own car too. Previously I don't have. I hang around at Lorong Haji Taib. Life was at mess. Slept on the box. From then onwards I ... if I don't recover and move on, I don't think I'm alive now. Maybe I'm dead long time ago. Relax for...forever. From then on, I realized, realized, realized, realized...till today. I feel happy also")

(Male, 50yrs, Upper secondary education, DU)

"Sekarang ni, saya tak ada putus asa. Biasa lah. Biar lah orang nak kata apa-apa, saya biasa. Tak ada masalah. Macam masa saya sakit, orang tak pergi melawat saya di rumah. Saya deman baru-baru ni pun, saya terima. Saya tak kisah, cuma keluarga saya datang melawat di hospital sini. Sekarang ni, masyarakat apa-apa masalah jumpa saya. Saya fakir biasa saja. Macam mana orang hina saya, biasa, tak ada perasaan nak...biar sajalah"

("Now, I don't give up. Let it be. Let what other people have to say, I'm used to it. No problem. When I'm sick, no one come and visit me at home. Recently I have fever, I endure it. I don't care, only my family came to hospital and visited me. Now, if anyone comes to me with any problem, I feel it [problem] is normal. Regardless of how people criticize me, normal, I don't have feelings anymore. Let it be")

(Female, 39yrs, Lower secondary education, Infected Partner)

"Saya sihat saya hidup dan saya tak perlu tengok ke belakang. Saya terus ke pergi ke depan...ah...tengok ke depan...ah...itulah saya"

("I'm healthy, alive and I don't look back. I look forward...ah...look forward...ah...that's me")

(Transgender, 40yrs, Lower secondary education, SW)

Some of the participants still have a problem coping with their illness, and this lack of coping strategies and the lack of support system could render them a poorer mental health or psychological state.

"I feel now, I rasa macam hidup I sekarang macam tak berharga. Tak berfungsi because everywhere I...since after that, after I knew that I had HIV/AIDS positive, I run away from facts. It's about 2 years now, dua tahun lepas, I actually cannot accept"

("I feel now, I feel like living. Now I'm feeling worthless. Not functioning because everywhere I...since after that I knew that I had HIV/AIDS positive, I run away from facts. It's about 2 years now, 2 years ago. I actually cannot accept")

(Transgender, 53yrs, Upper secondary education, SW)

Self-esteem and self image

Some of the participants also suffer from low self-esteem. This impact is seriously felt during the initial period following diagnoses of HIV and it may take a while to be emotionally strong depending on the support received.

“Saya rasa macam rendah diri lah. Rasa rendah diri memang adalah dalam diri kan”

(“I felt low self-esteem. Feeling of low self esteem is there, in ourself”)
(Female, 30yrs, University education, Infected Partner)

“Rasa malu lah. Macam kalau kita tengok orang lain, kita pun sihat juga. Kita macam orang biasa, tapi terasa lah tahu lah kita sendiri ini ada penyakit”

(“Feel embarrassed. Like how we look at other people, we are also healthy. We are like normal people, but felt it...we know that we ourselves have this illness”)
(Female, 35yrs, Primary education, Infected Partner)

“Having HIV positive feels so distress. I just want to stay alone. I mean, I just want to stay away from others”
(Male, 30yrs, Primary education, Refugee)

Religious participation and/or spirituality

The FGDs revealed mixed feeling towards religious beliefs and practices. Some of the participants turned to the higher power for help, while others remain the same. Some also shunned away from religious places for fear of being asked many questions, thus would rather not attend any religious services. Others turned to God for help, while some do find moral support from fellow religious members and counselled by religious authorities. The support can also be in the form of financial assistance or basic necessities (rice, flour, sugar, etc.), the latter being in the rural settings.

“Biasa dia orang yang banyak tanyalah. Dia orang yang banyak tanya. Kakak yang banyak tanya. Kadang-kadang, tiap-tiap jumaat, kita harus sebutkan. Kalau saya tak sebut pun, dia orang Tanya. Dia orang tanya macam mana, dia orang plan untuk saya lah. Dari situlah, kita macam buat kekuatan semula”

(“Usually they ask a lot of question. They asked a lot of question. Sister ask a lot. Sometimes, every Friday, I have to say it. If i didn’t say it, they will ask. They will ask, so how, they plan for me lah. From there, we regain our strength”)
(Female, 36yrs, Upper secondary education, Infected Partner)

”I used to ask them [church members] to pray for me, you know. I talked to them but I didn’t tell them the exact sickness I’m having. It’s sad, but in Sri Aman, I went to the priest there. I told him what exactly happened to me because that is a healing church. So, I think prayers help also lah. I

have been turning to God since and get closer to God. Go pray. God will never give me bad things. It is all from Satan. So, what happened now is I'm trying to empower myself lah so that I can fight the power of Satan. This is spiritual lah. I'm using spiritual"

(Female, 54yrs, Lower secondary education, SW)

"It really helps me a lot...Buddhism...Buddhism because I always think about...[God] since the virus chooses me as their host. I'm in their home. So, I need to take care of them. They also need to take care of me ok. I treat them good and they should treat me good and hope this is what I hope, that's all"

(Male, 36yrs, University education, MSM)

"Banyak-banyak berdoa pada Tuhan sekarang. Susah hati pasal masa depan saya tengok macam mana. Banyak doa saja"

("Pray constantly to God now. Worried about my future, lets see how. Just lots of prayer").

(Female, 29yrs, Upper secondary education, Infected Partner)

There are also participants who blame the higher power for their disease. They see this as a punishment from God.

"At first I was Buddhist, but when I was diagnosed with this disease, I was thinking of why? If God wants to punish me, is better not to give me the reproductive organ, don't give me the feeling of sex. If you [God] gives, certainly will request for it [sex]. The only thing different is I'm a gay. So, I was like quite anti and doesn't believe in religion for sometime. After a period of time, I being convinced myself. Felt like I'm too negative at that time. My thinking is that my blood is dirty ok. I couldn't ask God to give me longer life. But, just pray for my family good understanding. I realize that we have to fight for what we need and what we want, because God couldn't help you. You have to self-survived. I have to rescue myself first. This is about me, my individual thinking.... my feeling. Doesn't apply to others"

(Male, 43yrs, University education, MSM)

Coping

Coping strategies were also explored as to how participants coped with their illness.

"Sometimes, when we are sick, laughter is the best medicine. We tend to joke with ourselves, to leave the past. We try to avoid thinking that mental thought that we have HIV, we have AIDS. We try our best to avoid thinking about this kind of problem"

(Male, 44yrs, Upper secondary education, DU)

"Untuk saya mengurangkan tension, saya pergi jogging. Pergi jalan-jalan, pergi mana-mana lah"

(“For me, to reduce my tension, i go for jogging. Go for a walk, go anywhere”)

(Female, 25yrs, Upper secondary education, Infected Partner)

”Saya dekat kampung sana selalu pergi kebun, macam tu. Kalau saya susah, kalau masa tak sekolah, budak tak sekolah, saya keluar ke kebun dan bersawah. Kalau saya duduk di rumah, memang fikiran saya pusing-pusing”

(“When i’m in the village, i go very often to the farm. If i’m unhappy, if there’s no school, the kids don’t go to school, I’ll go to the farm and do some farming. If I stay at home, definitely I’ll get headache”)

(Female, 35yrs, Primary education, Infected Partner)

“There’s nothing to be shy of your sickness anymore. If they want to discriminate, it’s up to them. That is God’s will, you know. So, we have to do something. Life must go on. To me, I am thinking in that way”

(Female, 54yrs, Lower secondary education, SW)

Outlook on life

There are mixed feelings among participants as to how they see their life, some are positive whereas some are negative. To some, it’s a challenge and they change for the better. However, to some participants, the fear of the unknown of what is going to happen to them seems to be bothering them.

“But contrary to anything or whatever, I supposed my life now is better than before I was diagnosed. I think as a whole I felt that I’m a better person after being diagnosed”

(Male, 40yrs, Upper secondary education)

“I hope I could cooperate with NGO or any other organizations in propaganda HIV and AIDS. Let the young generation know how to prevent being infected by this disease. Don’t go the same way I did and hoping for the medicine that can cure this disease. But, I already take it easy because everyone will go through the process of birth till death. Nothing to be afraid. But, I couldn’t go back what I have before. So, I already learn to take it easy”

(Male, 36yrs, Primary education, Heterosexual)

“Sebab saya memang terdedah kepada HIV. Sebab saya menggunakan suntikan dadah. Jadi, terpaksa lah membuat kerja-kerja yang menyusahkan orang lain untuk kepentingan diri. Saya rasa saya memang tak elok lah. Tapi, dalam satu masa, saya akan berfikir bila saya dah normal, tak gian saya akan automatic berubah. Berubah. Dia tidak akan jadi seorang yang zalim dan tidak menjadi seorang yang ganas. Saya akan berubah”

(“Because I am exposed to HIV. Because I use injecting drug. So I get involved with works that put people into trouble for my own benefits. I

felt I'm indecent. But, at one time, I thought, when I'm normal again, not addicted to drug, I will automatically change. Change. I won't be a cruel and aggressive person. I will change")

(Male, 32yrs, Lower secondary education, DU)

"I always wondering what would happen next. Tomorrow what's going to happen. Will I, will I wake up tomorrow? This kind of things, you know. Today healthy. When I see somebody really sick, I'll be wondering will I be like him tomorrow or next week or next month. This kind of things I am thinking"

(Male, 40yrs, Upper secondary education, DU)

Major concerns for the future

Different concerns for the future have been explored. These concerns depend on one's own marital status such as the future of their children, some fearing death and some are pessimistic as to what the future holds for them. Some live one day at a time and wouldn't dare think of the future. Some hope to get a job to finance their medical expenses. Others hope for a cure for HIV and AIDS. Other concerns are on a macro level such as the concern for governmental policies affecting the lives of people living with HIV and AIDS.

"I was worried also at the same time what will happen to my children. Whom shall they turn to? All kind of things because my brothers have their own families. They won't take my family"

(Female, 54yrs, Lower secondary education, SW)

"I look at the future as very bright for people living with HIV and AIDS now. I mean, there's so much of medication. There's so much of information the government is giving. But it didn't keep its promise of giving all free lah. But at least we have various supports when I compared to other countries like Indonesia, Singapore, Thailand, Philippines. We've got better various supports for medication and things like this. So, it's better for us. Most of the people who are living with HIV and AIDS, as you can see, most of us are doing volunteer work. We don't have a fixed salary, fixed income and we are okay. This is the first line for some of us who are on medication. It's what the government is giving us. What will happen when they go to second line regime? Can the government still support? You know, we still have to look into these issues"

(Male, 50yrs, Upper secondary education)

"I don't know what the future holds for me. I am still searching what I want to do, you know. Peace of mind, you know and everything turns out smoothly. I think that'll be enough"

(Male, 44yrs, Upper secondary education, DU)

"There is no guarantee. I don't know how to plan for my future because I am not sure when I go smoke back or I will not smoke back. Even though if I will not smoke back, I will die because of HIV. It's very hard to plan for a person like me"

(Male, 49yrs, University education, DU)

“Masa depan anak-anak kita. Dia orang makin sehari makin besar. Makin sehari semakin bertambah. Makin mendengar kan. Jadi, suatu masa, satu ketika, kita kena perlu bagi tahu kepada mereka mengatakan kita ni positif, mak positif, isteri pun positif”

(“The future of my children. They grow up at each passing day. Their understanding will be better. So, at certain time, we have to tell them that we are positive, mum is positive, wife is also positive”)

(Male, 50yrs, Lower secondary education, DU)

“Yang paling fikir pasal anak lah sebab masih kecil kan. Kalau boleh kita minta kita sampai dia besar nanti umur dah besar dan tengok berjaya. Banyak-banyak berdoa pada Tuhan sekarang. Susah hati pasal masa depan saya tengok macam mana. Banyak doa saja”

(“The thing I keep thinking is concerning my child because he/she still young. If possible, I want to live to be able to see my child grows up and becomes successful. Pray fervently to God now. I’m distress to think about future, I’ll see how...Just pray only”)

(Female, 29yrs, Upper secondary education, Infected Partner)

“To resettle in another country by UNCHR and work for [my] family”

(Male, 30yrs, Primary education, Refugee)

“I am hoping and praying that one day HIV disease can be healed, and I can be healed too”

(Male, 24yrs, Primary education, Refugee)

“Saya rasa nak kerja untuk teruskan hidup. Boring lah tak kerja. Saya risau tentang sewa bilik saya dan saya rasa ceria nak teruskan hidup. Kita confident. If I get security job pun ok to keep me surviving”

(“I felt like working to continue living. Boring...if don’t work. I am worried about my room rental and I feel motivated to go on living. We are confident. If I get security job is also ok to keep me surviving”)

(Transgender, 53yrs, Upper secondary education, SW)

Economic Impact

Impact on work and income

For many respondents who are sick, they could not continue to work. Majority stopped working may it be due to being incapacitated by HIV illness, forced to resign due to open or tacit discrimination once diagnosis is revealed, or simply asked to leave their job. To many the loss of job and income is another huge blow and especially when expenses would certainly increase as respondents need to spend money on treatment and supplements, thus creating much worry and anxiety. Although many expressed they

would certainly want to continue working once they feel better or recover sufficiently, yet a number of them said they had experienced discrimination as no employer would want to hire a HIVinfected person even after he/she responded well to treatment and medication and would feel fit to work.

“...they are very sensitive. They are very sensitive with this particular disease and like HIV or either you have TB. Even though is the past record you have TB, also they won't accept. Even though now they are already okay, they seem scared, they seemed worried. It doesn't...it doesn't prove that the TB comes back. Because they already have the TB. So these are the things that fear...so, they give us a very ...hard time in our life...they give us a big worry...especially in our financial...”

(Male, 49 yrs, University education, DU)

The economic impact on persons with HIV/AIDS varies by sexual identity, class, gender and age. For example, transgender and sex workers in the study are found to be impacted greater than other groups. Once they fell ill and become very sick they could not carry on with sex work or some stopped because they felt it was wrong to infect others.

Some of the transgender sex workers in the study were almost destitute and on the brink of being homeless and abandoned to die until literally rescued from the streets by WAKE. Often, this group face double discrimination being transgender and sex worker when applying for welfare or monetary aid from local authorities and agencies.

“Mau beli satu ubat, vitamin pun...mau duit. Doktor sudah tadi kata dalam kaunseling cakap lu mau makan ini ubat macam ini macam mau jaga badan, kalau ada duit beli ini barang. Saya semua...ah...ini macam juga. Apa pun mau beli pun mau duit. Sekarang mau makan ubat HIV punya duit pun bulan bulan saya mau beli. Saya mana...macam mana mau pergi cari?”

(“To buy one medicine, vitamin...need money. Doctor told in the counselling you must take this medicine, like this you can take care of your body and health. Whatever needs to be bought, needs money. Now, (I) want to take the HIV medicine, every month I must have the money to buy. Where do I...how do I go find (the money)?”)

(Transgender, 29 yrs, Primary education, SW)

At the other end are the MSM respondents who were economically better off since they worked as professionals and are of higher income status. Women infected by husbands tended to also be badly affected economically, especially if and when husband had died of HIV/AIDS leaving her infected and having to fend for herself and the children as single parents.

“Saya resign sudah sebab aku punya kakak tolong sampai balik – balik sini...Dimana saya harus katakana....kalau saya resign pun...bagaimnana mahu kasi sekolah dia tu tapi nasib...”

“I resigned because my sister helped bring me back home here...how to say...if I resign...how to send (my child) to school...but it’s (my) fate...”)
(Female, 46 yrs, Lower secondary education, Infected partner)

“I do not have money to buy tonic. My husband only gives me RM20 to RM30...what can I buy? And I have to buy clothes and pay for my children’s school fees...Sometimes, I have to search for wild vegetables to make food. Sometimes, go for chopping firewood...”
(Female, 37 yrs, Primary education, Infected Partner)

Their situation deteriorates when they themselves become sick and cannot continue to work. A couple could still resort to Employment Provident Fund while some others had to rely on welfare or charity.

“Dia potong EPF saya. Itu wang juga saya dapat...kalau tak da kerja...tak da wang. Saya sudah berhenti...sudah empat tahun. Mm...saya ...dua tempat saya kerja...saya tak da sombong, tak da malas, tak da apa pun...saya terus kerja juga. Sekarang saya kena sakit...saya berhenti kerja...saya makan itu ubat ah...saya tak boleh...saya pusing...saya tak boleh buat kerja.”

“They cut my EPF. That’s the only money I have...if not working...no money. I stopped working...already 4 years. Mm... I... (used to) worked in two places...I was not proud, not lazy...continue working. Now I’m sick...I stopped working...I take the medicine ah...I can’t...I feel dizzy...I can’t work.”)
(Female, 44 yrs, No formal education, Infected Partner)

Older HIV/AIDS respondents would face greater economic difficulties particularly if they had stopped work prior to diagnosis since they could not have planned for such a financial burden brought about by HIV/AIDS. One retiree respondent was very traumatised and desperate for financial aid as he had used up all his retirement funds that he had withdrawn from the Employment Provident Fund since being diagnosed; he even had to sell off all property that he had - car, house, and even furniture leaving him threadbare with his clothes and a sleeping mattress.

“I’ve been working in hotel line for 20 years. Over 30 years. So I had enough EPF at that time...So I thought I want to relax. That time I feel difference in me. You know, I thought that I’m old. You know, so time for me to relax. Time for me to enjoy life. Because when you work ah...especially when you work in high level hotel industry, you have no time, not much time for yourself. So, I stopped (work), I went ah...Mecca, I came home, I thought want to relax but I became sick...Emm...like now I finish all my money because I have, I though that HIV emm...won’t live long...So, it’s my mistake once I withdrew my EPF, I finished all. Ah...because I thought if I die I won’t bring the money along so I finish my money. That was my mistake. So now...I got nothing left. I have car, I sold. I have a house, I sold. I have even (sold) furniture, my room furniture I sold out...I have got nothing. I have only my clothes my...mattress and nothing else.”

(Transgender, 53 yrs, Upper secondary education, SW)

Impact on career options and upward mobility

HIV/AIDS had impacted on career options and job mobility for all groups of respondents. The MSM, although better off working as professionals, some of them were forced to quit high-paying jobs, or even leave the country, and subsequently had to resort to lower paying jobs.

“Like for myself for example...is ...to compare with the pay that I used to have and my pay now. I mean...there’s a difference...you know...”

(Male, 40 yrs, Upper secondary education)

A member of the MSM group recounted when he was first diagnosed when still working in Singapore:

“No counselling...whether you go this...you go...there is the government in Singapore...They make it very confidential...they won’t tell the company that I work...but they ask me to resign la from the company...because they won’t let you stay in Singapore.”

(Male, 46 yrs, University education, MSM)

For many, the disease had removed whatever potential or better options in their careers.

“Before ...I was diagnosed, I have so many options...you know...I can do so many things.”

(Male, 40 yrs, Upper secondary education, DU)

The impact is far reaching and deep because, as some of them explained, even though they can maintain their health sufficiently to work, they would be discriminated each time they apply for a job as it is now a common requirement that applicants do a medical test and they fear their HIV/AIDS status would be revealed.

“Generally...ah I mean now if you asked us to for job interview...I mean I’ve applied for a couple of jobs and...you know...when you going for interview...there’s gonna be a medical test and...I mean...always when I think of it...I’m...err...it just...arr... it just remind me that may be I have to do a HIV test...of course I’m not going to do because once they do that...that shows there’s discrimination. Why should they do a HIV test...I mean a person living with HIV/AIDS, they still work...ah...so...why they need to do a HIV test...So, I mean but then...if we go and if we do it...if they find out that you’re HIV positive...will they accept you or not? Will any hmm...company or...anywhere...will they accept you or not? So...that...that’s the fear also.”

(Male, 50 yrs, Upper secondary education, DU)

It is particularly daunting for sex workers. A couple of them could not reveal their HIV+ status because they knew clients would refuse their service.

“Dia bukan tanya HIV ke, apa ke, tapi dia tanya kau ni ada sakit tak? Haa, dia cakap macam itu je. Kalau saya kata tak da, haa...kalau kita kata sakit memang dia, dia memang tak buat.”

(“He doesn’t ask about HIV or what not, but he asks are you sick or not? Haa, he talks like that. If I say no I don’t have, haa...if we say we’re sick, surely he, he will surely won’t want to do it.”)

(Female, 45 yrs, Primary education, SW)

However, several of them in the study pointed out they were honest and would reveal their HIV+ status to clients:

“Bagi tau customer”

(“Tell the customer.”)

(Female, 45 yrs, Primary education, SW)

“Tau HIV”

(“Knows HIV.”)

(Female, 49 yrs, No formal education, SW)

A couple of sex workers felt trapped and torn but yet they needed to work to survive, and this predicament could push some to be suicidal.

“Bagi tau lain-lain orang, haa. So malu la. Ada orang ah...boleh bunuh diri tau. Boleh bunuh...”

(“Tell to other people, haa. So ashamed la. There’re people ah...would kill themselves, you know. Will kill...”)

(Female, 36 yrs, Lower secondary education, SW)

Out of desperation, some sex workers would continue working but said they would take necessary precautions:

“Saya kerja pun, saya ada kerja ada pakai itu... (kondom).”

(“I still work, I have work, I use that ... (condom).”)

(Female, 48 yrs, No formal education, SW)

One transgender confessed:

“If I’m healthy, I’m not shy ...I’ll go I’ll put make up and go out find money you know. Until that stage I have to do. Catherine...sometimes at night see me... I wear the wig, I make up...have to look for money, have to eat...ah...that’s why I feel so bad.”

(Transgender, 53 yrs, Upper secondary education, SW)

This sort of predicament also affects the refugees group - some of whom had to hang on to their work despite being physically unwell.

“Sometimes I didn’t get enough sleep, but I have to work just for my daily life.”

(Male, 33 yrs, No formal education, Refugee)

“Yes, it has really affected (me), because I can’t sit long and stand long.”

(Male, 30 yrs, No formal education, Refugee)

Drug users said they were already having financial difficulties due to drug addiction, being diagnosed with HIV and requiring money for medication further compounded their problem. However, a few of them continued to find whatever odd jobs they could to survive when not under the influence of drugs. One even recounted his past when he had to commit crime to feed his drug habit viz. RM1500 per month for heroin.

“Financially then I had to look for odd jobs like selling VCD like that because I need to survive you see. Selling VCD and sometimes I cook with although small, small, small ah...restaurant. Ya, is already far, very far different...because ah...before I work as...I started architecture course I go for higher admin(instruction) in YTL Corporation. So I ...drawing a salary of 6000, so when I was on drugs, I relapse and then I leave the company. I decided on it because I leave a bad name in that place because I was not punctual.”

(Male, 49 yrs, University education, DU)

“Dulu saya terlibat dengan heroin....Saya rasa ah...mencari wang tu...susah sangatlah. Saya nak habiskan pun senang juga. Sebab saya cara gaya hidup saya memang havoc...Bila saya nak bekerja saya rasa duit saya yang kerja tu, saya nak menghabiskan untuk heroin. Untuk sebulan kerja, kalau satu hari kita menggunakan RM50, sebulan dah RM1500. Kalau semata-mata dia nak habiskan untuk me...menghisap heroin ini, lebih baik saya buat jenayah.”

(“In the past, I was involved with heroin...I felt ah...looking for money...was very difficult. (But) I want to spend money it is so easy. Because my lifestyle is truly havoc...When I work, I feel the money from the work, I just want to spend it all on heroin. For one month work, if one day use RM 50, one month already RM1500. If all the money is to be spent on heroin, it’s better I commit crime.”)

(Male, 32 yrs, Lower secondary education, DU)

Economic burden of HIV

With regards to the impact HIV diagnosis has on expenses, the majority would say the bulk of it would be spent on buying medication and supplements (Vitamin C, fish oil, spirulina) to maintain their health. The constant monitoring of the response to treatment in terms of trips to the hospital to check on their CD count also takes a toll on their expenses. This sum varies from RM 350 to RM 2000 monthly.

“The first thing, ya...finance is...every month have to pay...RM300 for medication. Three to six months have to pay RM400 for the blood

test...oh...RM500, ok...CD4...and one year time have to (do) live function (test)...this type of test...that quite costly...”

(Male, 36 yrs, University education, MSM)

To many of the MSM respondents, although relatively of better economic standing than the others, paying for medical expenses cuts deeply into their income amongst other pre-existing expenses such as paying for the car and apartment.

“...since I take medicine...since June I take medicine...and now I really stop smoking...OK la...you will think how you going to make more money to fill this and that...but of course it beats you financially...because I have my commitment to my apartment...car...things and all that. So, I think all of us like taking medicine is some kind of financial burden...”

(Male, 46 yrs, University education, MSM)

“In my case I actually I invested in an apartment...was supposed to be my parents’ old age...and then they can collect rental and all that...after I was diagnosed and I have to take medication...during those time, per month it was RM200...and it was only the medicine you know...and the CD4 (test) was sent outside to specialty lab...and all that was an extra cost...I ended up selling my apartment and using the money for treatment...and I never bought another apartment again...and then now...fortunate the medicine has dropped to such level that is about RM200-300 a month...which is manageable...”

(Male, 46 yrs, University education, MSM)

While the MSM respondents could still manage their treatment expenses somewhat, many of the others had to depend on welfare, charitable organisations, or the NGOs such as Pengasih, KLASS, or the UNCHR for the refugees.

HIV/AIDS Policies, Programmes and PLHIV Participation

Awareness of HIV/AIDS policies

From the study, it is clear that people living with HIV/AIDS themselves have their own opinions as to the level of HIV/AIDS awareness, extent of its acceptance by the public, and their feelings on the gaps and limitations in efforts to raise awareness of the disease.

Respondents from the Intravenous Drug User groups, both from urban (Kuala Lumpur) or rural areas (Kota Baru, Kelantan), have very strong feelings about the gaps and limitations in efforts to raise HIV/AIDS awareness. This could be due to the stereotyping of drug users with HIV/AIDS still prevalent in our society. Several DU respondents from urban group pointed out historically awareness or knowledge on HIV/AIDS tended to focus on negative aspects such as HIV kills and the media portrayal of HIV/AIDS is inevitably of death - pictures of hospitals, the bedridden, and the dying conjuring fear versus educating public to understand people living with HIV/AIDS. They further explained that although the authorities realise their mistake and aims to change the approach now, it is not going to be easy to suddenly dispel such fears long instilled in the public. The way to dispel fears and discrimination against HIV/AIDS is to constantly

positively portray people living with HIV/AIDS in their daily lives, going to work, working towards their future, and can be part of the community.

“Because ah...I feel like you know when first HIV was introduced to the public ah...is like in a way, that you know, they give to the stigma to the public already, you know. The awareness...you see the earliest posters ah...when they say about HIV/AIDS ah...they only show the people who are lying on the bed, you know in the dying stage. You know, the kind of side effects they have and everything. I was wondering why they don't want to show people like us. You know, people who are healthy. But now they are doing it slowly. But earlier, when HIV was you know was...they brought in a very negative way.”

(Male, 36 yrs, Upper secondary education, DU)

“In our country, we started off from the wrong foot. We started off scaring people. Not educating them...That, that is our mistake. Tend to give scare telling everybody you know don't go here, HIV and all that but you don't educate what.”

(Male, 44 yrs, Upper secondary education, DU)

“So they, they give like you know...they do ah... you know ah...documentaries on HIV on you know how the thing will spread and everything but they are very less exposed...about you know the life of people with HIV. You know how they go through their daily life something like that. You know and there's no specific program you know that really tells you know give a very positive...ah...feedback about people living with HIV you know like ah...community service, you know a combined community service, people with HIV and non-HIV...Everytime there's a topic come out with HIV the association they associate the topic with hospital. Hospice, you know are on your way to die. You know, something like that itself. You know, it is not something that you know ah...showing that you know that you can live with HIV, you can have a normal life, you can do things, you know, you can, you can have a future or something like that. Is always narrow down to you know to that (dying)...Maybe if they can broaden up.”

(Male, 36 yrs, Upper secondary education, DU)

Their rural counterparts in Kelantan, on the other hand, lamented the lack of knowledge, awareness, and acceptance of HIV/AIDS in the villages and interior; the reasons being lack of exposure and education on the issue. When there is lack of exposure, the rural community are not able to identify with the issue in their midst, and their perception of HIV/AIDS follows stereotypes such as HIV/AIDS is a problem of the drug user, the sex worker i.e. some other people's problem and not happening in their villages. Moreover, if there is any coverage on HIV/AIDS in the media, the message conveyed is one of fear i.e. HIV kills - agreeing with criticism of their urban counterparts.

“Jadi...arr...pendedahan...ataupun ilmu itu penting sebenarnya. Dan lepas tu masyarakat kita tak dapat accept...sebab...salah satu sebab ialah...dia fikir HIV tu bukan masalah saya. Ah...sebenarnya HIV tu ialah satu masalah...sebab...ia adalah satu ilmu pengetahuan untuk...untuk kita

buat sempadan...lah...untuk keluarga...Sekarang masalahnya dalam keluarga...HIV bukan masalah aku...HIV masalah penagih...masalah sex worker...masalah dia orang...dia orang...dia orang. So, itu yang menjadi menyebabkan...dia orang tak ambil tahu...Bila tak ambil tahu, dia orang tak tahu apa itu HIV."

("So...arr...exposure...or knowledge is important really. And also our society can't accept...because...one of the reasons is...they think HIV is not my problem. Ah...really, HIV is a problem...because...it is one knowledge for...for us to put up boundaries la...for our families. Now the problem in our family is...HIV is not my problem...HIV is problem of the drug user...problem of the sex worker...other people's problem...other people's problem. So, this is why they don't want to take the trouble to know...When don't know, they don't know anything about HIV")

(Male, 32 yrs, Upper secondary education, DU)

A couple of them proposed an awareness campaign should be conducted in the villages and interior distributing leaflets with factual information on transmission of HIV/AIDS to reduce fear and stigma about the disease. They suggested to mobilize the village religious teacher, Member of Parliament, village health clinics to be involved in the campaign.

A few of the respondents in the group of infected partners also criticized the early HIV/AIDS awareness efforts, especially conveying the message that HIV kills and that only the drug user and the sex worker contracts HIV/AIDS. Instead, efforts should focus on understanding and ways to help people living with HIV/AIDS.

"Lagi tu masa tu...dekat I from Kedah...kat situ ada besar-besar signboard...(jalan) ke rumah mother I...'AIDS membunuh'...Kalau AIDS tu...mesti kita mati...mungkin masa tu I boleh bunuh diri ke...apa ke kan...sebab kita tak tau...Jangan iklan tu...AIDS tu pembunuh...jangan main pelacur ahh...apa jangan hisap dadah. Bukan macam tu...I bukan pelacur...I bukan hisap dadah...kenapa saya pun boleh kena...masa tu I muda...macam mana saya boleh kena kan...bukan saja pelacur dan...drug addict yang boleh kena HIV. Semua orang boleh kena HIV...and then, kalau you dah kena HIV...macam mana keluarga boleh jaga you ahh...cara-cara tu yang...kena lagi banyak."

("Also at that time...near...I from Kedah...there is a big signboard... (on the road) to my mother's house...'AIDS kills'...If AIDS ... we must die...maybe at the time I could have killed myself or what not...because we did not know... Shouldn't have that advertisement...AIDS is a killer...don't play with prostitutes ah...what...don't get into drugs. It's not like that...I'm not a prostitute...I don't do drugs...why did I get it...at the time I was young...how did I get it...not only prostitutes and...drug addict that can get HIV. All can contract HIV...and then, if you get HIV...how can your family care for you ahh...these ways...should be more")

(Transgender, 27 yrs, Primary education, Infected Partner)

One respondent's views seemed to pose a good summary about HIV/AIDS awareness and advocacy:

“After my diagnosis...I’ll pay more attention to those AID news. So, I will look at four aspects. First, is government, second is education, third is information and media...fourth is personal. First is government...governement spend lots of money in the AIDS prevention activities but ...most of the times...the impact were not good enough. Basically, it is used to show for the high level committee. Not informative. They only know about what is AIDS and just run away from AIDS...is not enough propaganda. If they want to do this kind of thing...sometime they need many groups of people to voice up and let them know what they should do....Second...is education. We have our human rights, right? Is a normal thing if we bring along a condom...if you want to reduce the probability of people being infected...For the government aspect...we should one special TV program...let those people with AIDS share their experience...what happened to them after diagnosis...the depression on them...their friends’ concern...is either accept or not accept...let all Malaysians know about it...”

(Male, 31 yrs, Upper secondary education, MSM)

Policy/Programme implementation issues

Respondents in the study recounted their experiences of existing policies, practices and programs that tended to disadvantage and to discriminate them, particularly at the work place. Several had related how they had been asked by employers to take HIV test while labour laws currently do not sanction such requests without prior consent of workers concerned.

“HIV test...dia kena minta kita punya izin...tau...Ya...ya...beritahu dekat HR manager...jadi terus...lepas tu saya kena pergi buat test dan saya tak tau kan...dia...apa...Lepas tu saya pun...saya ada bacalah...memang company memang tak boleh buat HIV test tanpa kita punya persetujuan. Yang saya tahulah...macam itu.”

(“HIV test...they must ask your permission...you know...Yes...yes...told HR manager...after that I had to go a test and I didn’t know...after that I read la...it’s true that company can’t do HIV test without our consent. As far as I know...it’s like that”)

(Male, 32 yrs, Upper secondary education)

“This is international labour...a law that...that...shouldn’t do HIV test when they (are) employing people. They don’t need to.”

(Male, 50, Upper secondary education, DU)

Those diagnosed with HIV+ and wish to withdraw money from the Employment Provident Fund, SOCSO or pension had encountered many problems because the latter insisted medical proof that they have been incapacitated but the doctors are often reluctant to issue such medical reports for this purpose.

“Ya...I mean...this is some of the thing that we...we face...em...because we know the plight of the community, we know what their issues needs and

concerns are. And it's so tough for us to get this documentation for them because like for EPF and SOCSO...there is...as long as they've been paying SOCSO...so, there is this...this government insurances things for them. But when they go and ask the doctors...the doctors refused to give a report saying that arr...you...you...still *ada upaya* (have the capacity).”

(Male, 50 yrs, Upper secondary education, DU)

Many respondents also recalled their bad experiences at the hospital when they were first diagnosed. Not all medical doctors and nurses were sensitive and ethical, causing them even more trauma and hurt. Similarly, the humiliation suffered by transgender sex workers, drug users, as well as sex workers when their HIV+ status was announced publicly when tested in the jail or drug rehabilitation centres. The initial stages revealed a lack of pre- and post-test counselling.

“...As I mentioned before, the doctor and counsellor in HUKM wasn't have moral...Because I have tried before that once in the morning...The doctor came with his practical students to make a routine morning check, and looked the patients' medical reports. When he came to my bed and he shouted out when he looked at my medical report. Then he said loudly in Cantonese, that do you know you are diagnosed to AIDS? Would you feel like dying? If you don't feel like dying...ask your relatives and your family members to pay for your medicine about RM706 each month. The medicine at that time are TTD and D40 and cost about RM706. Then, the other patients start look at me unusually and never give me help anymore...none came to visit me and none buy me fruits.”

(Male, 36 yrs, Primary education, Heterosexual)

Another practice that many respondents, especially the Muslims, felt strongly was the manner in which hospitals treated the corpse of HIV+ person who had died. Apparently, it is a practice that the body would not be bathed in the Muslim way or according to any other custom of the other ethnic groups and would not be taken home but straight to the cemetery or crematorium. They are also not happy with the standard way hospitals treat the bodies i.e. sealing them into black body bags giving the wrong perception that HIV+ people could still be dangerous to the public even after death.

“...dia orang kalau meninggal di hospital even dekat rumah pun, dia orang akan ah...pegawai kalau dia tahu pesakit iut yang mati ada HIV dia orang tak mandi...dia orang terus masuk dalam plastic dia orang spray ini apa macam Sheltox...apa..Chlorox kan?...tak boleh buka. Is sealed. Nothing. HIV punya mayat...tak boleh bawa masuk rumah.”

(“...they if died in hospital even in the house, they...officer if he knows patient who has died had HIV, they won't bathe...they will straight put it into plastic bag they will spray with ...Sheltox...what...Chlorox? Can't open. Is sealed. Nothing. HIV corpse...can't bring back to the house.”)

(Transgender, 53 yrs, Upper secondary education, SW)

Related to dealing with dead bodies of HIV+ persons, some are very upset that current policy or practice in hospitals only allows direct family of the deceased HIV+ can sign to claim the body from the mortuary. This is because it is common that either the family did

not know or might not want to be bothered then the body would be kept for 14 days, after which the body could be claimed by non-family. They want this policy/practice to be changed so that a recognized HIV/AIDS NGO can apply to claim the body so that the deceased can be buried or given last rites according to respective cultures in a dignified manner. The Muslims felt very strongly since it is required that the body need to be buried before sunset.

Not surprisingly, majority of the infected women respondents asked if the government could help with free medication and treatment since they seemed the most in need and economically rather vulnerable group in the study.

“Kenapa HIV kena bayar...mmm...sekarang ni saya kena bekerja sendiri...kalau tak ada kerja memang tak ada duit...kalau saya sakit? Sekarang ni saya masih sihat...saya tanggung dua orang anak...yang masih bersekolah...Kalau ada mana-mana pihak yang boleh mengadakan benda ini kepada kerajaan...”

(“Why HIV (patients) have to pay...mmm...now I have to work alone...if not working surely no money...if I’m sick? Now I’m still healthy...I’ve to care for two children...who are still schooling...If there’s any agency that can bring this matter up to the government...”)

(Female, 46 yrs, Upper secondary education, Infected Partner)

As the DU respondents from the urban location tended to be living in homes, some of them expressed there should be an “after-care” program once they leave the homes.

“In this whole program is...something like “after-care”...after-care program is very less. Meaning like you know...we feel safe inside here. But what if we go out, what’s going to happen to us, you know, are we going to face again the same you know, back to square one. Start back the discrimination again...or is that going to have a program. I feel like you know like ah...what they are doing with the people with the addiction problem you know, they have like centres where people can go and for...to recharge back your energy you know to move on and to fight your life, is something like that. You know, they should have like more places for people with HIV to get access, you know, to counselling, to motivation, or to have a place where they can...sit and they can talk and they can feel among themselves you know free...”

(Male, 36 yrs, Upper secondary education, DU)

The transgender sex workers are another group that are also economically vulnerable and powerless. Since they encounter double discrimination, many of them expressed they would welcome more government, statutory bodies, NGOs or charitable organisations to come forward to help provide resources for their medication and treatment in particular. A number of them also asked if other resources like employment and temporary shelter could be made available. Since many of them were either sheltered or working for WAKE at the time of the study, they were grateful to such an organisation providing these resources and hoped there could be more of such set-ups or government could collaborate with such NGOs.

PLHIV participation

In the discussion on problems faced in trying to withdraw money from the EPF, SOCSO or pension schemes, it was said these problems arose because people who are HIV+ are not involved or do not participate in policymaking at the appropriate levels.

“Because we are...we are never...we are never...we are never called to make any decisions on HIV and AIDS. Whatever decisions...it’s people who are handling...I mean...let me be out la. I mean it’s Malaysian Aids Council. In MAC, there’s nobody who’s living with HIV and AIDS...who is working there. So, I mean where...where can we...voice our issues, needs and concerns?”

(Male, 50 yrs, Upper secondary education, DU)

On the other hand, several respondents said they were already involved in the various HIV-related NGOs, such as, KLASS, PENGASIH, Pink Triangle. They either work or are volunteers. Much of the participation is in terms of helping to disseminate information on HIV/AIDS in public places or volunteer in the hospitals to help those diagnosed with HIV/AIDS. A couple of them, especially the men, even had expressed willingness to come out in the public, on the TV, to share their own experiences.

“Like joining KLASS and as one of their members, they will call me for helping them in some activities...I’m already being a volunteer at GH (General Hospital) for 2 years. Go through lots of things and I’m happily seeing everyone doing well now.”

(Male, 36 yrs, Primary education, Heterosexual)

“Should get involved only when about to get the medication. IKHLAS. Pink Triangle and all that...I’m willing to help. I really willing to go openly and say I am HIV positive...The HIV (positive) should be the one of the policymakers because they know how it feels, they know what is happening because it is happening to them.”

(Male, 44 yrs, Upper secondary education, DU)

Generally, the male respondents from the heterosexual and MSM groups were more involved in participation in programs and advocacy. This could be due to their level of consciousness and empowerment given their higher levels of education and economic capacity.

Stigmatization and discrimination

It is well recognised that the stigma attached to HIV and AIDS, and associated discrimination and other violations of human rights against those infected or affected by it, undermines national responses in prevention, care, treatment and support. It is also recognised that HIV-related stigma, in fact, has promoted the transmission of HIV and exacerbated its multi-dimensional negative impact (UNAIDS 2005). It adds to the stigma already attached to behaviours judged as deviant, abnormal, immoral or irresponsible, such as drug use, commercial sex work, transgender and homosexual practices, or groups that are prejudiced against, such as, prisoners and migrants

(UNAIDS 2005). The factors which contribute to HIV/AIDS-related stigma are (UNAIDS 2000):

- ❖ HIV/AIDS is a life-threatening disease
- ❖ People are scared of contracting HIV
- ❖ The disease's is associated with behaviours (such as sex between men and injecting drug-use) that are already stigmatised in many societies
- ❖ People living with HIV/AIDS are often thought of as being responsible for becoming infected
- ❖ Religious or moral beliefs lead some people to believe that having HIV/AIDS is the result of moral fault (such as promiscuity or 'deviant sex') that deserves to be punished.

Resolution 49/1999 of the UN Commission on Human Rights reaffirms that “*Discrimination on the basis of HIV or AIDS status, actual or presumed, is prohibited by existing international human rights standards, and that the term ‘other status’ in non-discrimination human rights texts should be interpreted to cover health status, including HIV/AIDS*” (UNAIDS 2000). Stigmatizing and discriminating actions manifest at the family and community settings, and institutional settings. Examples at the family and community level include ostracization, such as the practice of forcing women to return to their family after being diagnosed HIV-positive, when they become ill or after their partner has died of AIDS; shunning and avoiding everyday contact; verbal harassment; physical violence; verbal discrediting and blaming; gossip; and denial of traditional funeral rites. Examples at the institutional settings include:

- ❖ Health-care services: reduced standard of care, denial of access to care and treatment, HIV testing without consent, breaches of confidentiality including identifying someone as HIV-positive to relatives and outside agencies, negative attitudes and degrading practices by healthcare workers
- ❖ Workplace: denial of employment based on HIV-positive status, compulsory HIV testing, exclusion of HIV-positive individuals from pension schemes or medical benefits
- ❖ Schools: denial of entry to HIV-affected children, or dismissal of teachers
- ❖ Prisons: mandatory segregation of HIV-positive individuals, exclusion from collective activities (UNAIDS 2005).

In this study, there was evidence of most of the above forms of stigmatization and discrimination, more so at the institutional level, and especially in healthcare and social welfare settings, i.e., institutions where PLHIV interact with on a regular basis because of one or other aspect related to HIV. Overall, there were fewer expressions of stigmatization at the family and community level but this was possibly because of limited disclosure. Many of the respondents do not disclose their HIV status, hence, other people – family members, friends and neighbours - are unaware. As noted by one participant, the fear of stigma and discrimination is worse than having the virus itself:

“They [people living with HIV/AIDS] are more scared of the discrimination, stigma instead of the virus itself”

(Male, 36yrs, Upper secondary education, DU)

The exception appears to be in East Malaysia where the HIV-positive study participants, comprising infected partners and sex workers, appear to be unconditionally accepted by their families and their community insofar as very few narrate negative experiences. A few reasons may be speculated for this acceptance: (1) it could be that they have the larger problem of poverty to contend with on a daily basis; (2) there is less exposure to past IEC campaigns which have resulted in perpetrating the stigma attached to HIV through associations with death, sin, punishment, perversion, etc.; (3) the relatively long distances between their residence and the hospitals and other institutions where their status is known makes it easier to keep their HIV confidential and unknown to their community. Which of these possible reasons apply, if any, cannot be ascertained without a study into the attitudes of the local communities in East Malaysia. Some of the same reasons, notably, the limited disclosure and relative isolation from society at large, may also explain the apparent lack of stigmatization and discrimination faced by refugees in this study.

For other participants in Peninsular Malaysia, recollections of poor treatment by the healthcare profession, particularly nurses, testify to the continued stigma attached to HIV, even by those who are most informed about the disease. As postulated by one participant (described under the Health section), some people remain unconvinced about the evidence on HIV, thus, they remain wary about the ways it can be transmitted. Hence, stigmatizing and discriminatory reactions continue to manifest despite years of IEC:

“Itu yang bikin stress tu. Saya selalu masuk hospital kan? Sometimes, ada setengah setengah Sister tu yang jujur.....aaah... Ada setengah setengah Sister juga, dia orang kasi sedia satu.....satu bekas untuk...apa. It's ok dia orang kasi sedia. Memang saya tahu, tapi jangan lah cakap cakap macam engkau begini begini.....macam kau tu nanti mau jangkit sema orang, gitu. Itu saya rasa macam saya tidak mau....tu lah, kadang kadang, saya tidak tahan tinggal di wad. Saya minta pulang. Saya bilang macam kita ni....macam....kadang kadang kita sini ada penyakit tinggi satu kali, semua kena kah satu wad...saya pernah jawab gitu. So, jangan begitu tapi itulah. Tapi, ada juga yang bagus juga lah. Yang bagus tu, kita rasa happy, jadi kita cepat baik. Tapi, kalau macam yang tidak ok ni, sudahlah kita stress, kita sakit, tambah lagi kita stress. Macam mana mau baik?”

(“That is the cause of stress. I am often admitted in hospital, right? Sometimes, there are some nurses who are honest....there are some nurses also who; they give you a....a basin for....whatever. It's ok [for them] to provide this. I do know, but don't say to us you are like this....like I want to infect others, like that. That's why, I feel I don't want...that's why, sometimes, I can't stand being in the ward. I ask to go home [be discharged]. I said like we....like....sometimes we have serious illness one time, [will] the illness spread to everyone in the ward, I've answered that way. But, there are also those who are good. We feel happy with those who are good, so we recover quickly. But, with those who are not okay, we are already stressed, already sick; we have more stress. How can we recover?”)

(Female, 29yrs, Upper secondary education, Infected Partner)

“...bawak saya pergi hospital. And then, pergi sana dah checked..repeated I am positif. Doktor umum dengan I...you are positive. Lepas tu, dia masuk, mask pakai. Tengok, itu cara doktor”

“I was brought to the hospital. And then, went there and checked...repeated I am positive. Doctor informed me...your are positive. Then he came in wearing a mask. Look, that’s the doctor’s way”

(Transgender, 27yrs, Primary education, Infected Partner)

“You go, you go for....endoscopy. The first thing he said was, ‘Okay, biohazard dulu (first).”

(Male, 44yrs, Upper secondary education, DU)

“The treatment not like what they give to normal people, there’s a difference. Like touching you.....they feel reluctant to touch. When the doctor tell them to draw blood...ah...they will think twice. They will ask us whether you can draw your own blood or not. If they touched also, immediately they go and wash their hands. [It] is happening everyday. You can go to the ward and see”

(Male, 40yrs, Upper secondary education, DU)

“There was a lot of discrimination. I was supposed to get operated on but...erm...the surgeon refused to operate on me because I was HIV positive. I was refused operation because of my HIV status. So, it was very very painful at that time, you know, you are being discriminated, discriminated by doctors and when I didn’t get this thing operated on, then I carried on living with it until the thing ruptured. And I was admitted to the general hospital. And then again I was discriminated because I was HIV positive”

(Male, 50yrs, Upper secondary education)

“Yang saya rasa ada berlaku saya discrimination semasa nak cabut gigi di hospital UKM. Sebabnya, sebelum kita cabut gigi dia bagi borang. Ada sakit apa...lepas tu kita ingat tak not bohong lah kan. Masa tu memang dah nak cabut..memang confirmed nak cabut. Tapi dia extend, dia postponed. Ahh....sebab bila I honest kata saya HIV positif kan, dia postponed. Lepas itu dah tak pergi lah situ dah”

“I felt discrimination happened to me when I wanted to get my tooth extracted in UKM Hospital. Because, when we want to have tooth extraction, we need to fill in form. Whether having any sickness...then I thought of not lying. At that moment, it’s going to extract...it’s confirmed extracting my tooth. But he extend, he postponed. Ahh... cause when i’m honest telling that i’m HIV positive, he postponed. Then, I didn’t go there anymore”

(Male, 42yrs, Upper secondary education)

The stigma and discrimination can deter a person living with HIV from seeking treatment, as noted in this quote. As time goes by, people living with HIV/AIDS become immune to this and has to get on with their own lives.

“When you walk in [to the] ID [Infectious Diseases] section only, you know, ID clinic or HIV - he’s even scared to go for treatment, you know. You see [from that] how much is the discrimination, in fact. Ah...the stigma is there! How do you cope with all these, I mean. All of you have gone through the treatment and the people look at you one kind, you know what I mean.”

(Male, 36yrs, Upper secondary education, DU)

“...and treatment is vital for people with HIV. It is crucial, you need to take treatment in order to survive, and this discrimination even scares you to go and take treatment”

(Male, 36yrs, Upper secondary education, DU)

Whether this treatment was due to the HIV status or applies to all bed-ridden patients in that ward cannot be ascertained but one participant told of how it was in hospital when she was so ill and unable to get out of bed or even sit up:

“Nurse sana kata apa? Orang kenal X [mentions own name] - hidung dengan gigi; lain tak kenal! Dekat Sungai Buloh memang X mandi pakai tu troli panjang, bukan kerusi roda, troli panjang. Tiap tiap pagi, nurse kejut, attendant kejut, suruh bangun, pusing, tolak ke bilik mandi, air siram – begitulah!”

(“The nurse there – what she said? People know you from your nose and teeth – the rest they can’t recognise! At Sungai Buloh [hospital], I was actually bathed on a [hospital] trolley, not from a wheelchair, a trolley. Every morning, the nurse wakes me, the attendant wakes me, tells me to get up, turns [the trolley], pushes it to the bathroom, showers me - just like that!”)

(Transgender, 46yrs, Upper secondary education, SW)

At the family and community level, PLHIV participants faced stigmatizing reactions from various sources, strangers, local residents, friends as well as family:

“Ha..macam dekat kampung, dia orang dah tau dia positif. Dia orang tak nak kawan dia, asingkan dia. Dia orang tak nak cakap dengan dia”

(“Ha...like in the village, the people know that he/she is positive. They don’t want to befriend him/her, isolate him/her. They don’t want to talk to him/her”)

(Transgender, 27yrs, Primary education, Infected Partner)

“They worried that when I look at them, they will become AIDS patients too...therefore all of them ran away from me”

(Male, 36yrs, Primary education, Heterosexual)

“Saperti mana kawan-kawan yang duduk dengan saya mula menjauhkan diri daripada saya. Tak apa. Dia orang tak ada pengetahuan tentang HIV. Yang dia orang tahu HIV boleh merebak. Itu saja. Kemudian, saya

berpindah ke tempat lain makin lama..ah...kesihatan badan saya down”

“Like my friends who lived with me, began to stay away from me. Never mind. They don’t have knowledge on HIV. All they know is HIV can spread. That’s all. Then, I moved to another place. As time passes by, my health [went] down”)

(Transgender, 40yrs, Lower secondary education, SW)

“Saya ada cerita dekat kawan baik saya...arr...pasal saya...saya punya status. Dekat ofis, lepas tu, dia pun beritahu pada management. Jadi, saya marah dengan dia sampai sekarang. Lepas tu, bila human resource dapat tahu, dia pun suruh saya berhenti. Dan lepas human resource tu tahu, macam mulut cepat sampai. Semua orang tahu. Saya pun terus tak pergi kerja lah. Saya terus tak pergi kerja, saya masuk rehab”

“I told my good friend...arr...about my...my status, in the office. Then, he/she informed the management. So, i’m angry at him/her until now. After that, when the Human Resource know, they asked me to resign. After the Human Resource knows, words spread very fast. Everyone knows. I immediately didn’t go to work. I didn’t go to work, I entered rehab.”)

(Male, 32yrs, Upper secondary education)

“There is one experience after I found out...after I diagnosed, I got to know one guy. We went out at the time. It’s very soon, quite soon after my diagnosis. I’m still not very sure whether to revealing my status. So, I went out with this person for a month, we made up once. I am sure we can safe as far as we could and on the controlling. After a month or plus, I told him I reveal to him...and not surprisingly he didn’t keep attached with me”

(Male, 24yrs, University education, MSM)

Clearly, not only for some members of the healthcare profession described earlier, fear of contagion is evident as a source for the stigma on HIV among the community:

“I was sitting with this guy, HIV patients and this guy sneeze. You know, and the officer working in the government section, suddenly, you know, close his mouth, you know, face and everything, and then he asked me, “can HIV spread through sneezing ah?” I got damn mad”

(Male, 36yrs, Upper secondary education, DU)

“Dia punya mak cakap macam itu - saya banyak susah hati. Itu baby, itu lima tahun punya budak cakap sama saya, “Mak Cik, mak cakap jangan duduk sama awak. Jangan duduk sama awak. Nanti, Mak Cik punya sakit saya kena”. Saya susah hati. Saya diam jugak. Tak apa lah. Ini budak kecil, tak boleh marah dia”

“His/her mother said to him/her like that - I [was] very upset. That baby, that 5 years old child said to me, “Aunty, my mum said don’t sit beside

you. Don't sit beside you. And then, your disease I will also get". I [was] upset. I kept silent. Never mind. That is just a small child, cannot scold him/her")

(Female, 44yrs, No formal education, Infected Partner)

There were accounts of stigmatization from family members, and for a few, this was enough reason to decide to move away:

"I yang paling kecil hati (truly upset) sekali adik beradik I sendiri (especially at my own siblings). My, my brother...erm...organised a wedding, the daughter's wedding in Johor Bharu. I was not invited. Just because they don't want me to be in their car"

(Transgender, 53yrs, Upper secondary education, SW)

"Especially, there are some relatives who are not....don't understand much about HIV. When they come to the house, they saw you, they are so scared that you will go and carry their children. They will ask their children "don't go near Uncle XXX ah...Uncle XXX is HIV person". This is very embarrassing. I can't scold because the result is already proven. I have to accept the fact. I think that's why we have to leave the house. Sometimes, is not like the parents chase you away from house. My parents are very understanding, just my relatives"

(Male, 49yrs, University education, DU)

"Anak buah sampai pernah I dengar. I dalam bilik I, tau. My sister is staying in one bungalow in Melawati. I overheard my nephew told my sister, Mak, uncle tu ada HIV. Takkan nak tidur sini, nanti berjangkit. You know, how do you feel? Your own nephew."

("I heard it before from my kin, I was in my room, you know. My sister is staying in one bungalow in Melawati. I overheard my nephew tell my sister, "Mother, that uncle has HIV. Surely, [we're] not sleeping here? Then, [we'll] be infected". You know, how do you feel? Your own nephew".)

(Transgender, 53yrs, Upper secondary education, SW)

However, stigma can be conveniently forgotten if it serves a purpose – a family in Kelantan had arranged a marriage for their son despite knowing he was drug dependent and concealing it from the prospective bride and her family. Although he later passed on HIV to his wife, their two daughters are not infected. He subsequently died leaving her, a housewife with lower secondary education, to fend for the family. Fortunately, she always had the support of her own family members, notably, her mother. It was her mother to whom she first disclosed the result of her HIV test after her husband's death.

In fact, drug users feel they face discrimination from society because of their drug dependence, and HIV is ancillary to those existing negative perceptions:

"Salah satu sebab...actually kalau orang kampung ni kebanyakan dia tengok pula, macam HIV, dia nampak pada negative behaviour tadi. Contoh, macam institut penagihan...penagih dadah. So, dia tak nampak"

pada HIV itu, dia nampak penagih. So, bila dah nampak penagih, dia tak nampak...jadi negatif lah. Buat apa kahwin dengan penagih...bercerai. Bukan dari segi sudut HIV tu tadi, tapi dri segi penagih itu. Ah...jadi masalahnya di situ. Masalahnya dari segi penagihan, bukan dari segi HIV tu. Ah...bila dia sudah test HIV, dia nampak sebab orang ni dapat HIV dari segi sebab menagih”

“One of the reasons...actually in the case of the villagers/locals, most of them look at, like HIV, they look at the negative behaviour. For example, like the addiction [rehabilitation] institution...drug addict. So, they don’t see the HIV, they see the drug addict. So, after seeing a drug addict, they don’t see...so it’s negative. Why marry a drug addict...divorce. Not from the HIV perspective but from the addiction perspective. Ah...so there lies the problem. The problem is from the addiction perspective not HIV. Ah...when tested for HIV, they see it as these people (drug addict) got infected because of addiction”)

(Male, 32yrs, Upper secondary education, DU)

It is known that certain categories of PLHIV face discrimination more than others in various ways, including access to resources. For example, until recently, HIV drug treatment was supplied free to certain PLHIV groups, i.e., women infected from their spouse, infected children, those infected through blood donation or through work-related hazards. Infected wives also have easier access to non-medical aid. There is a measure of public sympathy for these PLHIV groups who are seen in the public eye as innocent victims. Be that as it may, stigmatisation persists even for them – infected children may not be allowed to play with other children, wives may be blamed for their husband’s continued drug addiction or their sexual infidelities, people may refuse to eat the food they cook or prepare, or sit beside them in the mosque, the wife and children may opt to move to a location where no one knows of her HIV situation. These are the experiences of the study participants. In this regard, there is no doubt that marginalised groups endure more. Transsexuals, more so if they are also sex workers, bear the brunt of society’s non-acceptance in many ways, including, when attempting to access financial assistance:

“Ya lah, sekarang ada bantuan okay. Sekarang, derma untuk HIV AIDS, okay. Then, tiba tiba nak pergi je atau pun dapat tau je dia ni TS – yang kena HIV ni TS – and then dia orang fikir- nak bagi barang ni nak fikir dua tiga kali, nak bagi atau tidak. Itu masalahnya.”

“Yes, now there is assistance, okay. Now, there are donations for HIV AIDS, okay. Then, suddenly [we] go or [they] find out the person is a transsexual – the HIV-infected person is a TS – and then, they think – to give this thing [assistance], they think two or three times, whether to give or not. That’s the problem.”)

(Transgender, 40yrs, Lower secondary education, SW)

“Baitulmal memang ada satu guideline. Dia kata bukan semua pesakit HIV boleh bagi duit. Dia kata kalau orang itu terkena macam pertukaran darah ke....kalau macam tu, kita bagi. Kalau macam dia memang sex worker, memang kita tak bagi.”

“Baitulmal actually has a guideline. They say not all HIV patients can get money [financial assistance]. They say if a person gets it, like, from blood transfusion...or like that, we give. If he/she is a sex worker, in fact, we don't give.”

(Transgender, 46yrs, Lower secondary education, SW)

“Macam saya, hari itu, minta bantuan perubatan dekat Baitulmal. Dia tanya...first, first dia tanya – awak kerja apa dulu?”

“Like I, that day, asked Baitulmal for medical assistance. They asked...in the first place they asked – what work did you do before?”

(Transgender, 46yr, Lower secondary education, SW)

“Macam mana? Kita serba salah, kan? Kalau cerita sebenarnya, nanti tak dapat bantuan. Nak membohong pun, nanti, dia boleh, apa, trace balik. So kita serba salah, tak tahu nak cakap macam mana.”

(How? I'm in two minds, right? If I tell the truth, I may not get help. If I lie, they could trace back later. So, I am confused, not knowing how to tell them.”)

(Transgender, 40yrs, Lower secondary education, SW)

Perceived fear, stigma and discrimination

Apart from the actual experiences of stigma and discrimination faced by the participants, PLHIV also suffer from perceived fear, stigma and discrimination. To avoid any from actually happening to them, they isolate themselves away from non-positive people or keep to their circle of positive friends:

“Ini sakit ah tak boleh tau semua orang...banyak problem nanti. Saya tak boleh tahan. Itu pasal saya tak mau kasi tau sama dia orang. Dia kawan sama sama cerita lain lah”

“This illness ah...cannot tell everyone...and then, [there'll be] a lot of problems. I cannot take it [problems]. That is why I don't want to let others know. Being friends with those who have the same story [is] different.”)

(Female, 44yrs, No formal education, Infected Partner)

“When you already know that you already infected with HIV, you already have fear in that person. That fear is hard to explain, so I can still manage that kind of fear. But other things, that whenever we fill the form for that particular work that you go for interview. There's one particular column, they will write if...do you have any disease or sickness in that part. So, when you sincere to yourself...ah...you write yes HIV positive. So, when the boss read your particular form, everything, once come to the column HIV. I think I call you tomorrow...ah”

(Male, 49yrs, University education, DU)

“People looked....uneasy lah. They look at you like an alien. At times, it is as though they are looking at something that is dirty, you know, something that is already contaminated. No doubt...yeah... contaminated. But, the look they gave us is scarier than the words they have to say. We are only humans, we have emotions also”

(Male, 44yrs, Upper secondary education, DU)

“Fear others will look down on me. Fear others are afraid of me”

(Female, 43yrs, Primary education, Infected Partner)

“For me, if I tell the community/family, they may not love me like before. I mean, I fear that they may reject me lah”

(Male, 24yrs, Primary education, Refugee)

“I did not tell my family because I am afraid they will hate me. If my family knows, may be they kick me away”

(Female, 40yrs, Lower secondary education, SW)

To summarise, the FGDs revealed that PLHIV in this study, whether they are infected partners, heterosexual men, MSM, transsexuals, drug users, refugees or sex workers, face and fear stigmatization and discrimination in their every day lives. Some have experienced insults, harassment, ridicule and humiliation. Some have been forced, overtly or subtly, to resign from their place of employment.

Although moral judgements may play a part, it is evident that fear of contagion by HIV-infected people is one of the root causes of the stigma attached to HIV. Clearly, years of IEC have not convinced people of the routes of transmission and lay-persons, and even some healthcare workers, are still fearful of being infected from casual or close contact. The persistence of this misconception is supported by the FGDs with communities (described below) and needs to be redressed. Moreover, with such prejudice and discrimination against PLHIV, the breach of confidentiality from healthcare providers or related HIV agencies assumes greater significance in light of the severe psychological and emotional stress it causes. Whether real or perceived, this fear of stigmatization and discrimination affects their quality of life and denies them social and economic opportunities through not only negative actions by others but also self-imposed isolation and limitations.

Voices from the Community

Four FGDs were conducted, two in a rural community and two from an urban setting. In each of these communities, discussions were conducted in sex-specific groups of eight to ten participants each with ages ranging from 20 to 50 years of age.

Knowledge of HIV/AIDS

Transmission

All members of the community have heard of HIV/AIDS but their level of knowledge differed. All members associated HIV/AIDS with drug abuse. This was especially so in the rural community where according to the members they have had one of their village youths who worked in the city contracted it and was buried in the village. There were also conscious of the fact that it is the sharing of needles in drug abuse that spreads the infection – “*Jarum, Berkongsi lah. Suntikan dadahlah. Orang yang menagih dadah lah.*” (Sharing needles. Injecting drugs, people who are addicted to drugs). One participant felt that it was drugs that also lead those who abuse it to indulge in risky behavior including having “*seks bebas*” (free sex).

“Dadah yang negatif ah..yang dilarang oleh kerajaan. Bila dia kena dadah dia carilah perempuan – perempuan sumbangan hubungan seks kan”

(“Drugs that is negative, that is forbidden by the Government. When they get addicted they search for girls – girls source of sexual relations isn’t it?”)

(Urban, Malay, Male)

All the participants also agreed that the infection could spread through sex with multiple partners. Some the terms used included:

“seks rambang” (casual sex)

“Pergaulan bebas”(free socialising)

“Bertukar-tukar pasangan” (multiple sex partners)

“Seks bebas” (free sex)

They also mentioned that homosexuality can also spread the virus.

“membuat atau melakukan hubungan seks dengan sesiapa saja sama ada perempuan atau lelaki sama jenis ataupun sama jenis ini cara berlakunya.”

(“Having or doing sex with anybody be it women or men same sex or same sex that is how it spreads”)

(Rural, Malay, Male)

However this association with the needle and drug has also lead to a few members believing that that it can also be spread through blood donation as well as blood transfusion.

“derma darah kepada orang, orang itu pun kena.”

(“Donate blood to others. The recipient can be infected too”)

(Urban, Malay, Male)

Mother to child transmission was also named.

“Kelahiran, kalau katalah emak kepada bayi”

(“birth, if say from mother to baby”)

(Urban, Indian, Male)

A few of the members were of the thought that it can spread through crockery *“bekas makan”* as well as food. This is because they think that it can spread through saliva as well as the fact that food can be contaminated with blood of the infected person.

“Bekas makanan. Tulah....yang saya fahamlah.”

(“Food container that....as I understand”)

(Rural, Malay, Male)

Treatment/cure for HIV/AIDS

All members of the community were aware of the fact that there is no cure for HIV/AIDS. It is also this fact that makes people fearful of coming into contact with PLHIVs. There were also aware that when infected we are treated in hospitals. Some believe that they are isolated from others but others simply did not know.

“Saya, yang saya dengar, saya belum pernah dengar lah, tapi saya pernah terbaca di akhbar mengatakan kerajaan amerika syarikat masih lagi membuat research nak cari formula untuk ubat HIV ini, tapi masih belum lagi lah.”

(“I as I have heard, I have never heard, but I have read in the papers that the American government is still researching to find a formula for HIV drug, but not yet”)

(Urban, Malay, Female)

“Entah. Saya tak pernah dengar pulak ada wad lain”.

(“Don’t know. I have never heard of a separate ward”)

(Urban, Malay, Female)

Characteristics of an infected person

Most agreed that it is not possible to differentiate an infected person from one who isn't and that anybody can be infected. Even when they have AIDS we cannot tell if a person actually has AIDS.

“Pada peringkat akhir pun susah juga untuk tahu sebenarnya. Sebab I ada pengalaman, dengan sepupu I, penghidap HIV, doktor mengesahkan dia ada pesakit HIV, keluarga semuanya terperanjat sebab dia tak tahu sebelum ini dia ada sakit biasa sebenarnya dia sakit HIV, so rupa pun macam orang biasa tak macam orang sakit.”

(“Even towards the end it is difficult to know for sure. Because I have experience with my cousin infected with HIV, doctor confirmed that he was living with HIV, all family members were surprised because before this he was ill but he thought it was normal illness but it was HIV. He looked normal, not like a sick person”)

(Urban, Malay, Male)

Some associated being infected to drug abuse. Therefore it was not surprise to find some members saying that if they looked like a drug user there was reason to suspect. One member thought that they look pale. On the other hand another member said that as the disease progressed they grew thinner and thinner (this rural Malay woman witnessed her friend die of it)

Sources of Information on HIV/AIDS

Source of information about HIV/AIDS include the following:

- The Media including the television and the radio
- The Newspaper
- Websites
- Doctors
- Programs conducted by the Ministry of Health, PEMADAM and the National Drug Agency
- Friends
- From their children (teachers in the school had conducted a seminar on HIV/AIDS)
- Magazines

Attitudes and Perceptions Related to PLHIV

Stigma and discrimination

Attitude towards PLHIVs seem to be dependent on how they have acquired the infection. The general feeling is to sympathize with those who were infected through blood transfusion but with those who were infected through drugs or illicit sex received no sympathy from the community.

“.....depends on who is the person, like the drug addict or the sex worker, No, no, no feeling for them lah. So like those who accidentally *kena* (acquired) one, we just act normal. act normal ah, we friend, we act like you don't have the HIV lah. Don't avoid him.”

(Urban, Chinese, Male)

Nonetheless, it was obvious that while the participants feel that they should be sympathetic and caring they had reservations and this forces them to be cautious.

“Yalah biasanya...mereka yang dah kena HIV tu...biasa masyarakat biasanya tak boleh terimalah. Tak berani nak berkawan. Sebab yalah mungkin takut. Mungkin mereka pun berhati-hati takut terkena pada diri mereka ke. Tapi tulah....sebenarnya kita tak boleh pandang rendah jugakan?. Jadi...kita kena beri sokongan kepada tulah..kanak-kanak ke...orang yang dijangkiti HIV sebab HIV ni tak merebak melalui sentuhan...tapi melalui itulah...HIV darah...hubungan seks tukan?..contoh kalau kita berkawan, tak apa...boleh.”

(“Yes, it is common those who have been infected with HIV it is common that society do not accept them. Not brave enough to befriend. Because yes maybe they are afraid. Maybe they are also cautious because they are afraid of being infected. But actually we should not look down on them also isn't it? Therefore we should support them, to the children, to the infected because cannot be transmitted through touch but HIV is transmitted through blood and sex right? For example if we befriend them cannot”)

(Rural, Malay, Female)

“Guru pun sama. Bila macam dapat tahu, ada sebahagian guru-guru akan rasa kurang selesa. Mana...dari segi penerimaan tu terlalu berhati-hati. Mana mungkin takut nak sentuh dia....takut nak dekat, nak rapat, nak bercakap pun takut.”

(“Teachers are the same. When they get to know some of them feel uneasy. They will accept them with caution, where they are scared to touch, scared to be near to speak to them also fearful”)

(Urban, Malay, Female)

Not only society stigmatises people with HIV. They also tend to throw blame on the infected as well as their family members.

“Macam kawan saya tu...dia suami dia penagih kan. Tapi dia dapat kat dia tapi.. ah, macam famili suami dia tu pasal macam berpunca daripada dia. Tuduh dia.”

(“Like my friend...her husband was an addict. Then she got it from him but her husband's family says that it was from her. Blames her”)

(Rural, Malay, Female)

Attitudes towards PLHIV as neighbours

Stigma against PLHIVs and their family is rampant although the community FGD participants were not conscious of the fact that they were indeed stigmatizing PLHIVs. On the one hand they say that they will accept them into the neighbourhood they would also ask their family members to be careful (berhati-hati).

“Kalau apa, kalau kita tahu, memang tak ada masalah lah. Cuma dari segi keluarga kita, kita just inform dekat semua famili, untuk ...mungkin jangan pergi ke sebelah. Tapi kita, just inform pada keluarga tanpa pengetahuan merekalah. Dari segi nak duduk sebelah tak ada masalah.”

(“If we know, it is definitely not a problem. Only with our family we just inform them not to go next door. But we just inform our family without the infected person knowing. If they just want to live next door, no problem”)

(Rural, Malay, Male)

“Pada pandangan saya lah, saya buat macam biasalah. Kawan biasa, tapi macam Mr. G pun cakap kita take precaution.”

(“In my opinion, I will act normal. Normal friends but as MR. G said we take precautions”)

(Urban, Chinese, Male)

This obviously shows that by having to say the family should take precautions we have indeed driving a wedge between the infected and the community. Perhaps the avoidance is borne out of fear of being infected by them. One member was quick to point out that with knowledge on how it is spread he has changed his feelings from avoidance to one of sympathy. At no time should society hate them.

“So they will avoid him, that’s the first thing lah. The other thing I wanted to say, the public view also is created because of the Government. Because see as Che Kah was telling, when they brought the body of his cousin, they didn’t even let them go near. So the government has put, some sort of impression, you know, the seriousness of the sick. So, when you have a patient in the family, they will know the family, the outside also will feel the same thing. So, that actually ahh...part of it and I have come across a lot of that thing also they don’t even, don’t the coffin completely blocked, closed....so you can even by seeing it you can get it is it? So one you have a family member with AIDS, so the public have that type of impression you know.

(Urban, Indian, Male)

Perhaps the following statement sums up how out Malaysian society view PLHIVs

“Saya...pengalaman saya memang...memang masyarakat takkan terimalah. Mulut kata takpa-takpa tapi hati ini...memang tak boleh terima.”

“I ...my experience society will never accept. Mouth says never-mind, never-mind but they will never accept”

(Rural, Malay, Female)

Employment for PLHIV

Most feel that they should continue to be employed or be given employment because they need to sustain themselves, but some were quick to point out that they should given work that does not run the risk of being physically hurt (resulting in bleeding). Some say that they should be far enough so that there is no possibility of coming into contact with the saliva of the infected.

“sebenarnya kita kena beri peluanglah Kita kena beri peluang”

(“actually we have to give them the opportunity. We must give them the opportunity”)

(Urban, Malay, Female)

“Dan mereka ini perlu diasingkan dan diberi kerja tempat yang disediakan khas untuk...untuk mereka”

(“And they should be separated and given a space specially for them”)

(Urban, Malay, Male)

A few of the participants were of the thought that they should not be taken into the food industry because of the fear that they can contaminate the food they serve. Others felt that they should be treated like the disabled where they can come together and produce handicraft for sale.

Impact on the family

“Segan” [Shy] and “Malu” [Shame] explains how families feel when a member is infected. However, one member was quick to add that it was the community’s mistaken perception.

“Malu. Sebab masyarakat ini pandang seronglah kalau kata orang ada HIV ni. terkena HIV, mesti ada masyarakat pandang serong.”

(“Shame. Because the view of our society is distorted. Infected with HIV, society will have distorted views”.)

(Urban, Malay, Female)

“Yang pertama, mereka akan malulah, malu besar, sebab rata-rata kita tahu, semua orang tahu bahawa HIV/AIDS akan ditentukan datang daripada hubungan seks, itu yang pertama, sebab yang paling atas sekali, jadi dadah ini mungkin jatuh kepada nombor dua, nombor tiga yang lain, jadi bila mereka disahkan HIV, itu yang masyarakat tahu. Jadi yang itu yang menyebabkan mereka malu. Tapi pada saya, sebenarnya benda itu biasa saja, tinggal lagi mungkin kerana mereka tu tidak ada pengetahuan

untuk melaku seks secara selamat. Tapi mereka terpaksa menerima kesan yang mereka malu besarlah.....Oleh kerana you ni orang jahat, you ni jadi banyak benda yang akan dituduh kepada penyakit.”

(“First they will be shameful. Very shameful because everybody knows that HIV/AIDS is a result of sex, that is number one, because it is the highest, drug is perhaps the number two cause, three due to others. Therefore when it is confirm that he has HIV the society knows. This is what makes them shameful. For me it is a normal affair, it could be because they did not know how to have safe sex. But they must receive the consequences - very shameful.....Because you are a bad person you will be infected”)

(Rural, Malay, Male)

On the other hand affected families are already depressed over the matter and should be shown some sympathy. Furthermore the community does not really know how the person was infected in the first instance. In conclusion it could be noted that that some members were sympathetic but others do judge the family but whatever their feeling these families “*memang diabaikan*” (“definitely avoid them”) (Rural Malay Male) and participants were also aware that even after the death of the individual families continue to isolate themselves.

Marriage for PLHIV

Most of the participants felt that they should not marry if one of them tested positive before marriage but if both were positive it was different. Still others say that it is up to the couple themselves. They can marry but must receive counselling to understand the consequences as well as to protect themselves.

“Tak boleh lah..tak mau..kalau kalau perempuan kena HIV..laki-laki tentu dia tak mau.”

(“Cannot lah...don’t want ..if the woman tested positive the men will definitely not want”)

(Rural, Malay, Male)

“Jangkit satu orang lagi.Dia jadi dua kan. Nanti keadaan dia jadi tiga....kalau kita tahu tak payah lah.”

(“One infected, it becomes two. Then it becomes three. If we know no need lah”)

(Rural, Malay, Male)

“Boleh....boleh kahwin, no problem. Tapi you must knowlah you tak boleh dapat anak because of you. I you. So macam mana nak dapat anak. Kalau...kalau dia dah macam memanglah nowadays dah cinta sangat, dia tak kira apa. Makbapak cakap jangan, dia kahwin juga. Tapi we need to give counseling dan berpanjanganlah. That one kesan ...bahagian kaunselor dan NGO kena ambil..ambil tu lah.. dalam hal ini”)

“Can...can marry, no problem. But you must know you cannot have a child because of you. So how if you cannot have a child? If they really love each other and nowadays they do not heed their parent’s advice and they want to marry also. They must be counseled.....long term counselling. NGOs must give attention to this”)

(Urban, Malay, Female)

Schooling for positive children

Participants were in agreement that all children need to be given the opportunity to go to school. However there was debate on whether the schools should be informed.

“Kena beri peluanglah, sebab mereka ini kadang-kadang adalah mangsa dalam keadaan. Makna bukan salah mereka jadi kita kalau macam saya, saya ada anak...jadi saya kena beritahulah dengan anak saya, kan. Maknanya beri sokongan berkawan, kan. Dan cuma mungkin class teacherlah. Setiap guru yang masuk tu pastikan supaya mungkin kanakanak tersebut dia tak cedera, tidak ada berlaku perdarahan. Tapi kalau setakat pembelajaran biasa dalam kelas tu, saya rasa tak ada masalah. Kena terima sebab mereka ini pun sebenarnya mungkin berpeluang untuk ke peringkat yang lebih tingg.”

“Must give opportunity because they are sometime the victims of circumstances. This is not their fault. If it is me and I have a child, I will inform my child. Meaning support them by befriending them. And only perhaps with the class teacher.. Every teacher who teaches the child, ensure that he does not get hurt, does not bleed. But if it is just from the standpoint of allowing them to study most of the time in a class situation, I feel that is not a problem. We need to accept that they may be able to study to higher level”)

(Urban, Malay, Female)

“Tetapi guru kelas yang murid ada HIV tu ...guru kelas atau pun sekolah...ketua tu mesti tahu apa...murid itu ada HIV tetapi guru kelas mesti apa...ada main peranan penting...jangan beritahu, jangan hebohkan. nantihobkan...seluruh sekolah heboh jadi lagi apa terjadi”

“But the form teacher of the positive child or the head teacher must know that the child is positive. But the form teacher has an important role to play....don’t spread the work. Otherwise the whole school may know and then what will happen”)

(Urban, Indian, Female)

According to one urban Malay male perhaps we could run a residential school to house only children with HIV/AIDS so that better attention can be given to them.

Impact on the nation

Community members were aware of the impact of HIV/AIDS on the country. The following were way by which the infection can impact the country:

- Affect total population – we already cannot achieve the 70 million target
- Loss of human resource
- Affect the economy
- Brings shame to the nation
- Expense to the country having to treat the number of infected
- Affect tourism

Prevention and Control Strategies

Knowledge about policy and programmes

Participants were able to name the departments and agencies involved in HIV/AIDS work: Among those that were mentioned were:

- Ministry of Health
- NGOs
- Youth organisations
- Schools
- The Police

However because of their belief in the relationship between drugs and HIV/AIDS, Almost all of them felt that there is a need to control drug abuse and in some instances sex work in the country.

“Perlu menghalang penagihan-penagihan dadah, dadah yang mana punca dadah itu, tak ada dadah tak adalah HIV. Tak ada tempat maksiat tak adalah HIV. Di tempat-tempat itu, polis yang 100% kena jaga, selagi benda itu tak habis, selagi tu lah benda HIV ini tak putus...pada saya”

(“Must prevent the abuse of drugs, drug is the source, no drugs no HIV .no immorality no HIV. In such areas the polis must be vigilant, as long as these two matters are allow to go on the HIV matter will not end”)

(Rural, Malay, Male)

“Saya rasa yang utama tadi, saya berbalik kepada yang ...polis kena dengan...untuk jaga. Kurang-kurangnya kuatkuasa pelacuran dan dadah. Kalau dua ini dapat dihapuskan, saya rasalah....sebahagiannya kita dah boleh, mungkin lebih daripada itu, mungkin 70% boleh dapat dikurangkan”

(“I feel the most important..and I want to go back to the police who have to take care of. At the very least they should control prostitution and drugs. If these two areas can be rid off I feel at part of or perhaps we can have a reduction of 70% of the problem”)

(Urban, Indian, Male)

Harm Reduction programme

Some urban community members have heard about “Harm Reduction” but many were against it. This is partly due to their lack of clarity about the project,

“...yang terbaru saya dengar, mereka...apa, memberi setiap orang kondom, macam...like this, saya anggap tu adalah seperti mengalakkan...dari segi pengalakan, bukan mencegah tapi mengalakan orang itulah.”

(“Just recently I hear they what, give each person condoms, I feel it is like encouraging, not preventing but encouraging the person”)

(Urban, Malay)

“saya rasa tak berkesan lah”

(“I feel nor effective lah”)

(Urban, Malay, Male)

“Malah, mengalakkan....”

(“on the other hand it encourages”)

(Urban Malay, Male)

“kerana penagih, kalau dapat benda tu percuma, lagi banyak dia ambil. Sebab saya pun, pengalaman saya, saya bercampur pun....saya pernah campur dengan drug...drug addict. Kawan-kawan saya pun, ada yang penagih, Cuma belum jumpa yang ada HIV aje, macam ada program-program macam ini, dia orang, tak tahu, kerajaan buat apa dia tak tahu, dia sendiri seronok. Ahh tapi bila dapat tahu, kerajaan bagi dia lagi bertambah lah, bukan ingat nak kurang.”

(“Because, addicts when they get something free the more they will take.... I have mixed with drug addicts. Some of my friends are drug addict. Only have not known any who has been infected yet...if have such a program they do not know what the Government is doing they only get high themselves...don’t think of wanting to reduce”)

(Urban, Malay, Male)

On the other hand one participant was able to explain that it involved needle exchange and not needle dispensing. A few were supportive of it and felt that it is a good long term preventive measure.

“They’ll give you, you need the old needle, you need to give back government. Government will issue you the new one.”

(Urban, Chinese, Male)

“Tapi saya rasa lebih baik lagi bagi prevention. Macam hari dia orang kata bagi syringe. Disposable syringe.”

“But I feel it is better for prevention. Like they said the other day, they give syringes – disposable syringe”

(Urban, Malay, Female)

“Ya, saya rasa ya. Because mereka...you know....sebab kalau dia orang tidak dapat beli pun and then dia guna ok sharing ...so at least we prevent untuk mungkin yang ini ...yang itu belum dapat and then dia tak transfer dia punya viruslah.”

“Yes, I feel yes. Because they you know if they cannot buy they will share. So at least this way we prevent the possibility of them transferring their viruslah”

(Urban, Malay, Female)

HIV control

In order to control the spread all the participants felt that it must start with the control drug abuse in the country.

“Drug memang nombor satu. Kerajaan kena ambil langkah daripada awal,memang tak tahu, dadah itu sentiasa ada.....mungkin kerajaan boleh utamakan pada sempadan-sempadan negara kita ...mungkin pantai-pantai di negara kita itu perlu nak di sekat.”

“Drug is number one. The government must take action from the source ...actually do not know.drugs always there. Maybe the Government must focus on the borders of out country ...maybe the coastline also”

(Rural, Malay, Male)

One participant was of the thought that gay clubs should be shut down.

“Kelab, di dalam, studios dia pun, gambar-gambar lelaki dengan lelaki kena pakai kondom aje, tapi mereka masih lagi melakukan hubungan sesama dengan dia, dengan dia, dengan dia. ...harap kerajaan mencegah bukan mengalakkan , mengalakkan dari segi benda-benda macam tu lah.”

“Clubs and also studios there are pictures of men with men cautioning them to wear the condom but they are still having sex with one another...hope the Government can prevent not encourage this kind of activities”

(Urban, Malay, Male)

The participants, especially those from the rural area were of the opinion that parents play a very important role in building the moral values of their own children and should therefore involve themselves in the prevention of HIV. In this respect religion was cited as being of importance. Sex education was also suggested.

“pada pandangan saya, kempen ini adalah bermula daripada rumah lagi.”

“In my opinion such campaign starts from the home”

(Rural, Malay, Male)

“If children means parents should take care”

(Urban, Indian, Female)

“Sex education memang perlu...sekolah menengah. Sebab pelajar-pelajar ini terlalu terpengaruh ..apa...they attracted to outside world. So. Jadi sex education, drug education mesti nak beri”

“Sex education is needed...secondary school. Because students are ver much influenced...they are attracted to the outside world...So sex education, drug education must be given”

(Urban, Indian, Female)

National Service was also mentioned as an opportunity to impart knowledge of HIV to young people. Factory workers and foreign workers were two other populations which participants felt that we could target.

In terms of approach participants suggested:

- Awareness campaigns on a wide scale so that it can also reach the rural areas
- Control of the internet
- Testing of Tourists
- Education for foreign workers both legal as well as the illegal

In summary, twenty years into the epidemic yet the knowledge of community is shallow. The community has heard of the terms “HIV” and “AIDS” but the details of transmission are not clearly known. Only once in the four FGDs on community was there mention of “*unprotected sex*” as the cause. It was always moral loaded terms “*free sex*”, sex outside of marriage that cause the spread. The blame on drugs is universal partly because of the media and the manner we collect data in the country. Stigma, which is rampant in our community, is not really perceived as such by participants. Participants express statements such as “*We must show sympathy*”, “*...support*”, etc., “*like all good neighbours but we must be cautious*”, “*...cautious with our children playing with them*”, “*....with the food they offer us in return*” (as most good neighbours do).

For those aware of the process, this fear of infection is reinforced by the manner in which the remains of AIDS infected relatives is prepared for burial. The stigma from society that PLHIVs often perceive and express is, in fact, supported by reality. Clearly, the general community has yet to internalize the messages that HIV cannot be transmitted through touch or food. Furthermore, there are many who do not realise that by saying that they need to exercise caution when mixing with a certain group they are, in fact, manifesting stigma and discrimination. Possibly, the HIV epidemic has to reach the proportion of drug abuse in this country, i.e., when having an infected family member becomes so common-place, before society starts to believe that it cannot spread through those means.

Results of the Survey: “What we need”

Characteristics of the Study Population

The study population of 93 was made up of the following groups based on their vulnerability to infection. These groups included (Table 1):

- Male drug users (DU) which numbered 27 or 29% of the total population of respondents.
- Heterosexually infected men numbering eight and forming 8.6% of total population
- Men who have sex with men (MSM) numbering eight (8.6%)
- Heterosexually infected women numbering 22 or 23.7%
- Female sex workers numbering 13 or 14.0%
- Transgender sex workers (eight members or 8.6%),
- Refugees from Myanmar (7 or 7.5%) who incidentally were all male.

Table 1
Distribution of Respondents by FGD Groups

	GROUP	No.	%
1	Drug Users (DU)	27	29.0
2	Heterosexually infected men	8	8.6
3	Men who have sex with men (MSM)	8	8.6
4	Heterosexually Infected Women	22	23.7
5	Female sex workers	13	14.0
6	Transgender I Sex workers	8	8.6
7	Refugees from Myanmar (Chins)	7	7.5
	Total	93	100

Background of Respondents

Gender

More than half of the respondents (53.8%) were males (Table 2). Slightly over one third (36.6%) were females while 9.6% were transgender.

Ethnicity

About one third (31 or 33.3%) of the respondents were Malays, almost half (16) of whom came from the male DU group (Table 2). Incidentally, more than half of this group (59.3%) were Malays. About a quarter (7 out of 22) of the women infected by their

Table 2a
Distribution of Respondents by Socio-Demographic Background

Groups	DU	Hetero- sexually infected Men	MSM	Refugee	Hetero- sexually infected Women	Women Sex- Works	Trans- Gender Sex- Works	TOTAL	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
GENDER									
Males	27	8	8	7				50	53.8
Females					21	13		34	36.6
Transgender					1		8	9	9.6
ETHNICITY									
Malays	16	0	0	0	7	1	7	31	33.3
Chinese	6	8	8	0	3	0	0	25	26.8
Indians	4	0	0	0	3	6	1	14	15.1
Sarawakians	0	0	0	0	4	5	0	10	10.8
Sabahans	0	0	0	0	5	0	0	4	4.3
Chins	0	0	0	7	0	0	0	7	7.5
Others	1	0	0	0	0	1	0	2	2.2
AGE									
<26	1	0	1	1	3	3	0	9	9.68
26 – 30		0	0	3	5	1	1	10	10.8
31 – 25	6	1	2	2	2	0	3	16	17.2
36 – 40	9	5	1	1	5	5	1	27	29.0
41 – 45	6	1	1	0	4	1	1	14	15.1
>45	5	1	3	0		3	2	17	18.3
Mean: 37.4 Median: 37 Mode:36 Range: 22 to 53									
RELIGION									
Islam	16	0	0	0	8	2	7	33	35.5
Buddhist	3	5	4	0	4	0	0	16	17.2
Hindu	2	0	0	0	1	4	1	8	8.6
Christian	4	2	3	7	9	7	0	32	34.4
Others*	2	1	1	0	0	0	0	4	4.3
* Freethinker (2). Sikhism (1) and Believer of God (1)									
MARITAL STATUS									
Single	17	7	7	4	2	2	6	45	48.3
Married	4	0	0	3	7	2	0	16	17.2
Divorced/ separated	3	1	0	0	1	7	1	13	14.0
Widowed	2	0	0	0	12	2	0	16	17.2
Living together with partner	0	0	1	0	0	0	1	2	2.2
Others	1							1	1.1

husbands or partners and seven out of the eight transgender sex workers in the study were also Malays. The Chinese made up 26.8% of the total respondents but of this number, are included all the heterosexually infected men and MSM together totally 16. There were only three Chinese among the 22 heterosexually infected women.

There were only three Chinese women (all from the heterosexually infected women) who were Chinese.

Indians made up 15.1% of the total respondents but they were represented in almost all FDGs. Four males were from the male DU group, two were heterosexually infected women, six were female sex workers and another one was a transgender. Four of the Sarawakians as well as five Sabahans were heterosexually infected women while five Sarawakian women were infected sex workers. Meanwhile all the seven refugees involved were Chins from Myanmar, and one DU male was an Eurasian while another, a females sex workers was an “Orang Asli”. In conclusion it should be noted that while the DU males consisted of members from all races, most were Malays, all the heterosexually infected men and MSM were Chinese, all refugees were male and Chins. Heterosexually infected women were from all races including Sarawakians and Sabahans. Except for one Malay and another “Orang Asli” women, the rest of the sex workers were Indians but in the case of the transgender individuals all were Malays except for one Indian

Age

Respondents were aged between 22 and 53 years with an average age of 37.4 years and a median of 37.00 years. By age-groups more than quarters (29%) of the respondents were between the ages of 36 to 40 years and another 18.3% were above 45 years while less than 10% (9.7%) were below 25 years of age. The male DU group tended to be older with only one who was less than 26 years and the rest 31 and above. The heterosexual males were all above 30 years while the MSM were almost evenly distribute over the various age-groups. The refugees, on the other hand tended to be younger with nobody above 40 years. Heterosexually infected women were evenly distributed with 3 out of the 22 below 26 years. At the same time there were also 4 women who were above 40 years. The female sex workers were also older women with 5 between 36 and 40 years and three above 45. All the transgender were even distributed as is evident in Table 2a.

Religion

More than one third (35.5%) of the respondents were Muslims, followed by 34.4% Christians, 17.2% Buddhist/Taoist, 8.6% Hindus and 4.3% of other religions (2 respondents were free thinkers, 1 Sikhism and another respondents just said that he was a believer of God). The larger number of Christians was largely due to the fact that all the refugees were Christians. More than half of the DUs were Muslims as were most (7 out of 9) of the transgender. Due to the fact that all the heterosexually infected men and the MSM were all Chinese, they were either Christians or Buddhists. While most of the heterosexually transmitted women were Christians (9 out of 22) there were also eight Muslims and four Buddhists in this group. In the case of the female sex workers, four were Hindu, two Muslims and another seven Christians. Seven out of the nine transgender were Muslims while another one was a Hindu.

Marital status

Almost half (48.3%) of the respondents were single, 14% were divorced or separated and another 17.2% were widowed. Only 17.2% were married at the time of the study. Most of the DU men as well as almost all the heterosexually infected men and MSM were single as were the transsexuals. Four of the refugees were single but the other three were married. More than half of the heterosexually infected women (12 out of 22) were widowed, seven were married, two single and one divorced/separated. Meanwhile all the

female sex workers (seven out of 13) were divorced or separated and two were widowed. With the transgender, six were single, one divorced or separated and another was living with a partner (Table 2a).

Educational attainment

While almost one in ten (9.7%) had no formal education another 10.8% had tertiary level education. Those with tertiary education were mainly males with 5 out of 8 from the MSM group. In comparison, only one woman out of 34 had tertiary education. Of the respondents, 30.1% had completed their SPM or STPM, 20.4% their primary education and another 26.9% their lower secondary education and only two of them had completed their vocational education. By group all DU males had studied beyond their lower secondary, while the heterosexually infected men had lower secondary or less education. The MSM tended to be the best educated. The refugee had only primary or no education at all. Almost half (12 out of 26) had attained SPM/STPM or higher education, two had never been to school, five had completed their primary education and another seven completed their PMR. Female sex workers had very little education with half who had never been to school and the other half either completing their primary education (three) or one who had attained her PMR. Transgenders were better educated with one who had never been to school, two out of eight having completed their primary education, and the other six with completing their PMR and another three their upper school education (Table 2b).

Employment status

Almost half (47.4%) of the respondents were unemployed at the time of the study and only 22.6% were employed full time and another 10.8% self-employed. Meanwhile 8.6% worked as volunteers, 3.2% were employed part-time and one respondent was too ill to work. Generally, most of the heterosexually infected women (15 out of 22) were unemployed as were 11 out of 27 male DUs. All MSM were working full time either for others or self employed. Of the seven refugee men, four were unemployed, two employed fulltime and another part time. Of the eight transgender, five of them said that they were unemployed but to our knowledge they were sex workers. Of the 13 female sex workers, four of them said that they were unemployed while another five said that they were employed fulltime, one self employed and the final three reported that they were involved in sex work.

Types of full time employment varied widely ranging from managers and executives to middle management workers like clerks, nurse and technicians as well as general workers in restaurants and mini-markets. Two respondents worked full-time as sex workers. Those who were self employed were also in very varied occupations ranging from being electricians, designers, tailors, hairdressers, musician and sales personnel. One respondent reported that she was self-employed as a sex worker.

Table 2b
Distribution of Respondents by Education and Employment Status

Groups	DU	Hetero- sexually infected Men	MSM	Refugee	Hetero- sexually infected Women	Women Sex- Workers	Trans- Gender Sex- Workers	TOTAL	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
EDUCATIONAL ATTAINMENT									

No formal education	0	0	0	2	2	4	1	9	9.7
Completed primary sch.	0	3	1	5	6	3	1	19	20.4
Completed Form 3	9	5	0	0	4	4	3	25	26.9
Completed Forms 5 or 6	13	0	2	0	8	2	3	28	30.1
Completed vocational school	1	0	0	0	1	0	0	2	2.2
University /college	4	0	5	0	1	0	0	10	10.8
EMPLOYMENT STATUS									
Unemployed (not retired)	11	5	0	4	15	4	5	44	47.4
Employed fulltime	4	1	4	2	4	5	1	21	22.6
Employed part-time	0	0	0	1	1	0	1	3	3.2
Self-employed	4	0	4	0	1	1	0	10	10.8
Long term medical leave	1	0	0	0	0	0	0	1	1.1
Volunteer work	5	2	0	0	0	0	0	8	8.6
Others	2	0	0	0	1	3	1	6	6.5

Family background

Considering the fact that the average age of the respondents was more than thirty years, it was not surprising that three quarters (78.5%) of the respondents had no living grandparents while 8.6% had one, 6.5% had two and one individual reported having three living grandparents. Meanwhile five of the respondents did not respond to this question (Table 3a). Almost one third (30.1%) did not have any living parent, 26.9% had one, 36.6% had two living parents while seven respondents did not respond to this question. With reference to table 4 it is evident that most respondents have siblings of both sexes, most of whom had two brothers or two sisters.

Table 3a
Distribution of Respondents by Family Background

Groups	DU	Hetero- sexually infected Men	MSM	Refugee	Hetero- sexually infected Women	Women Sex- Worker	Trans- Gender Sex- Workers	TOTAL	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
NO. OF LIVING GRANDPARENTS									
Nobody	17	8	7	7	15	11	8	73	78.5
1 person	3	0	0	0	4	1	0	8	8.6
2 persons	3	0	1	0	1	1	0	6	6.5
3 persons	0	0	0	0	1	0	0	1	1.1
No. Response	4	0	0	0	1	0	0	5	5.4

NO. OF LIVING PARENTS									
Nobody	7	1	1	2	4	7	6	28	30.1
1 person	10	4	2	2	6	0	1	25	26.9
2 persons	5	3	5	3	11	5	1	33	36.6
No response	5	0	0	0	1	1	0	7	6.4
NO. OF LIVING MALE SIBLINGS (EXCLUDING SELF)									
Nobody	3	1	0	1	3	1	2	11	11.9
1 person	6	2	3	2	4	1	1	18	19.4
2 persons	5	2	3	2	2	5	4	23	24.7
3 persons	0	1	1	1	4	3	1	12	12.9
4 persons	5	1	1	1	7	0	0	15	16.1
> 4 persons	4	1	0	0	1	3	0	9	9.7
No response	4	0	0	0	1		0	5	5.4
NO. OF LIVING FEMALE SIBLINGS (EXCLUDING SELF)									
Nobody	7	0	2	1	5	2	2	19	20.4
1 person	4	2	2	2	1	3	1	15	16.1
2 persons	5	3	1	2	2	3	2	18	19.4
3 persons	3	1	2	0	4	3	1	14	15.1
4 persons	1	4	0	1	3	0	2	9	9.7
> 4 persons	3	0	1	1	6	2	0	13	14.0
No response	4	0	0	0	1		0	5	5.4

Living children

More than six out of ten respondents did not have any children, 61.3% in the case of female children and 63.4% in the case of male children (Table 3b). Meanwhile 15.1% had one female child and an equal number had two female children and very few of them had three male children or more. The pattern was also the same in the case of respondents with male children. All MSM and transgender sex workers did not have any children while only two heterosexually infected men had children. Of the refugees only three had children ranging from one to four. Only six out of 22 heterosexually infected women had no children. The rest have children of both sexes and in varying numbers. Five of the 13 female sex workers have no children while the rest had a few children ranging from one to four.

Table 3b
Distribution of Respondents by Family Background

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Works	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
NO. OF LIVING FEMALE CHILDREN									
Nobody	18	7	8	5	6	5	8	57	61.3
1 person	1	1	0	1	6	5	0	14	15.1
2 persons	3	0	0	1	7	3	0	14	15.1
3 persons	1	0	0	0	1	0	0	2	2.2
> 3 persons	0	1	0	0	1	0	0	1	1.1

No response	4	0	0	0	1	0	0	5	5.4
NO. OF LIVING MALE CHILDREN									
Nobody	18	7	8	4	8	6	8	59	63.4
1 person	3	1	0	2	7	3	0	16	17.2
2 persons	2	0	0	0	5	3	0	10	10.8
3 persons	0	0	0	0	1	0	0	1	1.1
4 persons	0	0	0	1	0	1	0	2	2.2
No response	4	0	0	0	1	0	0	5	5.4
OTHER POSITIVE MEMBERS IN FAMILY									
Nobody	26	8	8	5	16	11	7	79	84.9
Brother	0	0	0	0	0	0	1	1	1.1
1 Child	0	0	0	0	3	1	0	4	4.3
2 Children					1			2	2.2
Husband	0	0	0	0	3	1	0	4	4.3
Wife	1	0	0	2	0	0	0	3	3.2

Positive family members

While in 84.9% of the respondents they were the only positive member in their respective families, there were still others who had positive children or spouses. One DU male reported that his wife was also positive as did two refugees. Three of the heterosexually infected women had positive husbands, three had one positive child each and another had two positive children. One of the female sex workers reported having a positive child and another reported that her husband was also positive. One of the transgender sex worker had a positive brother.

Testing

Duration since HIV diagnosis

This section on testing (Table 4) begins with how long each of the respondents had known about their status, what prompted them to go for testing, whether they received pre and post test counseling. On the average the respondents had known of their positive status for more than four years (53.7 months) ranging from one to 168 months or 14 years. Generally about three quarters of them had known their status in the last six years although almost 20%, most of whom were DUs had known it for more than eight years. This is not unexpected because DUs are more likely to be picked up during drug raids and therefore could be tested earlier than others. By group, transgender sex workers tended to have been found positive more recently (seven out of eight) only in the last two years.

How HIV status was discovered

How the status of respondents were discovered varied but one in four (24.7%) were tested positive when they were advised by their doctors to go for testing. This was particularly true with the heterosexually infected men (four out of eight), the MSM (three out of eight) as well as the women sex workers (five out of 13). Another 16.1% were tested positive when their partners were positive and this was particularly so in the case of the heterosexually infected women. Similarly one refugee man and two female sex workers were tested positive due to partner status. As expected most of the DU men were

tested in drug rehabilitation centers and prisons (12 out of 27) as were three female and one transgender sex workers. Contracting tuberculosis was reason why 14% of the respondents went for testing and this more often with the refugee (five out of 8) as well as the transgender sex workers (four out of eight). Evident from table four, is the fact that antenatal care, blood donation, pre-marital testing and STD prompted only a few of them to go for testing. Other reasons for those who went for testing included visa to study overseas (1), medical check-up (2), surgery (1) and work permit to work overseas(1)

Of the ten respondents who went for voluntary testing, curiosity, weight loss, work permit to work overseas, free check-up at IKHLAS, husband had tuberculosis were the reasons cited and two respondents did not answer this question.

Table 4
Distribution Of Respondents By Information On Various Aspects Of Testing

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Works	Total	
								No.	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Distribution By Length Of Time Since They Knew Their Status Months									
0- 24	3	4	2	6	7	6	7	25	26.9
25-48	5	3	4	0	5	2	0	26	28
49-72	7	1	0	0	6	2	1	16	17.2
73-96	2	1	0	0	3	1	0	9	9.7
>96	10	1	2	1	1	2	0	17	18.2
Mean: 53.7 months Mediam: 36.00 months Mode:12.0 Range: 1 to 168 months									
HOW HIV STATUS WAS DISCOVERED									
Voluntary	4	2	0	0	3	1	0	10	10.8
Advised by Dr.	5	5	3	0	2	5	3	23	24.7
Antenatal	0	0	0	0	2	0	0	2	2.2
Blood donation	2	0	1	0	0	0	0	3	3.2
Pre-marital testing	1	0	0	0	0	0	0	1	1.1
Drug rehab	6	1	0	0	0	1	0	8	8.6
Prison	6	0	0	0	0	3	1	11	11.8
TB	1	0	0	5	3	0	4	13	14.0
STD	0	0	1	1	0	0	0	2	2.2
Infected Partner	0	0	0	1	12	2	0	15	16.1
Others*	2	0	3	0	0	1	0	5	5.4
* Visa to study overseas (1), Medical check-up (2), Surgery (1), Work permit to work overseas(1)									
VOLUNTARY TESTING: WHY? (N=10)									
Curiosity	1	0	0	0	1	0	0	2	20
Work permit	1	0	0	0	0	0	0	1	10
Check up at IKHLAS	0	0	0	0	0	0	1	1	10
Husband had TB	0	0	0	0	1	0	0	1	10
Losing weight	1	2	0	0	0	0	0	3	30
No reason	1	0	0	0	1	0	0	2	20

Pre- and post-test counselling

Everybody who is being tested should receive pre and post test counseling. In this instance more than half (58.4%) of the respondents had received post test counseling but only 25.8% had received pretest counseling and only 15.1% received both. Generally more of the heterosexually infected women (one third) and female sex workers (four out of 13) received both pre and post test counseling than any other group reflecting also the attitude of the Malaysian society towards infected women (Table 5).

Table 5
Pre And Post Test Counselling

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans- Gender Sex-Workers	Total	
								No.	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Had pre-test Counselling	6	0	0	0	10	5	3	24	25.8
Had post test Counselling	11	3	2	4	12	8	5	51	54.8
Had pre and Post test Counselling	3	0	0	0	7	4	0	14	15.1

Relationship with their families

Only 14% of the respondents claimed that they had been disowned by their families, but it is also reflective of their lifestyles rather than their status. In this instance only 15 out of 27 IDUs said that they were not disowned and only five were disowned but seven of them did not respond to this question (very high compared to the other groups) perhaps reflective of the uncertainty of their relationship with their families (Table 6). In contrast none of the heterosexually infected women was disowned and three out of 22 did not respond. Almost one third (four out of 13) of the women sex workers were disowned as were one quarter of transgender sex workers Only one MSM man was disowned by his family. One should also note that not being disowned does not mean acceptance because many may not have revealed their status to their respective families. It is perhaps risky lifestyles which are obvious as in the case of the IDUs, transgender and sex work that cause the families to disown them.

Almost one third of the respondents depended on their families for care and support and more than half are dependent on families for emotional support. At the same time more than one quarter (26.9%) of them also depended on their families for financial support. However respondents also provide care and support to their families, albeit, to a lesser degree. In this instance 23.7%, 30.1% and 21.5% claimed that they provided care and support, emotional and financial support respectively to their families (Table 6).

Table 6
Relationship with Their Families

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	W.omen Sex-Workes	Trans-Gender Sex-Works	Total	
								No.	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
RELATIONSHIP WITH FAMILY									
Disowned	5	1	1	0	0	4	2	13	14
Not Disowned	15	6	7	5	19	8	5	65	69.9
No. Response	7	1	0	2	3	1	1	15	16.1
DEPEND ON FAMILY FOR:									
1. For Care & support	8	1	2	0	9	6	1	27	29.0
2. Emotional support	12	6	6	4	12	6	3	49	52.7
3. Financial support	7	3	1	0	8	6	0	25	26.9
THEY SUPPORT FAMILY IN:									
1. For Care & support	4	0	4	0	9	3	2	22	23.7
2. Emotional support	5	1	7	1	8	3	3	28	30.1
3. Financial support	4	0	6	1	7	2	0	20	21.5

Information received at the time of testing

As part of their post-test counselling, respondents also received other information. These included advice on nutrition (24.7%), AIDS Related NGOs (21.5%), PLHIV networks, Government services available to them (18.3%) and others [information on programs & policy in Singapore (1 DU), referral letter (1 MSM), advice not to have sex anymore (1 hetero female)]. At the same time 14%, most of whom were the DU (8 out of 27) did not receive any follow-up information at all (Table 7).

Accessing information and services

More than a third (35.5%) of respondents had no problem accessing information. One in five (21.5%) did not know where to find relevant information, and another 15% either were too ill to access information or had transport problems. Transport problems were mainly faced by heterosexually infected women from Sabah or Sarawak. However 43% were not accessing information out of fear of being stigmatized. This was felt by all groups most of which were by the heterosexually infected women (14 out of 22). Five out of eight MSM, six out of 13 and half of the transgender sex workers were also afraid of being stigmatized (Table 8).

Table 7
Information Received At The Time Of Testing

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
NGOs	5	0	1	2	3	8	1	20	21.5
Networks/ Groups For PLWHs	2	2	2	0	4	5	1	16	17.2
Proper Nutrition/ Diet	2	5	1	3	10	5	0	2	24.7
Government Service	1	1	2	1	7	5	0	17	18.3
Other Info	1	0	1	0	0	1	0	3	3.2
No Info Offered	8	2	1	1	0	1	0	13	14
*others: info on programs & policy in Singapore (1 DU), referral letter (1 MSM), Advice not to have sex anymore (1 hetero female)									

Table 8
Why It Is Difficult To Access Information And Services

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No.	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Had no problem	11	6	3	6	3	3	1	33	35.5
Don't know where to find	5	0	2	1	6	4	2	20	21.5
Worried about stigma	9	2	5	0	14	6	4	40	43
Not well, don't leave home	0	0	0	0	4	2	1	7	7.5
Transport problem	0	0	0	0	4	3	0	7	7.5
Others	2	0	0	0	0	2	0	4	4.3
No money (1 female sex worker), no NGOs (1 DU), don't want to know (1 DU)									

Treatment

In this study 14.0% were not in need of regular treatment and 73.1% were getting regular treatment. Another three were not getting it regularly due to finance (in the case of an infected refugee and a female sex worker). Most of those who could not afford payment were female sex workers but generally less than 10% were not receiving treatment due to lack of money (Table 9). Eight out of ten participants were getting treated in Hospital run

by the Ministry of Health (74.2%) or from the University Hospital (7.5%) run by the Ministry of Education. In actual fact most of the MSM get their treatment from the University hospital as do two DUs but the rest were being treated in MOH hospitals. Other places from where respondents get their medication are medicine shops and pharmacies.

Mode of payment for treatment

In this study 69 respondents were receiving treatment from the Ministry of Health's government hospitals almost half (40.0%) of them were getting it free. Another 8.8% were getting their treatment partially subsidized by the Government. Family and friends were helping to pay for 11.3% of the respondents and 32.5% were getting their treatment paid by other sources. The seven refugees' treatment were paid for by UNHCR and the Malaysian AIDS foundation was paying for the medication one DU man, a Buddhist foundation for one heterosexually infected man and another three DUs claim their medication was being paid for by the Catholic Church under their Welcome Community Home (where they were living at the time of the study). One DU was also using insurance money to pay for his treatment. Of the seven respondents receiving treatment from the university hospital, only one was paying for it by himself and the rest were being partially subsidized. Although 11 respondent reported that they were receiving treatment from places other than the general and university hospitals, only seven proceeded to answer the subsequent question. In this instance two MSM reported paying themselves for treatment elsewhere, one heterosexually infected woman reported that family and friends assisted her in seeking treatment elsewhere.

It would seem evident that the almost all heterosexually infected women were able to get treatment from public hospitals either totally free or at least partially subsidized. Given the fact that not all PLHIV need to be on treatment, the total number (more than 81%) assisted by the Government is quite formidable. However on the other hand having partial subsidy would still be too expensive for respondents whose ability to earn an income is compromised by their health.

Table 9
HIV Related Treatment

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No.	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
ACCESS TO TREATMENT									
Yes, regularly	19	8	7	6	18	4	6	68	73.1
Yes, not regularly	1**	0	0	1*		1*	0	3	3.2
Don't need it	4	0	1	0	2	5	1	13	14.0
Need it, cant pay	1	0	0	0	0	3	1	5	5.4
No response	2				2	0	0	4	4.3
* financial problems		** does not need it regularly yet							
SOURCE OF MEDICAL CARE N MEDICATION									

In Gov. hosp	21	8	2	7	21	5	6	69	74.2
University hosp	2	0	5	0	0	0	0	7	7.5
Others	2	0	4	0	1	8	3	11	11.8
*Others: medicine shops and pharmacies									
HOW THEY ARE PAYING FOR TREATMENT									
MOH HOSPITAL (N= 69)									
Themselves	0	1	0	0	1	03	0	5	6.3
Family & friends	6	3	0	0	0	0	0	9	11.3
Fully Government	4	3	0	0	18	2	5	32	40
Partial by Government	4	0	1	0	1	0	1	7	8.8
Insurance	1	0	0	0	0	0	0	1	1.3
Others	6	1	0	7	2	8	2	26	32.5
UNIVERSITY HOSPITAL (N=7)									
Themselves	1	0	0	0	0	0	0	1	14.3
Partial by Government	1	0	5	0	0	0	0	6	85.7
OTHERS (N=7)									
Themselves	0	0	2	0		0	1	3	42.9
Family & friends	0	0	0	0	1	0	0	1	14.3
Others	2	0	1	0	0	0	0	3	42.8

Problems experienced by respondents

Physical health problems

Generally, because of the manner we recruited respondents (mobile and at be able to travel to a center where the Focus group discussion was held), it was therefore not surprising to find that there were not many reporting that they experienced the physical health problems itemized (Table 10a and 10b). These items included, problem with eating, drinking or appetite, sleep, mobility, daily activities like caring for oneself, household chores, taking care of children, getting treatment regularly, problems related to drug or alcohol, sex or others. Among the other problems pointed out by respondents were blurred vision, nerve problem and slurred speech, TB, skin and heart disease. Generally they were also getting help for their problems. Again this is not reflective of PLHIVs in the country because respondents were also recruited by NGOs who were already assisting them in various ways.

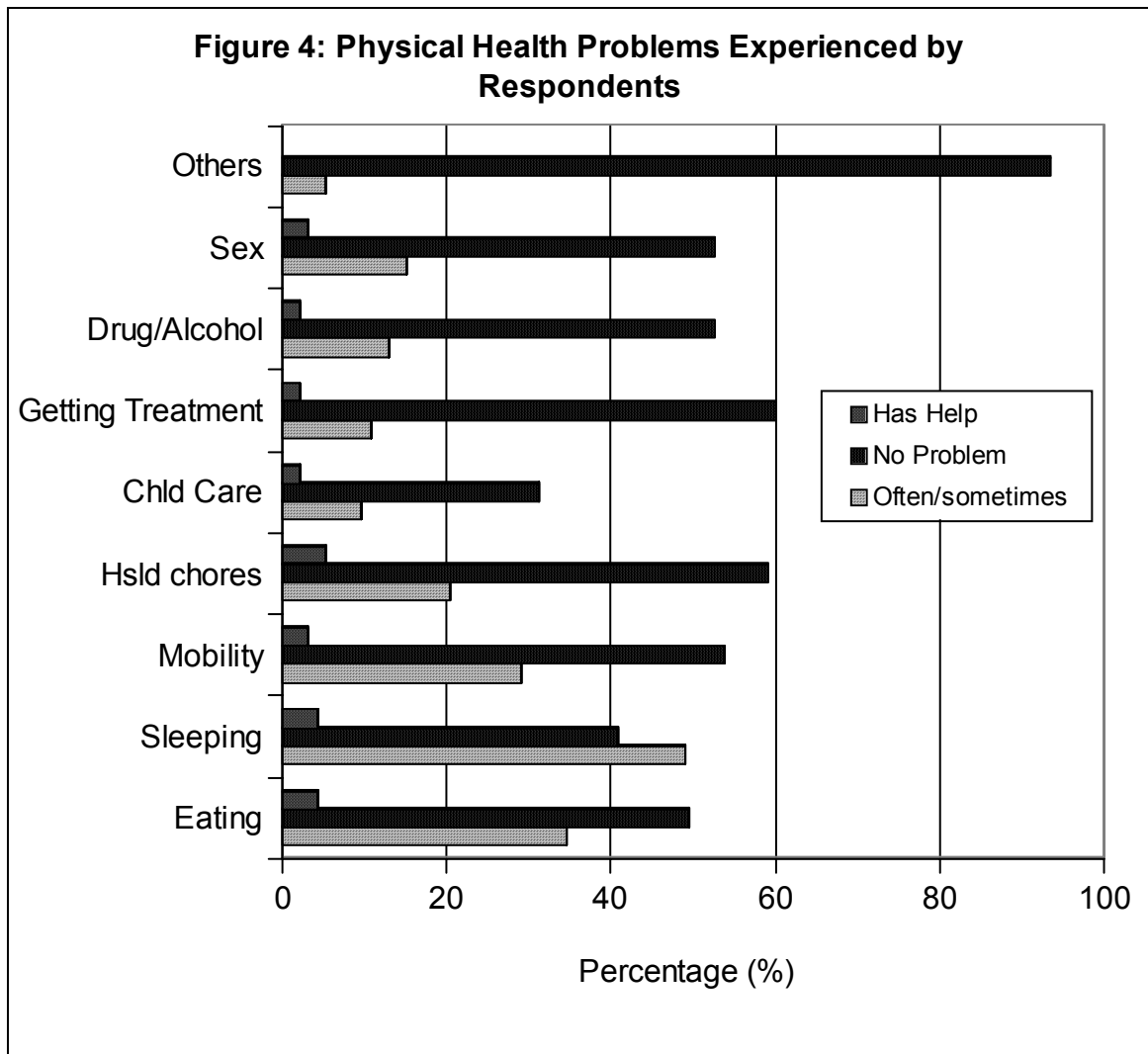
Table 10a
Physical Health Problems Experienced by Respondents

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Eating Problems									
Yes, often	0	1	0	0	2	1	2	6	6.5
Sometimes	7	2	4	1	7	4	1	26	28
No problem	9	5	4	6	10	8	4	46	49.5
Has help (n=6)	1	0	0	0	1	0	2	4	66.7
Sleeping Problem									
Yes, often	4	0	1	1	3	2	2	15	16.1
Sometimes	9	4	2	0	5	2	4	26	28
No problem	4	4	5	6	11	7	1	38	40.9
Has help (n=15)	0	1	3	0	0	0	0	4	26.7
Mobility Problem									
Yes, often	2	1	0	0	1	4	3	11	11.8
Sometimes	5	2	1	0	7	1	0	16	17.2
No problem	11	4	6	7	11	7	4	50	53.8
Has help (n=11)	1	0	1	0	0	0	0	3	27.2
Daily Activities									
Yes, often	1	2	0	1	2	1	1	8	8.6
Sometimes	2	1	1	0	3	2	1	10	10.8
No problem	13	5	6	6	13	10	5	58	62.4
Has help	0	0	0	0	1	1	1	3	3.2

Table 10b
Physical Health Problems Experienced by Respondents

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugee	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Household Chores									
Yes, often	1	0	0	0	2	0	0	3	3.2
Sometimes	5	2	0	0	5	2	2	16	17.2
No Problem	10	6	7	7	11	9	5	55	59.1
Has help	1	0	0	0	2	1	1	5	5.4

Child Care									
Yes, often	0	0	0	1	0	1	0	2	2.2
Sometimes	1	0	0	0	6	0	0	7	7.5
No problem	7	3	3	3	7	0	2	29	31.2
Has help	0	0	0	0	2	0	0	2	2.2
Getting Treatment									
Yes, often	1	0	0	1	0	2	0	4	4.3
Sometimes	2	1	0	0	1	1	1	6	6.5
No problem	12	6	6	6	17	3	6	56	60.2
Has help	0	0	0	1	0	0	1	2	2.2
Drug and alcohol problems									
Yes, often	0	0	0	0	0	4	0	4	4.3
Sometimes	3	0	1	0	0	3	1	8	8.6
No problem	12	6	5	7	12	2	5	49	52.7
Has help	1	0	0	0	0	0	1	2	2.2
Sex Problems									
Yes, often	1	0	2	0	0	1	0	4	4.3
Sometimes	2	1	2	0	1	3	1	10	10.8
No problem	10	6	3	6	12	6	6	49	52.7
Has help	0	0	2	0	0	0	1	3	3.2
Others (Vision, Nerve Problem And Slurred Speech, TB, Skin And Heart Disease)									
Yes, often	2	0	0	0	0	0	1	3	3.2
Sometimes	2	0	0	0	0	0	0	2	2.2
No problem	22	8	8	7	26	8	8	87	93.5



Financial problems

In general, more of the respondents reported having financial problems more often or sometimes than physical problems. The areas where most have financial constrains was in the purchase of vitamins or supplements where one in five said that they often had financial problems buying it and another 16.1% experiencing it sometimes and only 29% did not face such a problem (Table 12a). Another recurring expense which was quoted as frequently or sometimes experienced by the respondent was in the purchase of food. In this instance, 16.1% often and 28% sometimes experienced problems buying food. Money to access antiretroviral drugs was often a problem to 11.8% of the respondents and another 15.1% reported that they sometimes experience this problem. In terms of groups the MSM (4 out of eight), DUs (nine out of 27), women sex workers (three out of 13) and the transgender sex workers (two out of eight) were the groups most affected.

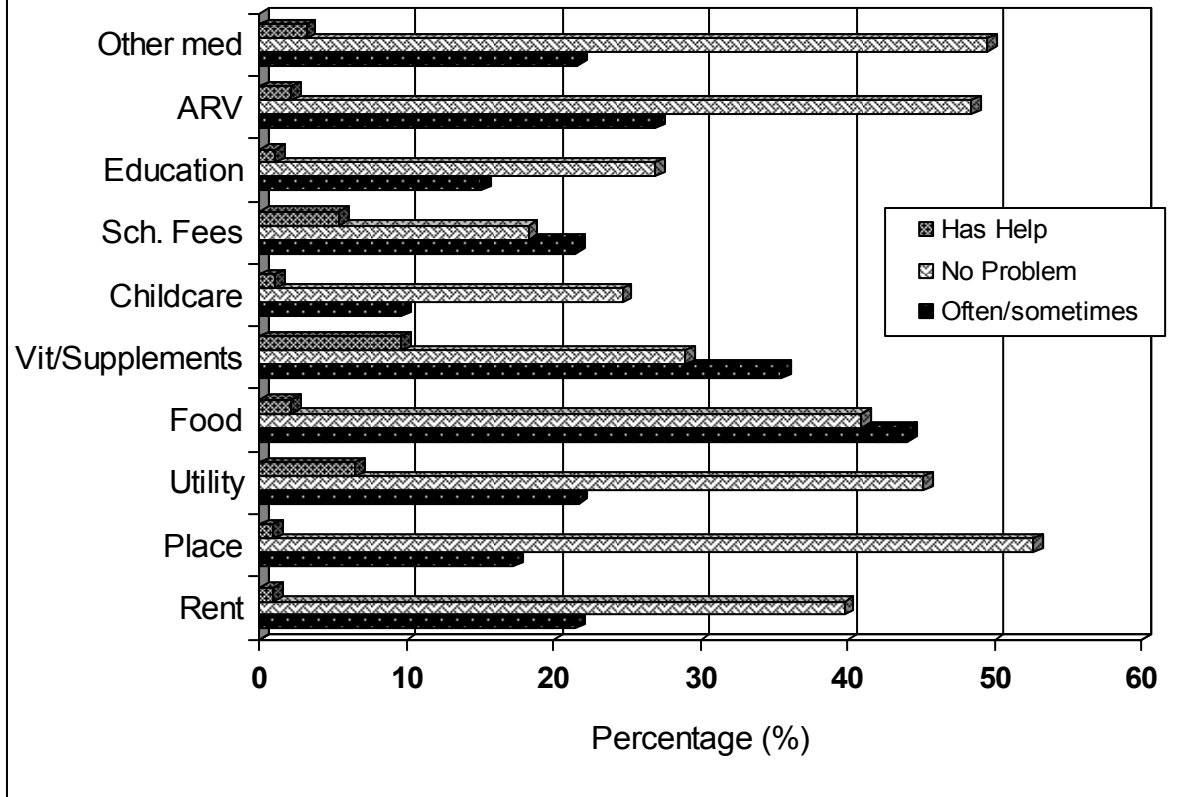
Table 11a
Financial Problems Experienced

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
House rent/mortgage									
Yes, often	1	1	0	4	1	5	0	12	12.9
Yes, sometimes	1	2	1	0	1	3	0	8	8.6
No problem	8	5	4	3	9	1	7	37	39.8
Has Help	0	0	1	0	0	0	0	1	1.0
No fixed place to stay									
Yes, often	2	1	0	1	0	4	2	10	10.8
Yes, sometimes	5	1	0	0	0	0	0	6	6.5
No problem	9	4	7	9	12	6	5	49	52.7
Has Help	2	0	0	0	3	0	1	6	6.5
Paying Utility Bills									
Yes, often	2	1	0	2	3	3	0	11	11.8
Yes, sometimes	1	1	1	0	8	1	0	12	12.9
No problem	9	4	6	5	4	4	7	42	45.2
Has Help	0	0	0	0	0	2	0	2	2.2
Buying food stuff									
Yes, often	4	0	1	1	3	2	2	15	16.1
Sometimes	9	4	2	0	5	2	4	26	28
No problem	4	4	5	6	11	7	1	38	40.9
Has help	0	1	3	0	0	0	0	4	4.0
Buying vitamins/supplements									
Yes, often	6	0	0	5	3	1	3	18	19.4
Yes, sometimes	1	2	2	0	6	2	2	15	16.1
No problem	6	5	5	2	5	2	2	27	29
Has help	1	0	1	4	3	0	0	9	9.7
Childcare payments									
Yes, often	1	0	0	2	2	1	0	6	6.5
Yes, sometimes	1	1	0	0	1	0	0	3	3.2
No problem	4	3	2	2	8	1	3	23	24.7
Has Help	0	0	0	0	1	0	0	1	1.1

Table 11b
Financial Problems Experienced

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Children's School Fees									
Yes, often	1	0	0	2	5	1	0	9	9.7
Yes, sometimes	4	1	0	0	6	0	0	11	11.8
No problem	3	3	2	2	4	0	3	17	18.3
Has Help	1	0	0	0	3	0	1	5	5.4
Fees for own education									
Yes, often	3	0	0	0	3	0	0	6	6.5
Yes, sometimes	3	1	2	0	2	0	0	8	8.6
No problem	4	3	2	2	7	0	7	25	26.9
Has Help	0	0	1	0	0	0	0	1	1.1
Obtaining HIV therapy									
Yes, often	3	1	0	2	2	1	2	11	11.8
Yes, sometimes	6	2	4	0	0	2	0	14	15.1
No problem	8	5	4	5	15	3	5	45	48.4
Has Help	1	0	0	1	0	0	0	2	2.2
Obtain other medical care									
Yes, often	3	1	0	1	0	1	0	6	6.5
Yes, sometimes	4	1	4	0	2	2	2	14	15.1
No problem	8	6	4	6	13	5	4	46	49.5
Has Help	1	0	1	1	0	0	0	3	3.2

Figure 5: Percentage of Respondents by Types and Frequency of Financial Problems Faced



Emotional problems

Of all the types of emotional problems listed, management of their anxiety or depression was experienced by most respondents (26.9% often and 35.5% sometimes) [Table 12a and figure 2]. The emotion was felt by all the refugees and women sex workers, five out of the eight transgender sex-workers, half of the MSM and the hetero-sexually infected men as well as ten out of the 27 DUs. At the same time almost 15 out the 22 heterosexually infected women also often or sometimes experience this problem.

More than half of the respondents also reported having low self esteem and they were reported by almost all groups. With the refugee (seven out of eight), DUs (15 out of 27), women sex workers (nine out of 13) heterosexually infected women (12 out of 22) as well as half of the MSM and heterosexually infected men reported experiencing this problem. It was also therefore not unexpected to have more than half of them to feel isolated or alone. In this instance, all groups experience this problem with the women sex workers reporting (10 out of 13), MSM (more than half), half of the refugees and 12 out of 22 hetero-sexually infected women feeling likewise. The infection has also affected respondents outlook of the future. This was reported by slightly more than half of the respondents, but mainly by the women sex workers, DU and the heterosexually infected women, not forgetting the refugees who now not only experience uncertainty over relocation but their health status as well.

Not many (10.8%) quoted emotional problem related to relationships with spouses but this is partly due to the fact that only 17.2% of the respondents were married and 2.2%

were living with a partner. Emotional problems related to relationship with friends was reported by almost one third of the respondents but mostly by the DUs and the female sex workers (understandly so) because it can affect their ability to find clients). This is despite the fact that not all of them had the courage to disclose their status to all friends.

Almost one third (31.2%) were also often or sometimes afraid to disclosure their status to family members and even more of them (49.5%) to friends. More women sex workers and heterosexually infected women fell into this category than the other groups.

The answer to the number of respondents who quoted has having no problems in the various areas was also related to the fact that respondents had not disclose their status to many people. Thus it was not unusual to see almost half saying that they do not fact relationship problem with family and friends or co-workers for that matter.

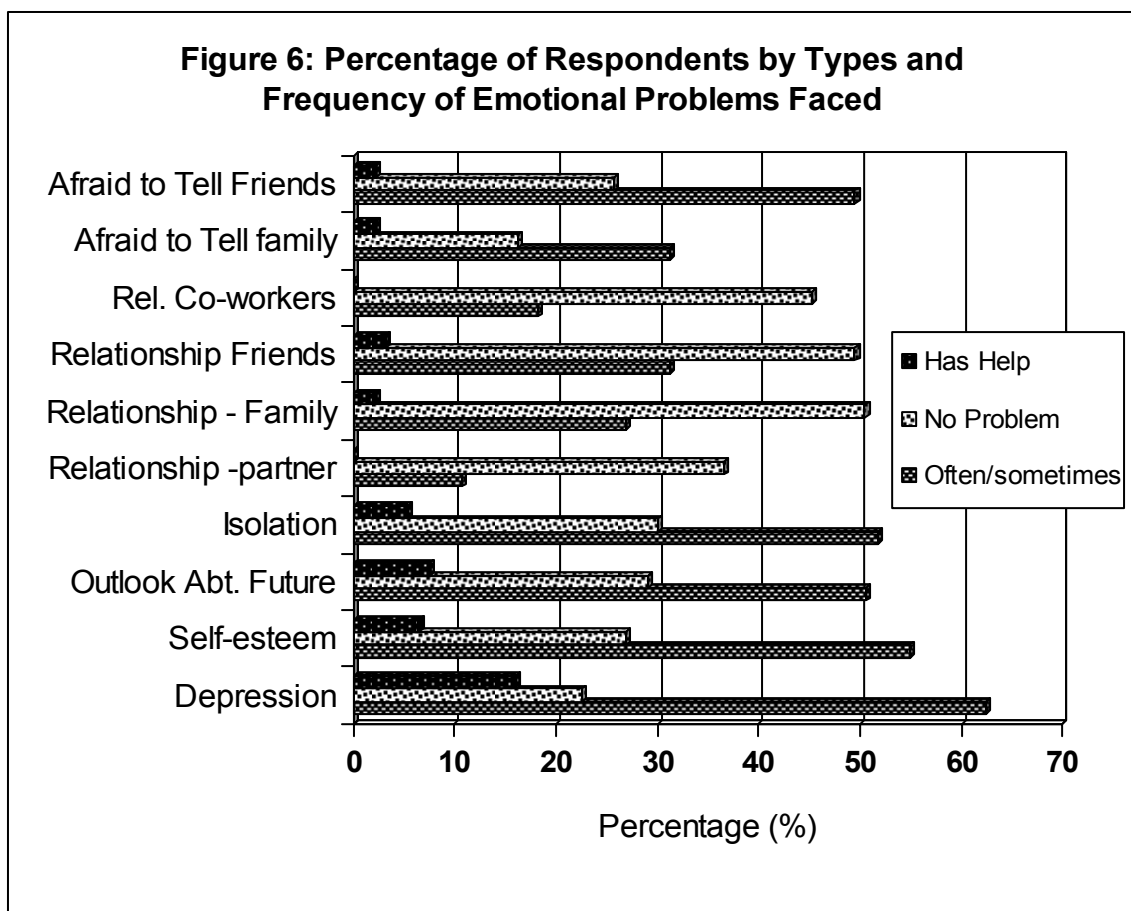


Table 12a
Emotional Problems Experienced as a Result of HIV Status

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Difficulty Managing Depression/Anxiety									
Yes, often	2	2	2	7	5	5	3	25	26.9
Sometimes	8	2	2	0	10	8	2	33	35.5
No problem	7	4	3	0	4	1	2	21	22.6
Has Help	1	0	1	4	5	1	3	15	16.1
Low Self-Esteem									
Yes, often	4	1	1	6	3	3	0	18	19.4
Sometimes	11	3	3	0	9	6	1	33	35.5
No problem	1	3	3	1	7	4	6	25	26.9
Has Help	1	0	0	1	4	0	0	6	6.5
Poor Outlook on Future									
Yes, often	4	0	0	6	6	2	0	18	19.4
Sometimes	7	2	3	0	8	7	2	29	31.2
No problem	6	5	3	1	4	3	5	27	29
Has Help	2	0	0	1	4	0	0	7	7.5
Feeling Isolation or Alone									
Yes, often	3	1	4	1	1	4	0	14	15.1
Sometimes	10	1	1	3	11	6	2	34	36.6
No problem	5	4	2	4	6	3	4	28	30.1
Has help	1	0	0	0	4	0	0	5	5.4
Relationship Problem with Partner/spouse									
Yes, often	3	0	0	2	0	0	0	5	5.4
Sometimes	1	0	2	0	2	0	0	5	5.4
No problem	4	4	4	3	11	2	6	34	36.6
Has help	0	0	0	0	0	0	0	0	0
Relationship Problem with family Members									
Yes, often	2	1	0	0	0	3	1	7	7.5
Sometimes	9	1	1	0	4	1	2	18	19.4
No problem	5	5	6	5	13	9	4	47	50.5
Has Help	0	0	0	0	1	0	1	2	2.2
Relationship Problem with Friends									
Yes, often	2	1	0	2	0	0	1	6	6.5
Sometimes	8	2	1	1	5	4	2	23	24.7
No problem	7	5	6	4	11	9	4	46	49.5
Has help	0	0	0	1	1	0	1	3	3.2

Table 12b
Emotional Problems Experienced as a Result of HIV Status

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Relationship Problem with Co-workers									
Yes, often	3	1	0	0	0	1	0	5	5.4
Sometimes	5	2	0	0	2	3	0	12	12.9
No problem	5	4	7	5	8	3	7	42	45.2
Has Help	0	0	0	0	0	0	0	0	0
Afraid To Tell Family Members About My HIV Status									
Yes, often	3	1	3	3	3	0	1	22	23.7
Sometimes	3	0	0	0	3	5	2	7	7.5
No problem	9	7	5	4	11	0	0	43	46.2
Has help	1	0	0	0	1	0	0	2	2.2
Afraid To Tell Friends About My HIV Status									
Yes, often	4	1	4	4	7	6	0	26	28
Sometimes	5	1	3	0	7	2	2	20	21.5
No problem	6	6	1	3	3	3	2	24	25.8
Has help	0	0	0	0	2	0	0	2	2.2

Table 13
Types of Help Needed to Cope With The Problems

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans-Gender Sex-Workers	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Family help	2	0	0	0	0	0	0	2	2.3
Counseling	2	0	0	1	3	0	0	6	6.5
Financial	1	2	2	4	11	1	1	22	23.7
Moral support	1	0	1	1	1	0	0	4	4.3
Support group	2	0	2	1	0	0	1	6	6.5

Types of help needed to cope with problems

Finance was the area of help needed by most respondents (23.7%) to cope with the problems faced as a result of their infection. This was followed by respondents who expressed the need for support group and counseling (6.5%), moral support (4.3% and family (2.3%).

Stigmatization and how it has affected activities of daily living

More than half of the respondents (57%) (Table 14) reported that they have experienced stigma and only 19.4% reported not have experienced it. However 22.5% said that they did not experience stigma because nobody knows of their status. Of those who experienced stigma, there were more transsexual sex workers (seven if the eight) and DUs (22 out of 27) than any other groups have experienced this. One wonders if the stigma is exacerbated by their addiction in the case of the DUs and their transgender status rather than being infected. At the same time half of the heterosexually infected women, six out of the 13 women sex workers also reported having experienced stigma.

When asked about how stigma has affected their daily activities, one in five said that it has prevented friends from socializing with them, 12.9% said that it has prevented treatment from health personnel and the same number reported loss of employment. Another 6.5% reported that neighbours did not allow their children to play with theirs and at the same time another 6.5% reported that it has affected their attendance at religious activities. Other activities reportedly affected by their status included being isolated, having to move house, being stigmatized by family and society.

Table 14
Distribution Of Respondents Who Have Experienced Stigma And How It Has Affected Their Daily Activities

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans- Gender Sex- Works	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Yes	22	2	3	2	11	6	7	53	57.0
No	4	1	3	1	4	4	1	18	19.4
No. Because nobody knows	0	5	2	4	7	3	0	21	22.5
No. Response	1	0	0	0	0	0	0	1	1.1
How Stigma Affects Normal Activities									
Prevent children from school	1	0	0	0	0	1	0	2	2.2
Health personnel reluctant to treat	6	1	1	0	3	1	0	12	12.9
Change/lose job	9	0	0	0	2	0	1	12	12.9
Friends don't socialize with me	8	2	1	2	1	1	4	19	20.4
Neighbors don't play with my children	3	0	0	0	2	1	0	6	6.5
Attendance at religious activities	5	0	0	0	0	1	0	6	6.5
Others *	8	0	1	0	3	2	1	15	16.1
<ul style="list-style-type: none"> • isolated (2 DU), • move house (1 DU, 1 heterosexually infected woman, 1 transgender), • stigma from family members (1 DU, 1 heterosexually infected woman), • stigma by society (1 DU, 1 heterosexually infected woman) 									

How respondents cope with the challenges they face

Medical and health personnel (doctors, and nurses) and family members were quoted by more than half of the respondents as their source of help to cope with the challenges they face. Counselors and staff of HIV/AIDS support organization were also of help to 53.8% of the respondents as were other PLHIVs (51.6%). Long time friends were only of help to one in five but this could also be affected by the fact that not all of them have disclosed their positive status to their friends. Another 28% of respondents were able to get information from pamphlets on PLHIVs to help them cope.

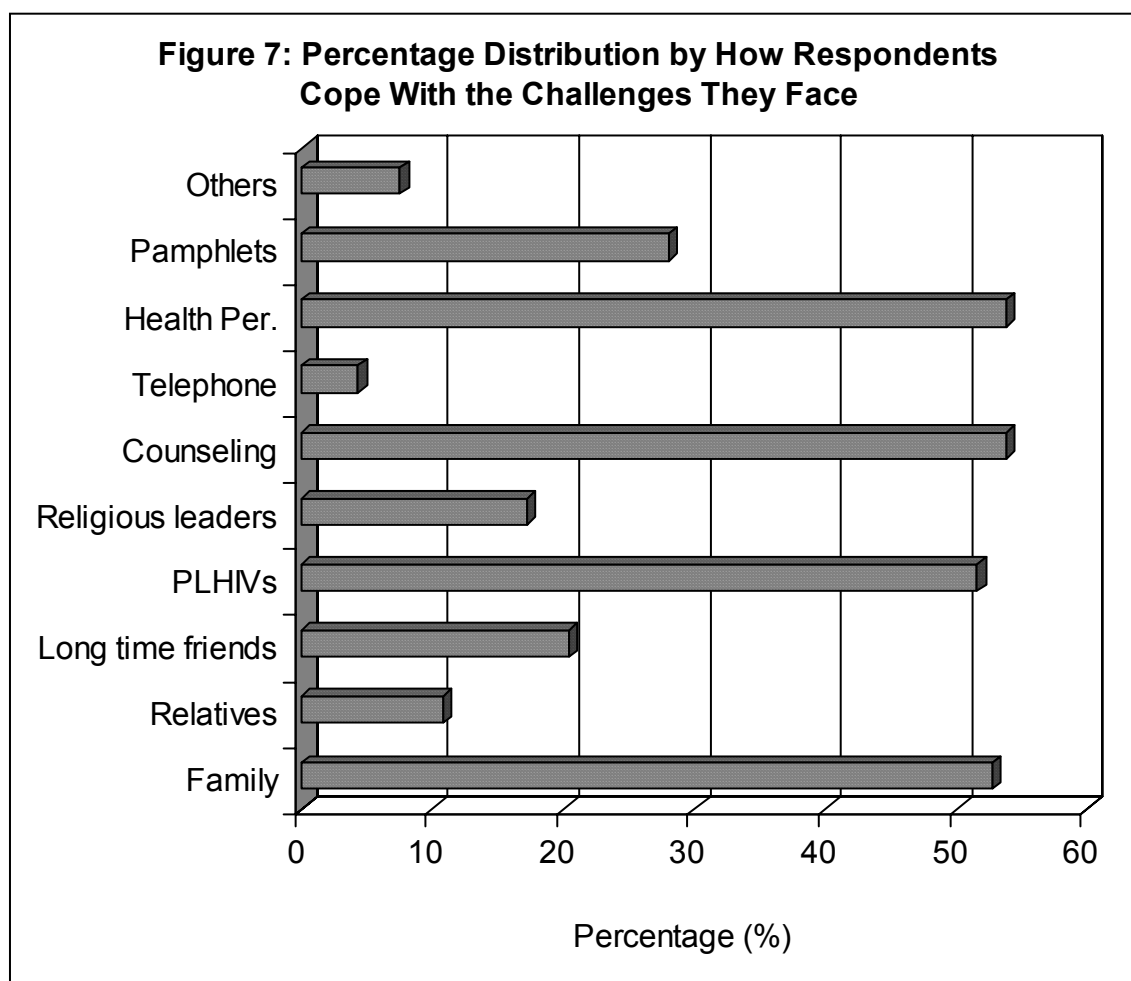


Table 15
How They Cope With The Challenges They Face

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans-gender Sex-Works	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
COPE WITH THE CHALLENGES WITH SUPPORT FROM:									
Immediate family	15	5	6	1	15	5	2	49	52.7
Relatives	5	0	0	0	5	1	2	10	10.8
Long time friends	8	2	4	0	3	1	1	19	20.4
Other PLWHs	21	3	7	0	10	4	3	48	51.6
Religious leaders	7	0	0	1	4	1	3	16	17.2
Counselor/staff at HIV orgs.	16	3	6	0	12	8	5	50	53.8
Telephone helpline	1	2	0	0	1	0	0	4	4.3
Health Personnel	11	4	6	6	14	6	3	50	53.8
Pamphlets	7	2	3	1	7	5	1	26	28
Others*	1	0	1	2	0	2	0	7	7.5
*Others:									
<ul style="list-style-type: none"> ▪ Conferences (1 DU), ▪ IKHLAS (1 women sex worker), ▪ WAKE (1 transgender), ▪ my partner (1 MSM), ▪ UNCHR (2 refugees) 									

Main concerns

One in four (25%) of the respondents, especially the refugees (6 out of seven) were worried about their own health but 12 out of the 22 heterosexually infected women were worried about care of their children when they become too ill or when they die. At the same time another 18.1% were worried about death, 16.7% about their finance and 11.1% about their family becoming aware of their status (Table 16).

Table 16
Main Worries

Groups	DU	Hetero-sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans gender Sex-Works	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Own health	3	3	3	6	1	0	2	18	25
Financial	2	0	5	1	2	1	1	12	16.7
Knowledge of status to family	3	0	0	0	2	1	2	8	11.1
Stigma-society	3	0	0	0	1	0	1	5	6.9
Care of children	1	0	0	0	12	0	0	13	18.1
Financial (children)	0	0	0	0	1	0	0	1	1.4

Death/uncertain future	5	2	0	0	4	2	0	13	18.1
Loneliness	1	0	0	0	0	0	0	1	1.4
Others	0	1	0	0	0	0	0	1	1.4

Awareness of Government Help for PLHIVs

More than half (51.6%) of the respondents said that they were aware of help for PLHIVs but only 30.1% quoted the government hospitals and medical support they received as such a service provided by the government. Another 7.5% mentioned NGOs (Table 17).

Table 17
Awareness of Government Help for PLHIVs

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans gender Sex-Works	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Yes, know	11	6	6	2	14	3	6	48	51.6
TYPE OF SUPPORT KNOWN									
Govt hosp/medical support	5	4	5	2	12	0	3	28	30.1
NGOs	0	1	3	0	0	3	0	7	7.5
Baitumal	0	0	0	0	0	0	1	1	1.1
KWSP/SOSCO	0	1	0	0	0	0	1	2	2.2
Welfare department	1	0	0	0	1	0	0	2	2.2
Tax reduction	0	0	1	0	0	0	0	1	1.1

Desire to be involved in various activities

Almost eight out of ten respondents (77.4%) want to be involved in some activities and when asked to specify, 54.2% reported that they wanted to be involved in counseling or providing moral support to other PLHIVs, 11.1% in training workshops and 9.7% want to volunteer their time with NGOs (Table 18). For those who did not want to get involved 21.1% quoted health as the reason while another 10.5% cited transport problems.

Table 18
Percentage Of Respondents Who Want To Be Involved In Various Activities

Groups	DU	Hetero-Sexually Infected Men	MSM	Refugees	Hetero-sexually Infected Women	Women Sex-Workers	Trans gender Sex-Works	Total	
								No	%
NUMBER (N)	27	8	8	7	22	13	8	93	100
Yes	22	3	7	7	21	4	8	72	77.4
Areas they want to be involved in N= 72									
Consultation HIV issues	3	0	0	0	0	0	0	3	4.2
Training/workshop	5	0	1	0	2	0	0	8	11.1
Counseling/moral support	11	1	4	5	12	2	4	39	54.2
Campaigns	2	0	0	0	0	0	1	3	4.2
Volunteers/involve in NGO	0	1	2	0	4	0	0	7	9.7
No stated reason	1	1	0	2	3	2	3	12	16.7
missing	1	0	0	0	1	0	0	2	2.8
If no, why don want to be involved, reasons: N= 21									
Transport problem	0	0	0	0	2	0	0	2	10.5
Working	0	1	0	0	0	0	0	1	5.3
Not educated	0	0	0	0	0	1	0	1	5.3
Sensitive to family	0	1	0	0	0	0	0	1	5.3
Health condition	1	2	0	0	0	1	0	4	21.1

Summary of Findings

HEALTH IMPACT

In terms of present health status, about half of the PLHIV in this study reported a range of health outcomes, the most common of which is fatigue or feeling easily tired. Others were sleep problems, frequent headaches, poor recall or concentration, and weight loss or loss of appetite. Problems sleeping may also be associated with feeling tired. Others especially among women also stated depression, diabetes, stroke and ovarian cancer. Overall, women reported more health symptoms or conditions than men.

In the past, however, several had suffered serious illnesses, including severe weight loss, coma or loss of consciousness and tuberculosis, which led to HIV testing by their doctors. A few of the transgender sex workers, in fact, had been rescued from near-death by workers from an NGO.

Although the time of infection cannot be determined, the participants in this study were diagnosed between a few months to more than 10 years ago. Hence, this could be the reason that only about half felt or had any change to their health, most of which was tiredness and difficulty sleeping or needing more sleep.

While many were not on medication yet, a few attributed HIV drugs as the reason for their present well-being. Without a doubt, proper medication has led to improved life span for those living with HIV. The high cost of these drugs was a hardship to many of them who had to pay for all or part of their treatment. It necessitated one to sell off his apartment, and others to stop taking drugs. That some PLHIV, regardless of mode of transmission, are able to obtain needed HIV medications free for a number of years, for example through drug trials, is understandably well-received. All the participants seemed to have no problems maintaining their drug regimens for themselves, or, for a few of the women, their HIV-infected children. Only one woman said that she kept forgetting to keep strictly to the schedule when she was working.

For DU men, drug use was the major problem in their life with negative social and financial consequences. They felt that they were already marginalised as injecting drug users, and a few felt that the majority of IDUs were probably HIV-infected as well – a “*two in one*” package. This perception contributes to an apathetic attitude towards preventive actions, such as using clean needles, or even taking HIV drugs. The Ministry of Health has targeted 4,000 PLHIV as needing HAART but less than 2000 started it⁷. Yet, for some, HIV infection appeared to be the nadir in their life that prompted them finally to commit to ending their drug dependence. For some, their outlook on life appeared positive, especially with the availability of medical treatment and support from their families or other sources. Several are now involved in working for or volunteering with NGOs. One DU man affirmed his belief that HIV is not a life sentence; “...*it is just a virus living inside me*”.

It was clear that many of the men, including DU men who are no longer using drugs, are aware, vocal, responsible towards their healthcare and, for the few who are married,

⁷ Source: Ministry of Health

responsible for their families. As mentioned, some are involved with the work at the NGO they patronize. Indeed, most male participants, except those still using drugs, could cite their CD4 counts, indicating regular healthcare monitoring. These are the positive outcomes of involvement with their respective NGOs. In this regard, it emerged that more men than women are conscious of their CD4 count.

On the other hand, more women than men said that they have changed their diet; in particular, they try to eat more vegetables. Vitamin supplements were prescribed by doctors for some of the participants but the consumption of traditional medicine was not common. A few mentioned hearing about traditional or herbal cures, but these were expensive and not easily available. Only one DU man said he had tried one herbal remedy for three months but it did not help him. Only one woman drank water blessed by a spiritual healer. None of the refugees took or even knew of traditional medicines.

With regards to healthcare, all the participants have access to affordable medical care through public hospitals. Clearly, this access is facilitated by the NGOs with which they are affiliated and, for those who receive it, by the caring attitude of their healthcare providers. This includes refugees, all of whom receive regular healthcare checks facilitated by UNHCR. The exceptions are active drug users, who include a few of the women sex workers. They go to hospital or the NGO drop-in centre for treatment only when they are sick. In fact, at the time of one FGD with sex workers in Kuala Lumpur, one had severe oedema on her legs but had not sought medical attention for it. As they explained, a drug dependent's primary concern in life is getting money and/or drugs for their next fix. This singular overwhelming impulse casts aside any concerns about HIV, its impact on their own health, or that of their families, and in the case of sex workers, of their clients.

An important aspect of the national response to HIV in preventive action is promoting condom use. It was heartening to find that all the participants are aware of the need to use condoms every time to prevent transmission. In regards to practice, however, more men gave assurances that they used condoms every time but not the women in this study. Women, who were married, said that their HIV-positive husband only sometimes use condoms during sex. Sexual frequency, however, has declined for most of them. One woman, who remarried an uninfected man after her HIV-infected husband died, said her new spouse only started using condoms after she gave birth to their first baby. He did not use condoms despite their agreement to do so before marriage and medical advice. His desire for a child as the reason became apparent to her only after her pregnancy. In other words, there was no communication between them on the matter. Both husband and baby remain uninfected at the time of the FGD.

All of the sex workers are aware of the need to use condoms. Indeed, some sex workers expressed concern about infecting their clients and causing them the suffering they have gone through. Some even claim to tell their clients they are HIV-positive. However, all maintain that it is their clients who refuse. A majority - "*...in 100, maybe five will agree to use*" - of their clients prefer not to use condoms. When sex workers suggest condoms, they say their clients question whether are sick. Obviously, to avoid losing their clients, a sex worker will not admit to having any STI, let alone HIV. Continuing to work is even more imperative for sex workers who are drug or alcohol dependent. It should be noted that all of the sex workers in this study were introduced to drugs by their boyfriend or husband.

It should be pointed out that the sex workers in this study work on the street and conduct business primarily in rented rooms. Some of them say condoms are available in these rooms. It is a matter of grave concern that HIV-positive sex workers are continuing to work and, despite all the past years of IEC on prevention, their clients do not want to use condoms. As one accurately summed up, “*Men give...we receive. Whatever... Man....is still the source*”.

In terms of quality of healthcare, there were distinct differences ascribed to the care provided by doctors, particularly specialists in public tertiary hospitals, and that provided by nurses. With few exceptions, PLHIV participants commended their doctors as competent, understanding and non-discriminating professionals. There were a few exceptions. One man told of an incident when a doctor in a private hospital informed his employer about his HIV diagnosis without his consent, which led to his forced resignation. There was another who was insensitive in requesting for a “bio-hazard” assessment before attending to him. There was also another complaint from a woman infected partner about a doctor who estimated the time she had left to live at three months soon after her diagnosis, leaving her feeling hopeless and worried about her children.

In contrast to the general praise for doctors, there were many complaints about nursing staff, such as, nurses who just left bed-ridden and severely ill patients to themselves, unable to eat, clean or take medications, there were those who did not want to touch them, who told their family members or others about their HIV without their consent, and those who were not competent in nursing. Quoting one participant, “*they have no confidence in what they have learned [about HIV].*” Nurses are in the front-line as healthcare providers and have the most interactions with patients. Hence, the quality of their care is significant.

Counselling is a service that slightly over half of the PLHIV (based on the survey findings) in this study received. Most of this comprised post-test counselling, and only a quarter received pre-test counselling. Furthermore, it emerged that more women than men received pre-test or both pre- and post-test. This is because some of the DU men had been tested and diagnosed in prison or a drug rehabilitation centre, and none of the heterosexual, MSM or refugee men had received pre-test counselling.

The study also found that HIV testing is done as a routine procedure in prison and drug rehabilitation centres with no pre-test nor post-test counselling. The study participants who had been in prison, either for drugs or sex work, said that they were informed of their positive results “*just like that*” and given a referral letter upon release for the purpose of medical follow-up. Whether or not the released HIV-infected prisoners go for follow-up is left up to the individual. It is not surprising that most of those who go back to using drugs upon release from prison tend not to bother with follow-up medical care. In the same way, drug dependent sex workers just go back to the streets intent upon getting clients to get money for their next drug fix.

NGOs provide much needed services in the form of drop-in centres and outreach. There were several voices, especially from men among DU and MSM participants, stating how much they benefited from HIV-positive persons who have gone through similar experiences. Clearly, the infected women partners benefit too.

In this study, it took more effort to convene the FGD group of women infected by their husbands. Women who were no longer doing sex work were also difficult to recruit, as were MSM and heterosexual men. However, overall, women participants were generally far less vocal compared to the men's groups, less aware of their rights, less educated, and visibly, still emotionally scarred. In particular, the FGDs with women partners were tearful discussions, particularly for those whose husband has died.

PSYCHOSOCIAL IMPACT

The impact of HIV/AIDS on social and psychological well being was explored from various perspectives, including, disclosure, stigma, prejudice and discrimination, change in social relationships and interactions, religious/spirituality involvement, coping skills and outlook in life.

As far as the issue of disclosure of their HIV status is concerned, generally, participants are very selective as to whom they disclose their status. PLHIV choose not to disclose their status for fear of repercussions, such as ostracism by family members and others, and fear of being discriminated. This well-kept secret renders them more stressed. Both positive and negative experiences from disclosure were experienced by the participants. There were a few who informed a family member immediately, and without hesitation, with the assurance of his/her support. Many others were more hesitant in deciding whether and how to disclose their status. The difficulties in disclosing their status could perhaps be minimized if people living with HIV can be taught how to disclose the matter to their loved ones. In fact, several recounted how useful it was to have counselling and for counsellors or doctors inform and explain to their family in terms of gaining understanding and acceptance.

Stigma and discrimination, real or perceived, deterred PLHIV from seeking treatment, and encouraged some to limit social interactions and live in secrecy. The stigmatization and discrimination faced by the PLHIV is due to society's lack of understanding of and the negative perception towards PLHIV. Without a doubt, this further aggravates the burden of HIV not only for those infected but also their families.

Relationships with significant others or friends are also affected. Many keep to themselves or to the HIV-positive community. One or two refugees declined their wife and family's pleas for them to come home after telling them of their HIV status. While a minority have been disowned by their parents or other immediate family (mainly SWs and DUs), and a few isolate themselves from family members, it was clear that family members are also the source of physical, financial and moral support for some PLHIV, especially for infected partners. Love, care and acceptance come particularly from mothers – *“They didn't isolate me. Our relationship is still the same...healthy people with sick people. My mum is my pillar of strength”*.

A vast difference was shown in terms of psycho-social and emotional state at the time of diagnosis and currently, at the time of the FGDs. Following diagnosis, participants were overwhelmed with a variety of emotions; worries, anxieties, fears, feelings of betrayal, hatred, anger, frustration and even suicide, and they find themselves suddenly at a loss. The participants experienced low self-esteem, self-worth and low self-image. This impact is acutely felt during the initial period following diagnoses of HIV and it may take a while to be emotionally strong depending on the support received. Over time, most of

the participants more or less accept their condition and some have now learnt to cope and live with it. However, some of the participants still have a problem coping with their illness, and this lack of coping strategies and the lack of a support system undermine their mental health or psychological well-being. Some resort to religion for solace, laughter, keeping themselves occupied with daily activities, and keeping themselves healthy. Without a doubt, social networks, especially with other PLHIV and with NGOs, offer solace, empathy and companionship.

Mixed responses with regards to their spirituality or religious practices and beliefs following their diagnoses were also found. Some participants turn to religion or spirituality to cope – *“Pray constantly to God now. Worried about my future, let’s see how. Just lots of prayer”*, while a few others shun away from religious affiliations perhaps due to shame or anger from the view that HIV is a punishment from God – *“I realise that we have to fight for what we need and what we want because God couldn’t help you”*. For a few, faith-based institutions also provide financial support, namely, paying for medications, and basic foods, such as rice, flour, sugar.

PLHIV experience tremendous impact on their psychological well-being. This psychological impact is attributed by the negative consequences of disclosure, the need to maintain secrecy, from the stigma and discrimination experienced or their perceived fear of stigma and discrimination, worries about their health, impending death and from their own personal long term concerns and anxieties.

There are also mixed feelings among participants as to how they see their life and what the future holds for them. Some have a positive outlook on life, whereas some are more negative and pessimistic. Some of the concerns for the future are fear for the future of their children, especially for infected partners, fear of the unknown and fear of death.

ECONOMIC IMPACT

From the survey on needs assessment, less than a third of the study participants are currently employed in full or part-time work or self-employed. In the FGDs, participants revealed that HIV has a direct impact on a person’s work, income, career options or job mobility. Many respondents who were sick could not continue to work. A majority stopped working due to being incapacitated by HIV-related illness, forced to resign due to open or tacit discrimination once diagnosis is revealed, or simply asked to leave their job. One woman stopped working because of an embarrassing side effect of HIV medication which darkened her skin. Some, like the refugees, are forced to continue working despite feeling sick. To many, the loss of work and income aggravates their worry and anxiety, especially, with the increased financial burden of HIV treatment and supplements.

The economic impact on persons with HIV varies by sexual identity, class, gender and age. For example, transgender and sex workers in the study are found to be more adversely affected than other groups. Once they fell ill and became very sick, they could not carry on with sex work. Some have returned to their families in the rural areas after diagnosis. A few stopped because they felt it was wrong to infect others. Indeed, some of the transgender sex workers in the study said they were almost destitute and on the brink of being homeless, very sick and abandoned to die on the streets until they were, literally, rescued by WAKE (NGO). Often, this group faces double discrimination from

being transgender and sex worker when applying for welfare or monetary aid from local authorities and agencies, including *Baitumal*, the welfare arm of the state religious agency.

Women infected by their husband are also badly affected economically, especially if and when the husband has died of AIDS leaving her HIV-infected and having to fend for herself and the children as a single parent. Most of the wives were housewives and their husband the sole breadwinner. Their situation deteriorates when they themselves become sick and cannot continue to work or care for their children. A few could still resort to their Employment Provident Fund (EPF) while some others had to rely on welfare, charity or shelters run by NGOs. A few infected women were fortunate that their own siblings or family members were helping them financially, but this was not common in the study.

Generally, older HIV infected persons would be even more disadvantaged economically as they would face even more difficulties getting a job. One older HIV positive respondent in the study was very traumatised and desperate for financial aid as he had used up all his retirement funds that he had withdrawn from the EPF since being diagnosed. He even had to sell off all property that he had painstakingly acquired through his working years - his car, house, and even furniture - leaving him threadbare with just his clothes and a sleeping mattress.

The economic repercussion is particularly daunting for sex workers. Several said they would not reveal their HIV positive status because they knew clients would refuse their services. This is particularly the case for drug-using sex workers who are desperate for work to pay for their drugs. However, some of them in this study claimed they were honest and reveal their HIV status to clients. A few sex workers felt trapped and torn, yet, they needed to work to survive, and this predicament could push some to be suicidal. Some sex workers said they would continue working out of desperation but said they would take necessary precautions, i.e., ask their clients to use the condom. Regrettably, however, with clients who prefer not to use condoms – a majority, in fact - sex workers are not in a position to demand it.

Drug users said they were already financially strained due to drug addiction. Being diagnosed with HIV and requiring money for medication further compound their financial problem. However, when not under the influence of drugs, a few of them continue to find whatever odd jobs they could to survive. One even admitted that in the past he had to resort to committing crime to feed his drug habit which came to RM1500 per month for heroin.

At the other end of the spectrum are the MSM participants. They are generally of higher educational level and work as professionals with higher income status. In other words, the economic impact is less severe for those of higher social class compared to their less educated and lower income counterparts.

With regards to the impact on personal expenses, the majority of PLHIV in this study would say the bulk of their income is spent on buying medication and supplements (Vitamin C, fish oil, spirulina) to maintain their health. The constant monitoring of the response to treatment in terms of trips to the hospital to check on their CD count also takes a toll on their expenses. This sum varies from RM350 to RM2000 monthly. Even

for many of the MSM respondents, who are relatively of better economic standing than the others, medical expenses cut deeply into their income amongst other pre-existing expenses, such as, paying for their car and apartment. While the MSM respondents still manage their treatment expenses, many of the others have to depend on welfare, charitable organisations, or the NGOs, such as Pengasih, KLASS, or for refugees, the UNHCR.

Although many in the study expressed they would certainly want to continue working once they feel better or recover sufficiently, a number of them said they had experienced discrimination as no employer would want to hire an HIV-infected person even after he/she responded well to treatment and medication and feels fit to work.

HIV has an impact on career options and job mobility for all groups of respondents. Some MSM respondents, although better off working as professionals, were forced to quit high-paying jobs, or even leave the country of work, and subsequently accept lower paying jobs. A member of the MSM group recounted that after he was first diagnosed whilst working in a neighbouring country, he asked to quit and leave the country. For many, contracting HIV limited their career potential or upward mobility.

The impact is far reaching and deep because, as some of them explained, even though they can maintain their health sufficiently to work, they would be discriminated each time they apply for a job as it is now a common requirement that applicants do a medical test and they fear their HIV/AIDS status would be revealed.

In summary, the economic impact of HIV affects study participants from being employed to unemployed or underemployed; slipping from high-paying to lower-paying jobs; from career potential to zero chances for career advancement; and from being financially independent or dependent on a husband to being dependent on welfare, charitable NGOs, or their savings, such as EPF.

STIGMATIZATION AND DISCRIMINATION

It was evident from the study participants that HIV-positive people, whether they are infected partners, heterosexual men, MSM, transsexuals, drug users, refugees or sex workers, face and fear stigmatization and discrimination in this society. As described in the findings, these manifest at family, community and institutional levels.

Some experienced insults, harassment, ridicule and humiliation. Some were forced, overtly or subtly, to resign from their place of employment. In particular, the fear of contagion by HIV-infected people is one of the root causes of the stigma attached to HIV. Others felt they had to isolate themselves, and their families, by moving away to avoid being stigmatized. Clearly, years of IEC have not convinced people of the routes of transmission and lay-persons, and even some healthcare workers, are still fearful of being infected from casual or close contact. The persistence of this misconception is supported by the FGDs with communities and needs to be redressed.

Moreover, with such prejudice and discrimination against PLHIV, the breach of confidentiality from healthcare providers and, to a lesser extent, from within their family or friendship networks inflict severe psychological and emotional stress. Whether real or perceived, this fear of stigmatization and discrimination affects their quality of life and

denies them social and economic opportunities through not only negative actions by others but also via self-imposed isolation and limitation. It discourages PLHIV from seeking employment because of pre-employment medical disclosure requirements, and also has the effect of discouraging PLHIV from seeking healthcare and medical treatment regularly, if at all. This may partly explain why less than half of the estimated 4,000 PLHIV who can benefit from HAART take it up.

In particular, the majority of DU men in the study reported experiencing some form of discrimination, primarily from healthcare staff or prison staff but also from their own families/communities. As beholders of two socially undesirable traits, i.e., drug addiction and HIV, it emerged from the needs assessment survey that 22 of 27 DU men in this study reported facing some form of discrimination. It is unclear how much of it arises from their HIV status or from their drug use. At the family and community level, some of the DU men spoke of the reactions from their families, many of which were negative, more so in Kota Baru. A few noted that there was more discrimination in Kota Baru compared to Kuala Lumpur. Many in the group agreed on this. They surmised it was due to the greater ignorance and lack of understanding about the disease in places such as Kota Baru. Interestingly, they pointed out that it was the IEC (Information, Education and Communication) campaigns that labelled HIV in tandem with drug use, promiscuous sexual activity and commercial sex. The conservative society in Kota Baru may also play a part in fostering prejudices against socially undesirable behaviours, such as drug use.

A majority of transgender PLHIV also said they faced some form of stigmatization and discrimination, including from Government aid agencies. As for drug users, transgender people also face discrimination regardless of their HIV status. As far as drug addiction and HIV is seen as a “*two in one package*”, transgender persons bear the prejudice of association with commercial sex. The group with the least to narrate such experiences were refugees and heterosexual men. In large part, this lies in non-disclosure, i.e., because their HIV status is not known. For refugees in this study, this is contributed by limited access to the larger society, and also, they have the support of UNHCR.

In contrast, participants in Kuching and Kota Kinabalu (comprising infected wives and women sex workers) appeared to be accepted by their families and did not experience much stigmatization and discrimination at the family, community or institutional level. If ignorance of HIV were to be blamed, one would expect people in lesser developed East Malaysia, where it is presumed there is less exposure to IEC campaigns, to suffer the same consequences. However, this appears not to be the case. It is possible that since half the East Malaysian participants are infected partners (wives), and the families of the others (sex workers) may not be aware of their commercial sex work, they are viewed as “innocent victims”. Consequently, they receive more sympathy and support compared to the drug users. To add support to this, they have no complaints about the treatment they receive from healthcare staff. Another possible reason is that they tend to live far away from the urban centres where they access HIV-related resources, notably, healthcare, hence, their HIV status remains unknown amongst their community.

This classification of HIV-positive persons into groups according to route of transmission is institutionalised in Malaysia. In effect, this practice identifies whether or not a person was infected by his/her behaviour or activity. Until recently, HIV drug treatment was supplied free to certain PLHIV groups, i.e., women infected from their spouse, infected

children, those infected through blood donation or through work-related hazards; in other words, those who cannot be held responsible, i.e., blamed, for their exposure to HIV. Infected wives also appear to have easier access, and are perceived as such by other groups, to financial aid. There is more public sympathy for these groups of PLHIV. Be that as it may, stigmatization persists even for them – infected children may not be allowed to play with other children, wives may be blamed for their husband's drug addiction or their sexual infidelities, people may refuse to eat the food they cook or prepare, or sit beside them in the mosque, an infected wife may opt to move to another location with her children where no one knows of her HIV situation. These are the actual experiences of the study participants; similar to others documented in other Asian countries (APN+ 2004).

From the community FGD, many participants verbalised the need to be sympathetic and to not discriminate PLHIV. However, at the same time, they also expressed caution if they had a neighbour who is positive, and if their children were to play with or be in school with HIV-positive children. In other words, they were not cognizant that such actions were stigmatizing. One participant admitted that the fear of contagion, from casual contact or from food that a PLHIV prepares, remains despite the information disseminated about ways of transmission. This fear of contagion persists even among some healthcare workers as this study shows. Again, the basis seems to be disbelief or lack of confidence in what is taught about HIV transmission.

In fact, there were numerous cases of institutionalised stigmatization and discrimination, including using medical files of a different colour for HIV patients and segregation of HIV-infected prison inmates, which identify them to others without their consent. Although routine testing of prison inmates and drug rehabilitation residents is not mandatory, there is no precedence of anyone refusing or allowed to refuse testing. Prison inmates also say they received no pre- or post-test counselling. Some of the women sex workers who had been in prison, said that their food trays were labelled with the words 'HIV'. While the segregation may have protected them in some way from other prisoners, the greater problem they felt was that it led to more people outside prison finding out about their HIV status from fellow inmates, with negative consequences. The absence of counselling and active follow-up also means that HIV-infected released inmates are left to cope on their own, some with fatalism and apathy. Those who return to drug use are not likely to change their behaviour.

HIV POLICIES, PROGRAMME IMPLEMENTATION AND PLHIV PARTICIPATION

Comparatively, women infected by their partners were the least aware of public policies and programmes related to HIV/AIDS that could provide resources and support to HIV infected persons in the country. However, a majority of respondents were instead aggrieved by the stereotypical and fear-arousing HIV/AIDS awareness campaigns mounted by the Government. They lamented that such campaigns instilled fear in the society that HIV kills as well as blamed HIV-infected persons' behaviour, deemed immoral or deviant, for contracting the disease, namely, the constant association of HIV with drug users and sex workers in particular. Instead, many of them expressed the Government should educate the public about HIV and AIDS in a factual manner without moralizing people's behaviours so that society can understand their challenges for positive living. Specifically, several of the study participants pointed out the need to portray HIV-infected persons as trying to continue day to day living, going to work,

working towards their future, who can contribute to society. Effective medication has enabled PLHIV a longer lease of life but the stigma on HIV prevents them from living it as others in the community.

Several respondents related their negative experiences of some of the HIV/AIDS programmes or practices pertaining to HIV/AIDS. These include indiscriminate disclosure of HIV diagnosis and status in prisons and drug rehabilitation centres where HIV testing is routinely conducted, often without pre-test, and sometimes without post-test counselling. Some of them were greatly traumatised and humiliated by such unethical and insensitive practices. Coercion to have the HIV test done at work places was also revealed. In addition, many were visibly upset with the current practice in public hospitals that deny a dignified death for HIV-infected persons. This hospital practice, whereby HIV-infected persons who die in hospitals are cleaned up, if relevant, and sealed in body bags, does not allow close family members to be involved or perform proper last rites. Furthermore, transporting the body in sealed body bags reveals the HIV status of the deceased to others in the community and reinforces the fear of contagion and, consequently, the stigma of HIV for the surviving family.

When asked about the extent of participation in HIV policies and programme implementation, those who were more empowered and articulate (some drug users and MSM) were very keen for PLHIV to be directly involved in policymaking relevant to all HIV infected persons. Several of these participants were already actively involved with various HIV-related NGOs in outreach to hospitals, prisons, and drug rehabilitation centres. Drug users, in particular, expressed the need to create support groups and “after-care” post-rehabilitation programmes to ensure they could cope and be integrated back to society. Others voiced the need for self-help, vocational and income-generating programmes to enable positive living for HIV infected persons. It is pertinent to note, however, that some of the respondents pointed out that HIV infected persons themselves need to, first, be confident of their own HIV status in order that they can step out to be involved and participate in HIV policymaking and programmes towards positive living. That is, PLHIV need to be more visible to facilitate society’s acceptance but, at the same time, it is recognised that ensuing negative repercussions discourage them from doing so, hence, a chicken and egg dilemma. As such, efforts to protect PLHIV from the negative effects of disclosure, such as loss of employment, must be enforced. Avenues for such protection in critical areas, such as healthcare and workplace settings, are already available in the form of the Patient’s Charter (MMA 1995) and the Code of Practice for the Prevention and Management of HIV/AIDS in the Work-Place (MOH/DOSH/MAC/UNAIDS 2001). What remain lacking are implementation and/or enforcement.

IMPACT ON THE COMMUNITY

From the FGDs with communities, it was learnt that Malaysian society, both urban and rural, has heard of the terms “HIV” and “AIDS”. However, their knowledge of transmission is flawed and arises from inaccurate media propagation. “*Free sex*”, “*multiple sex partners*”, sex with sex workers and abuse of drugs through the use of injections, all morally unacceptable by our standards to a large extent, influence how society feel about the ways the virus spreads. Attention to the presence of the virus in blood contributes to the fear of any contact with the blood and saliva of an infected person (through play, work or food/drink). Although the participants are aware that

anybody, irrespective of socio-economic background is vulnerable to infection, some mistakenly think they can identify PLHIV through their outward appearances.

Fear of infection, accentuated by various public health policies, e.g., hospital procedures for burial of those who die from infectious disease, is partly to be blamed for the “stigma” attached to HIV and those infected with it and their families. Interestingly, while some participants voiced the need to be sympathetic and understanding, they do not recognise that they are stigmatizing PLHIV by expressing words such as “*we will be careful, when we or our children mix with them.*” By the same token, although the community participants feel that PLHIV should be allowed to continue working, it is again the same fear that causes many of them to say that they should be transferred to an area of work that does not expose them to injury (and therefore bleeding) and far enough from others (those non-infected) so that there is no potential for contact with their saliva.

Participants are aware of the Government’s efforts in prevention. However, the feeling is that it must begin with arresting the problem of drug abuse. Education programmes for the community are also advocated and, for this, they suggest that many more agencies (other than the Ministry of Health) should be involved. In addition, schools and parents were called upon to do their part. This concept of multi-sectoral action falls in line with the National Strategic Plan 2006-2010.

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Annex I: FGD Operational Flow Chart

Focus Group Discussion with PLHIV

IMPACT

Health

Economic

Social

Psychological/ emotional

1. Coping factors/ obstacles

- Health affected?
- Changed your physical behaviour/lifestyle?

- Educational status/access to education /motivation

- Disclosure to whom? Experiences?

- Circumstances of initial HIV test?

2. Motivations to seek help/resources

- Access to healthcare? Any changes?

- Employment status/career prospect

- Stigmatization/ discrimination?

- Feelings at times of HIV disclosure?

3. Awareness of law/ policies

- Self-help?

- Discrimination at workplace?

- Home and family life?

- Self esteem/ image?

4. Desire to participate in HIV/AIDS issues

- HIV-related resources accessed?

- Financial status (earning capacity)

- Friendships?
- Relationships with neighbors/ community?

- Outlook of life?

- Discrimination?

- Accommodation and transportation

- Religious participation/ networks & spirituality

- Fears? How addressed?

- Major concerns for the future?

Annex II: FGD Guide for PLHIV Groups

Focus Group Discussion Guide

*The Impact of HIV/AIDS on People Living with HIV/AIDS and
Their Families and Community in Malaysia
(UNCT Project)*

Introduction:

1. Ice-breaking session
2. Explain purpose of discussion
3. Interested in personal experiences and views
4. Encourage each participant to express his or her views on each topic as well as respond to the views expressed by others
5. It's alright to disagree with others
6. Participants do not have to respond to an issue if they do not feel comfortable doing so
7. Views to be kept confidential
8. Explain the necessity to audiotape
9. Take verbal consent (for both FGD and audio-taping)
10. Any questions before we start?

The purpose of today's discussion is to talk about how being diagnosed with HIV/AIDS has affected your life and what impact it has had on different aspects of your life.

❖ How were you diagnosed with HIV?

- I. **Health/Physical Impact:** How has HIV affected your health and physical well-being?
 - **Physical effects/current needs**
 - *How is your health; What are your needs?*
 - **Changes in behavior/lifestyle**
 - *Such as diet, sexual behavior, prevention practices, etc.*
 - **Access to healthcare**
 - *How has it changed after your HIV diagnosis? What medical treatment or remedies have you undergone?*
 - **Self-help**
 - **HIV-related resources**
 - *For example, do you access any support networks or counseling, welfare/financial aid, information & education on HIV/AIDS, harm reduction programs? How do you feel about them?*
 - **Discrimination** when seeking medical care?
-

II. Economic Impact: How has your HIV status affected you financially and how has that, in turn, affected your life?

- **Educational status and/or access to education**
 - *Of self, spouse, children, or other family members*
 - *Has HIV changed your or your family members' motivation for education?*
 - **Employment status and career prospects**
 - *How was your employment status affected after your HIV diagnosis?*
 - *Physical health (more frequent medical leave)*
 - *Income*
 - *Change of jobs*
 - *Did you experience any discrimination at your workplace from your employers or co-workers? How did you respond?*
 - **Financial status (earning capacity)**
 - *How do you feel your incoming generating potential has changed after you were diagnosed with HIV?*
 - *How did your expenditures change after you discovered you had HIV?*
 - *Education*
 - *Medical care (drugs, hospital visits)*
 - *Food*
 - *How did/do you address your new financial problems and worries?*
 - **Housing/accommodation and transportation status**
 - *Did you have to make any changes in your housing and/or transportation arrangements? If yes, why?*
 - *What problems in housing and transportation do you face?*
-

III. Social Impact: Can you share about how being HIV positive has affected your relationships with people close to you?

- **Disclosure**
 - *To whom?*
 - *What were your experiences of disclosure like?*
- **Stigmatization and discrimination**
 - *Can you share about some specific instances?*
 - *How did you respond to it? How has it changed your behavior or lifestyle?*
 - *Do you still experience such discrimination today?*
- **Home & family life**
 - *Who in your family did you disclose your status to?*
 - *How did they react when you disclosed your status? Did they accept you? If yes, how long did it take?*
 - *How has your status affected your:*
 - *nuclear family relations:*

- ◆ *Spouse: marital/sexual relations (divorce, childbearing)*
- ◆ *Children (fostered or sent to other care-providers, education, sent to work, treated differently by community)*
- ◆ *Household structure*
 - *Parents and other elders in your family*
 - *Extended family relationships*
- **Friendships**
 - *(i.e. acceptance, disown, outcast, etc.)*
 - *How did it affect your relationship with your partner? (prospect of marriage)*
- **Neighbours/community**
- **Religious participation and/or spirituality**
 - *Decrease/increase of faith?*
 - *What changes occurred within your religious networks?*
 - *How did religion or religious institutions help or hinder your coping with HIV?*

IV. Psychological/Emotional Impact: How has your HIV status affected you personally on an emotional or psychological level?

- **Circumstances of your initial HIV test?**
 - *How did you feel after you discovered your HIV status?*
- **Times of disclosure**
 - *To your family, friends, neighbors, colleagues? How did they react? How did you feel?*
- **Self-esteem and self-image**
 - *How has this changed since you were first diagnosed? Why do you feel this way?*
- **Outlook on life**
 - *Since your diagnosis, do you feel less happy/hopeful/purposeful?*
- **Fears**
 - *At the time of your diagnosis, at the present time? How have these been addressed?*
- **Major concerns for the future?**
- **To whom or where do you go for help?**
- **Coping**
 - *What is your support system like?*

V. HIV/AIDS-related Policies & Laws: Can you talk about how you have been involved with HIV-related policies and programs?

- ❖ *What HIV/AIDS-related policies and laws are you aware of and how have they made a difference to you and/or your family?*
- ❖ *What organizations have you been going to for help?*
- ❖ *How would you like to participate in shaping future HIV/AIDS policies and programs?*

Annex III: FGD Guide for Community Group

Focus Group Discussion Guide (Community) *The Impact of HIV/AIDS on People Living with HIV/AIDS and Their Families and Community in Malaysia (UNCT Project)*

Introduction:

11. Ice-breaking session
12. Explain purpose of discussion
13. Interested in personal experiences and views
14. Encourage each participant to express his or her views on each topic as well as respond to the views expressed by others
15. It's alright to disagree with others
16. Participants do not have to respond to an issue if they do not feel comfortable doing so
17. Views to be kept confidential
18. Explain the necessity to audiotape
19. Take verbal consent (for both FGD and audio-taping)
20. Any questions before we start?

The purpose of today's discussion is to talk about your understanding of HIV/AIDS and your personal perspective/feelings about people living with HIV/AIDS.

I. Knowledge related to HIV/AIDS

A. Knowledge about the disease

- Have you heard about HIV/AIDS?
- Where have you obtained information on HIV/AIDS - sources?
- What do you know about HIV/AIDS?
 - Ways infection is spread
 - Treatment or cure for HIV
 - Sources of treatment – integrated clinics or separate HIV clinics
 - Physical features (what they look like; socio-demographic background, etc) of someone infected with HIV
 - Social background of people who are infected
- How does HIV affect a person who is infected – what is the impact of the disease – on the family, on the nation?

B. Knowledge about policy and programmes

- Which sector or authority is (or authorities are) responsible for controlling the spread of this disease? (Government and Non-Government)
- How effective do you feel these steps have been so far?
- What steps have been taken in Malaysia to control this infection?

I. Attitudes and Perceptions related to HIV/AIDS

A. Stigma and discrimination

- What do you feel about people who get infected with HIV?
(Explore manifestations of stigma and discrimination)
 - Employment for HIV+ people
 - Schooling for HIV+ children
 - Marriage and having children (marriage between two HIV + people?; marriage between one HIV+ and another not HIV+?)
 - Living with HIV+ neighbour
 - Working with HIV+ person
 - Your children schooling with HIV+ children
 - Your children playing with/being friends with HIV+ children
- What do you think about Government-subsidies for medical treatment, support and welfare aid for HIV infected people?
- HIV can be compared to other chronic diseases like diabetes and hypertension that can be managed for many years with proper treatment – what do you feel about that?

B. Prevention and control strategies

- What do you think should be done in Malaysia to control or stop the spread of this disease?
 - What do you think the Government should do?
 - How about other sectors - employers, private education centres, social organizations, religious bodies?
- Do you feel local communities have a role in controlling the spread of HIV?
- What do you feel about people living with HIV participating in formulating policies on treatment and prevention of HIV/AIDS?

II. Involvement in HIV/AIDS Prevention, Treatment and Support

- Have you any friends/colleagues/family who work or volunteer in any NGO/community services related to HIV/AIDS and / or with HIV+ persons?
- Would you yourself volunteer at such NGOs/community services?

Annex IV: FGD Guide for Refugee Group

Focus Group Discussion Guide (R)

The Impact of HIV/AIDS on People Living with HIV/AIDS and Their Families and Community in Malaysia (UNCT Project)

Introduction:

21. Ice-breaking session
22. Explain purpose of discussion
23. Interested in personal experiences and views
24. Encourage each participant to express his or her views on each topic as well as respond to the views expressed by others
25. It's alright to disagree with others
26. Participants do not have to respond to an issue if they do not feel comfortable doing so
27. Views to be kept confidential
28. Explain the necessity to audiotape
29. Take verbal consent (for both FGD and audio-taping)
30. Any questions before we start?

The purpose of today's discussion is to talk about how being diagnosed with HIV/AIDS has affected you and the impact it has had on different aspects of your life.

- ❖ How long have you been in Malaysia?
 - What were the reasons for you migrating here - work or economic or political asylum?
 - What are your present general living conditions like – housing situation, job situation, family and/or community network?
 - Is there any resource or support network or organisation that helps you as a refugee in Malaysia? (local and/or international organisation)
 - What is your relationship with the local residents where you live and local resources (e.g., healthcare, welfare, religious institution)? Do you have any contacts/dealings with them (social or business)?
 - Do you seek help from the local residents? If so, are they helpful to you?
 - ❖ How did you find out you were HIV-positive?
 - Why did you get yourself tested or, if not voluntarily, why were you sent for HIV testing?
 - Where and how was the testing done? Did you receive counselling before and/or after the test was done?
-

I. HIV/AIDS Knowledge

- What did you know about HIV/AIDS at the time you were tested?
- What do you know about HIV/AIDS now? Where have you received information on HIV/AIDS? How about support (psychological/counselling, financial, etc)?
- Has the information and support helped you with living with HIV?
- Are there any resource or support network or organisation where you can go to for help?

II. Health/Physical Impact

- *Physical effects*
 - In what ways has HIV affected you physically? Are you able to carry out your usual daily activities, such as taking care of yourself, cleaning, cooking, etc?
- *Changes in behaviour/lifestyle*
 - Have you made changes in your lifestyle, such as sexual practices, diet, physical activities?
- *Access to healthcare*
 - Has your health suffered because of HIV – do you have any health problems?
 - Where do you go for healthcare visits? Do you have problems getting health care?
 - How has it changed after your HIV diagnosis? What medical treatment or remedies have you undergone?
 - Have you faced discrimination when seeking healthcare?
- *NGOs/Community Resources*
 - What HIV-related resources are available to you?
(For example, through UNHCR; community support networks, welfare/financial aid, information & education on HIV/AIDS)
How do you feel about them?

III. Social and Economic Impact

- *How has HIV affected your financial status?*
 - Ability to work/be employed/earn income?
 - More sick leave?
 - Reaction of/response from employers (if employed); Support from employers; Retrenchment?
 - How did your expenses change after you discovered you had HIV (on medical care; drug treatments; supplements)?
 - How are you able to cope?
- *How has HIV affected your social life and circumstances?*
 - Who else knows about your HIV status; whom have you informed?
What was their reaction?

- Relationships with others - family members here in Malaysia (if any) and/or those at home in Myanmar; romantic/sexual relationships; marriage prospects; desire for children?
Relationships within your community here in Malaysia?
 - How has HIV affected your religious participation and/or spirituality (decrease/increase of faith)? What changes occurred within your religious networks?
 - What types of stigma and discrimination have you experienced? Can you share these instances?
 - How did you respond to it? How has it changed your behaviour or lifestyle?
- ❖ *How has HIV affected you emotionally or psychologically?*
- How did you feel when you discovered your HIV status? How do you feel now?
 - How has HIV infection affected your confidence, self-esteem and self-image? Why did you feel this way?
 - What fears did you have at the time of your diagnosis? How have these been addressed?
 - To whom or where do you go for help?
 - How have you coped with these emotional consequences of HIV? What or who has helped you most with coping with HIV?
 - How would you describe your outlook on life since your diagnosis? (i.e. happiness, purposefulness)
 - What are your major concerns for the future?

IV. Policies & Programs on HIV/AIDS

- Are there any policies or programmes you know of specifically for HIV+ refugees?
- Are the existing policies and programmes/services available to you? How about to other HIV+ refugee communities?
- Do refugees need separate policies/programs more specific for your own needs? How do you think these can be organized and made available?

Annex V: Rapid Needs Assessment Questionnaire⁸

The Impact of HIV/AIDS on People Living with HIV/AIDS and Their Families and Community in Malaysia **(UNCT Project)**

Needs Assessment Questionnaire

All information is strictly CONFIDENTIAL

Please answer the following questions by putting a tick (√) at the appropriate number or writing in your response. Please answer all the questions.

1. Gender

- [1] Male
- [2] Female
- [3] Transgender

2. Age _____ years

3. Ethnicity

- [1] Malay
- [2] Chinese
- [3] Indian
- [4] Sarawakian indigenous, please specify _____
- [5] Sabahan indigenous, please specify _____
- [6] Others, please specify _____

4. Religion

- [1] Islam
- [2] Buddhist
- [3] Taoist /Confucianism
- [4] Hindu
- [5] Christian
- [6] Others, please specify _____

5. What is your current marital status?

- [1] Single
- [2] Married
- [3] Divorced
- [4] Separated
- [5] Widowed
- [6] Living together with partner
- [7] Others, please specify _____

6. What is your current employment status?

- [1] Unemployed (not retired)

⁸ Coding columns on right side of pages not shown

[2] Employed full-time, please specify _____

[3] Employed part-time, please specify _____

[4] Self-employed, please specify _____

[5] Long term medical leave

[6] Volunteer work

[7] Others, please specify _____

7. What is your highest educational level?

[1] No formal education

[2] Completed primary school

[3] Completed lower secondary school (Form 3)

[4] Completed upper secondary school (Form 5 or 6)

[5] Completed vocational school

[6] University / College

[7] Others, please specify _____

8. Please tell us more about your immediate family members.

Family members	No. of person
Grandparents	_____
Parents	_____
Siblings (excluding myself)	
Male	_____
Female	_____
Children (including adopted child)	
Male	_____
Female	_____

9. Apart from you, who is HIV positive in your family? Please specify the relationship (for the child involved, including adopted children, please specify the age if the child is below 18 years old).

Relationship	For child under 18 years old, please specify the age (years)
1) _____	_____
2) _____	_____
3) _____	_____
4) _____	_____

10. Are you dependent on your family members, or are your family members dependent on you? Please tick (✓) all that apply.

Types of support or responsibility	My family members take care of me or support me	I provide care or support my family
[A] None, my family members have disowned me (cut off relations with me)		
[B] Caring for daily needs, eg. providing meals, clothing, bathing, cleaning, etc		
[C] Providing love and emotional support		
[D] Providing financial support for various needs, eg. rent, school fees, clothes, food		

11. When did you find out that you are HIV-positive?

_____ months ago (if less than 1 year ago)

_____ year(s) ago (if 1 or more years ago)

12. How did you discover your HIV status?

Please tick (✓) one only.

[1] Voluntary testing, please specify why you went for voluntary testing _____

[2] Recommended by doctor because I was sick

[3] Tested during antenatal care

[4] Blood donation

[5] Mandatory pre-marital testing

[6] Tested at a drug rehabilitation centre

[7] Tested in prison

[8] Due to confirmed tuberculosis (TB)

[9] Due to sexually transmitted disease (STD)

[10] I went for a HIV test after I knew that my partner is HIV positive

[11] Others, please specify _____

13. What information and / or services were offered to you at the time of your testing or receiving the test results? Please tick (✓) all that apply.

[A] Pre-test counseling

[B] Post-test counseling

[C] Information about non-Governmental HIV/AIDS-related organizations and their services

[D] Information regarding support networks / groups for people living with HIV

[E] Information about proper nutrition / diet

[F] Information regarding HIV/AIDS-related government services and help

[G] Others, please specify _____

[H] None

14. What has made it difficult for you to access HIV/AIDS-related information and / or services?

Please tick (✓) all that apply.

- [A] I have not had problems
- [B] I did not know about them or where to find them
- [C] I am worried about stigmatization against people living with HIV
- [D] I am not well to leave my house
- [E] Transport problems to get to the services
- [F] Others, please specify _____

- 15 Are you receiving HIV-related treatment and / or drugs regularly as prescribed by your doctor(s)?
- [1] Yes, regularly as prescribed by my doctor
 - [2] Yes, but not regularly as prescribed, please specify why _____
 - [3] No, I do not need it (**Please go to Question 17a**)
 - [4] No, I need it but I cannot pay for it (**Please go to Question 17a**)
 - [5] No, I need it but I do not know where to go for treatment (**Please go to Question 17a**)

16. Where do you obtain your medical care and medication, for HIV and associated illness? How do you pay for this service or medication?

A. Source of medical care and medication Please tick (✓) all that apply	B. Method of payment Please tick (✓) all that apply
[A] Government Hospital	[A] Pay for them myself [B] Get help from family / friends [C] Government fully subsidized [D] Government partially subsidized [E] Private insurance [F] Others, please specify _____
[B] University Hospital (Example: UH, HUKM, HUSM)	[A] Pay for them myself [B] Get help from family / friends [C] Government fully subsidized [D] Government partially subsidized [E] Private insurance [F] Others, please specify _____
[C] Others, please specify _____	[A] Pay for them myself [B] Get help from family / friends [C] Others, please specify _____

- 17a. Please tell us what physical health problems you experience currently as a result of your HIV status. Please tick (✓) all that apply.

Health problems	Please tick (✓) one only				If yes, please tick (✓)
	Yes, often	Yes, sometimes	No problem	Not relevant	Do you receive help for this problem currently?
[A] Problem with eating, drinking or appetite					
[B] Problem sleeping					
[C] Mobility problems like getting up, walking					
[D] Difficulty with daily life activities, like taking care of myself					
[E] Difficulty doing household chores					
[F] Difficulty taking care of my children					
[G] Difficulty taking treatments regularly					
[H] Problems with drugs or alcohol					
[I] Problems with sex					
[J] Others, please specify _____					

17b. Please tell us what financial problems you experience currently as a result of your HIV status. Please tick (✓) all that apply.

Financial problems	Please tick (✓) one only				If yes, please tick (✓)
	Yes, often	Yes, sometimes	No problem	Not relevant	Do you receive help for this problem currently?
[A] Housing rent / mortgage payments					
[B] No fixed place to stay					
[C] Utility bills (electricity, water, phone) payments					
[D] Buying food stuff					

[E] Buying vitamins / food supplements					
[F] Childcare payments					
[G] Children's school fees, books, etc					
[H] Fees for my own education or training					
[I] Obtaining HIV-related medical therapies and treatment					
[J] Obtaining other medical care or treatment					
[K] Others, please specify _____					

17c. Please tell us what social / emotional problems you experience currently as a result of your HIV status. Please tick (✓) all that apply.

Social / emotional problems	Please tick (✓) one only				If yes, please tick (✓)
	Yes, often	Yes, sometimes	No problem	Not relevant	Do you receive help for this problem currently?
[A] Difficulty managing depression / anxiety					
[B] Low self-esteem					
[C] Poor outlook on future					
[D] Feeling isolation or alone					
[E] Relationship problem with your partner / husband / wife					
[F] Relationship problem with family members					
[G] Relationship problem with friends					
[H] Relationship problem with co-workers					
[I] Afraid to tell family members about my HIV status					
[J] Afraid to tell friends about my HIV status					
[K] Others, please specify _____					

18. For those problems you have listed above (**Questions 17a, 17b, 17c**), do you think

more help would be useful for you in coping with the problems? Please tell us for which problems you need more help.

19. Do you experience stigmatization / discrimination because of your HIV status?

- [1] Yes
- [2] No (**Please go to Question 21**)
- [3] No, because no one knows (**Please go to Question 21**)

20. How has stigmatization / discrimination affected normal activities in your life?

Please tick (✓) all that apply.

- [A] Prevented me or my children from attending school
- [B] Health care workers now seem reluctant / anxious to treat me (eg. they avoid touching me or postpone my appointments)
- [C] Cause me to change workplace or lose my job
- [D] Friends do not want to socialize with me
- [E] Neighbors do not allow their children to play with mine
- [F] Prevented me from attending religious activities due to the reaction of other

worshippers

- [G] Others, please specify _____

21. How do you cope with the challenges of being HIV positive?

Please tick (✓) all that apply.

- [A] Support from immediate family (eg. your parents, brothers & sisters, grandparents, your children)
- [B] Support from relatives (eg. cousin, uncle, aunt)
- [C] Support from long time friends
- [D] Support from other people living with HIV
- [E] Support from religious leaders
- [F] Support from counselor / staff at HIV/AIDS organization
- [G] Telephone helpline
- [H] Support from doctors / nurses / healthcare staff
- [I] Pamphlets for people living with HIV
- [J] Others, please specify _____

22. What are your main worries currently because of your HIV status?

23. Are you aware of any government help or services for people living with HIV? (Eg. treatment, medicine, school, welfare).

[1] Yes, please specify the support that you know of

[2] No

24. Do you want to be involved in efforts to help people living with HIV?

[1] Yes, please specify what _____

[2] No, please specify why _____

Thank you very much for participating in this study!

Annex VI: Ethics Approval Letter



JAWATANKUASA ETIKA PERUBATAN

PUSAT PERUBATAN UNIVERSITI MALAYA
59100 LEMBAH PANTAI
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19 Jun 2006

Rujukan: HU-61/12/1-

Prof. Low Wah Yun
Jabatan Pembangunan Penyelidikan Kesihatan

Puan

SURAT PEMAKLUMAN KEPUTUSAN PERMOHONAN MENJALANKAN PROJEK
PENYELIDIKAN

The Impact Of HIV/AIDS On People Living With HIV/AIDS, Their Families And
Communities In Malaysia.

MEC. REF. NO.: 505.1

Dengan hormatnya saya merujuk kepada perkara di atas.

Bersama-sama ini dilampirkan surat pemakluman keputusan Jawatankuasa Etika Perubatan yang bermesyuarat pada 17 Mei 2006 untuk makluman dan tindakan puan selanjutnya.

Sekian, terima kasih.

Yang benar

MARIAM MANSOR
Setiausaha
Jawatankuasa Etika Perubatan
Pusat Perubatan Universiti Malaya

s.k Ketua
Jabatan Pembangunan Penyelidikan Kesihatan



PUSAT PERUBATAN UNIVERSITI MALAYA

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NAME OF ETHICS COMMITTEE/IRB: Medical Ethics Committee, University Malaya Medical Centre	ETHICS COMMITTEE/IRB REFERENCE NUMBER: 505.1
ADDRESS: LEMBAH PANTAI 59100 KUALA LUMPUR	
PROTOCOL NO:	
TITLE: The Impact Of HIV/AIDS On People Living With HIV/AIDS, Their Families And Communities In Malaysia.	
PRINCIPAL INVESTIGATOR: Prof. Low Wah Yun	SPONSOR:
TELEPHONE: KOMTEL:	

The following item have been received and reviewed in connection with the above study to be conducted by the above investigator.

<input checked="" type="checkbox"/> Borang Permohonan Penyelidikan	Ver date: 8 May 2006
<input checked="" type="checkbox"/> Focus Group Discussion Guide	Ver date:
<input type="checkbox"/> Investigator's Brochure	Ver date:
<input type="checkbox"/> Patient Information Sheet	Ver date:
<input type="checkbox"/> Consent Form	Ver date:
<input type="checkbox"/> Advertisement/Compensation to Subject	Ver date:
<input checked="" type="checkbox"/> Investigator(s) CV's (Prof. Low Wah Yun)	

and have been

Approved
Conditionally approved (identify item and specify modification below or in accompanying letter)
Rejected (identify item and specify reasons below or in accompanying letter)

Comments:

Investigator is required to follow instructions, guidelines and requirements of the Medical Ethics Committee.


Investigator is required to report any protocol deviations/violations through the Clinical Investigation Centre and provide annual/closure reports to the Medical Ethics Committee.

Date of approval: 17th May 2006

c.c Ketua
Jabatan Pembangunan Penyelidikan Kesihatan

Timbalan Dekan (Penyelidikan)
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Jawatankuasa Penyelidikan Pusat Perubatan
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PROF. LOOI LAI MENG
Chairman
Medical Ethics Committee

¹ AVERT (2005). The impact of HIV and AIDS on Africa. <http://www.avert.org/aidsimpact.htm>; July 26 2005.