



FIRST DO NO HARM:

Discrimination in Health Care Settings against People Living with HIV in Cambodia, China, Myanmar, and Viet Nam

Discrimination in health care settings is one of the foremost barriers preventing people living with HIV and key populations from accessing critical health services. For people living with HIV, disclosure can mean they are denied surgery or treatment. This report summarizes documented experiences of discrimination against people living with HIV in health care settings, and discusses the devastating consequences for those patients in the region who are turned away by health care practitioners because of their status.

Based on 202 interviews conducted by 8 community based organizations in Cambodia, China, Myanmar and Viet Nam, this report documents discriminatory practices against people living with HIV, including involuntary testing, disclosure, segregation, and arbitrary additional expenses for patients due to their HIV status. For women living with HIV, discrimination also extends to sexual and reproductive health services, including advice against pregnancy and, in some cases, sterilization on the advice of doctors due to their HIV status.

This report also documents health care done right. Examples where affected communities, health care providers and governments work together to increase awareness of HIV prevention, illustrate best practices to reduce discrimination and ensure the right to health for all.

The recommendations in this report lay the foundation for an inclusive response that strengthens implementation of national HIV plans and global targets. Moving towards zero discrimination means stamping out discrimination by health professionals, clinic by clinic, across hospitals, and entire health care systems. A strong collaboration between government agencies, hospital administrations, international development partners, and community-based organizations at all levels is required to ensure the outcomes protect the rights of all.

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ACRONYMS IN THIS REPORT

AMA	Aye Myanmar's Association, Sex Workers' Association
APAC	Asia and the Pacific
ART	Antiretroviral Therapy
AUA	ARV Users' Association
CBO	Community Based Organization
CCW	Cambodia Community for Women living with HIV
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
HCW	Health Care Workers
HIV	Human Immunodeficiency Virus
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICCPR	International Covenant on Civil and Political Rights
KSG	Kids Sun Group
MSM	Men who have sex with men
MPG	Myanmar Positive Group
NGO	Non-Government Organization
OI	Opportunistic Infection
PMTCT	Prevention of Mother to Child Transmission
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
VYPN	Viet Nam Youth Network of HIV AIDs Prevention
WLHIV	Women Living with HIV

I. Executive Summary

There are 4.8 million people living with HIV in the Asia-Pacific region today, with new infections every year, and many people still unaware of their status or on appropriate treatment.

Discrimination remains the foremost barrier to achieving the right to health for people living with HIV and ending the global epidemic. Discrimination against people living with HIV in health care settings is therefore particularly egregious as it can also have devastating consequences, and potential loss of life, for those patients who are denied care by health care practitioners because of stigma, legal frameworks or weak policy enforcement. Fear of discrimination can also prevent people from seeking care in the first place, or from disclosing their status to healthcare practitioners, thus potentially compromising any treatment they do receive.

Discrimination in health care settings manifests in myriad ways, including denial of services, segregation, and arbitrary additional fees for a broad range of health services. For women living with HIV, discrimination can also extend to access and the appropriateness of sexual and reproductive health services, including advice against pregnancy, and coerced abortions or sterilization.

Non-discrimination is an inherent component of the international human rights framework and is articulated in many national constitutions and laws. It is seen as a cornerstone of human rights protections as, without it, a broad array of other rights, including the right to health, cannot be fulfilled. However, domestic frameworks protecting the right to non-discrimination are not always codified or consistently enforced. The consequences for people living with HIV and the key populations most at risk of contracting HIV or affected by it, can be severe.

As a first step in trying to address the root causes of such discrimination, Asia Catalyst embarked on an 18 month community led regional research project to document the types of discrimination in health care settings experienced by people living with HIV and the impact it has on their access to healthcare and related services. The study focused on China, Cambodia, Myanmar and Viet Nam, which represent some of the Asia Pacific countries with the highest HIV burden and highest numbers of new infections in the region.

This report is based on 202 interviews with people living with HIV conducted between May – July 2015, in Cambodia, China, Myanmar and Viet Nam. The interviews were carried out by staff and volunteers of eight community based organizations (CBOs) representing key population communities living with or affected by HIV in those four countries. The eight CBOs included the Cambodian Community for Women Living with HIV in Cambodia and Kids Sun

Group in Viet Nam who specifically focused on researching and documenting discrimination against women living with HIV (WLHIV) when trying to access sexual and reproductive health services in Cambodia and Vietnam; the Consultation Centre for AIDS and Health Services in China who focused on discrimination against transgender women living with HIV when trying to access breast augmentation procedures; Chengdu Tongle Health Counselling Centre in China and the Vietnam Youth Network for HIV/AIDS Prevention in Viet Nam who focused on discrimination against men who have sex with men (MSM) living with HIV when trying to access health services in China and Viet Nam; and Aye Myanmar's Association, Sex Workers' Association and Myanmar Positive Group who focused on discriminatory fees charged to people living with HIV when accessing general health services in Myanmar.

While all four countries have national mechanisms including, in some instances, HIV –specific policies to protect the right to non-discrimination and ensure the rights of people living with HIV and key populations, the research found widespread stigma against people living with HIV, and structural discrimination preventing access to a broad array of health care services.

Involuntary testing and disclosure without consent was documented in a few cases in China and Myanmar. Following voluntary or involuntary disclosure of HIV status, people living with HIV in all four countries also faced denial of services. Although a few cases in Myanmar found denial of services in accessing HIV treatment, the majority of service denials were related to surgery and treatment unrelated to HIV. Women living with HIV reported denial of pregnancy related services in Myanmar, China and Cambodia, including information and services related to Prevention of Mother to Child Transmission (PMTCT) of HIV in Myanmar. All transgender interviewees in China were denied breast augmentation surgery because of their HIV-status.

The research also found more nuanced manifestations of discrimination including subtle changes of treatment in China and Viet Nam, usually from surgery as the best recommended option, to topical or oral medication instead. In Myanmar people living with HIV reported additional fees and expenses charged to them because of their HIV status. Following disclosure of HIV status, interviewees from China, Myanmar and Cambodia also reported they were forced to leave the hospital early, preventing appropriate after care and treatment and adversely affecting the quality of health services.

A number of interviewees from Myanmar and Cambodia reported segregated waiting areas and bed spaces for people living with HIV, as well as visible markers identifying case files of HIV patients at both government and private run health care facilities. People living with HIV in Cambodia, Myanmar and Vietnam reported that medical staff deliberately shared information

related to the HIV status of their patients unnecessarily to other support staff, resulting in discriminatory behavior and violating their right to privacy.

The research also found stigma and discrimination against women living with HIV resulted in denial of critical and medically accurate information that would enable women to make an informed decision on whether and when to have child, and how to minimize the risk of HIV transmission from mother to child. A few women from Cambodia and Myanmar reported they underwent sterilization procedures without adequate information or a clear understanding of the consequences of sterilization.

The impact of these types of discrimination in healthcare settings can be profound and wide reaching. The denial of the best available of treatment can unnecessarily prolong disease and, in some cases can lead to a chronic deterioration in health. Discrimination in health care settings can also have an economic impact as people living with HIV spend more time seeking healthcare providers that will treat them, and often face discriminatory additional expenses. This climate of stigma and humiliation can result in a heavy emotional burden for people living with HIV, can also impact mental health which, over time, can also have a detrimental impact on physical health.

Understanding the human toll of the impact of discrimination is fundamental to designing positive policies, programs and legal frameworks to address root causes and ensure a holistic response to the HIV epidemic. While this report is not a comparative or comprehensive analysis of the situation for people living with HIV in Asia, the illustrative examples from Cambodia, China, Myanmar and Viet Nam do contribute to the growing body of evidence on HIV-related stigma and discrimination and the consequences and impact of such discrimination on people's lives, as well as the efficacy of current models of HIV prevention, treatment and care in those four countries. Furthermore, the research highlights the essential part that community based organizations play in leading the design and collection of such an evidence base. This report is enriched by in-depth experiences of people living with HIV and other key populations which would not have been possible if the research were not conducted by community representatives. Strong community responses from key populations and vulnerable groups are "essential" to controlling the epidemic, as they are "key providers of prevention, treatment, care, and support services, and also work to create the social, political, legal and financial environment needed to effectively respond to the epidemic."¹ This essential need is magnified when widespread stigma dissuades or prevents people living with HIV from openly seeking appropriate care and support. Involvement and support of representative CBOs is therefore

¹ "Supporting Community-based responses to AIDS, Tuberculosis, and Malaria." UNAIDS, June, 2010

at the heart of good HIV/AIDS policy and funding. Such involvement also contributes to a stronger, more resilient civil society empowered to leverage change for broader protections, freedoms, and human rights for all.

As the evidence highlights, discrimination against people living with HIV in health care settings manifests at individual, environmental and policy levels and therefore has to be addressed at all levels. Documenting human rights violations against key populations, including people living with HIV, and finding common solutions necessitates a collective effort. Addressing discrimination on issues that cut across countries at national and regional levels requires collective action. In line with the broader frameworks of the Sustainable Development Agenda and UNAIDS' Fast-Track Strategy to eliminate stigma, discrimination and violence related to HIV in healthcare settings, the following key recommendations illustrate what localized CBO-led stigma-reduction advocacy programs and policy responses might 'look like,' and how localized action can reflect and align with it.

To National Governments:

- Conduct an assessment of the legal environment to see whether all aspects of the legal environment (e.g. law, law enforcement and access to justice) are working to reduce and provide redress for HIV-related stigma and discrimination that blocks HIV prevention, treatment, care and support;
- Repeal punitive legislation, including the criminalization of HIV transmission, sex work, drug use and harm reduction and consensual same-sex activity;
- Integrate HIV awareness and training as part of medical degrees for all new students;
- Strengthen collaboration with community-based organizations for evidence collection and the design and implementation of HIV programming.

To Health Care Service Administrations:

- Establish and operationalize workplace policies against discrimination, including functioning mechanisms for redress;
- Institute health-care workplace programs and training on non-discrimination and medical ethics related to HIV for health workers and all hospital administration staff;
- Provide comprehensive sexual and reproductive health training,

including on HIV and AIDS, for health care workers;

- Thoroughly investigate and take action against breaches of confidentiality, denial of treatment, or any other forms of discriminatory attitudes amongst health care workers

To International Development Partners:

- Support CBOs to strengthen their human rights and legal rights knowledge and advocacy skills;
- Provide financial and technical support for the continuation of program, documentation, and advocacy activities;
- Facilitate linking resources between different CBOs and multi-sectoral collaborations between CBOs and legal service providers, health care providers, human rights NGOs, judiciary and law enforcement;
- Support community-led monitoring of rights violations (e.g. through initiatives such as the People Living with HIV Stigma Index);
- Fund HIV-related awareness campaigns that are responsive to the needs of those most marginalized.

To Community Based Organisations:

- Strengthen networks and collaboration at the local, national and regional levels;
- Increase awareness of human rights and existing legal frameworks;
- Strengthen and continue documentation of human rights violations;
- Collaborate with government partners and health care providers at all levels, from local to national;
- Increase knowledge and awareness of the communities on regular HIV treatment.

II. Background

There are 4.8 million people living with HIV in Asia and the Pacific (APAC) today.² For this group, HIV-related stigma is pervasive, often manifesting in HIV-related discrimination in private and public settings. Discrimination and stigma have a wide array of negative consequences, but discrimination in the medical field is particularly egregious and, as such, practices can prevent access to basic, sometimes life-saving, care for thousands of people. The UNAIDS APAC regional averages for the People Living with HIV Stigma Index make “a sobering read”:³ 22% of respondents avoid going to local clinics for medical care, 17% avoid hospitals, and 11% have been denied healthcare (including dental) because of discrimination related to their HIV status.³ The report, for which data were collected between 2008 and 2010, reported that HIV-related stigma reduces access to healthcare for people living with HIV and that healthcare providers become unsupportive after discovering patients’ HIV status⁴.

According to 2012 UNAIDS estimates, 12 countries account for more than 90% of people living with HIV in APAC, as well as more than 90% of new HIV infections.⁵ Among these 12 countries, and of those relevant to this report, the number of people living with HIV according to the latest government estimates, total 501,000 in China⁶, 256,000 in Viet Nam⁷, 212,000 in Myanmar⁸, and 75,000 in Cambodia⁹. Since HIV was first detected in these four countries, around the end of the 1980s or early 1991, HIV has been prioritized as a public health and social issue in all four countries. Although the prevalence rate has decreased in the general population,¹⁰ the epidemic continues to be concentrated primarily in three key populations across all four countries: sex workers, men who have sex with men, and people who use drugs. Sexual contact, both heterosexual and homosexual, is the primary mode of transmissions in all four countries.

Studies conducted in the four countries have established there is widespread stigma and

2 The Gap Report. UNAIDS, 2014, http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf

3 People Living with HIV Stigma Index data collected in 2008-2010: Bangladesh 2008, Cambodia 2010, China 2009, Fiji 2009, Myanmar 2009, Pakistan 2009-10, Philippines 2009, Sri Lanka 2009-10, Thailand 2009, UNAIDS.

4 Up to 3-29% of people living with HIV in these countries reported health care workers were unsupportive after learning of the respondent’s HIV positive status. People living with Stigma Index, Asia Pacific Analysis, UNAIDS, 2011

5 HIV in Asia and the Pacific: UNAIDS Report, 2013

6 2015 China AIDS Response Progress Report, National Health and Family Planning Commission of the People’s Republic of China, May 2015. http://aidsdatahub.org/sites/default/files/publication/China_narrative_report_2015.pdf

7 Vietnam AIDS Response Progress Report 2014, Following up 2011 Political Declaration on HIV AIDS, Reporting period: January 2012 – December 2013, National Committee for Aids Drug and Prostitution Prevention and Control. Socialist Republic of Viet Nam, Ha Noi, March 2014 <http://www.aidsdatahub.org/Vietnam-Global-AIDS-Response-Progress-Report-2014>

8 Myanmar Global Aids Response Progress 2015. National Aids Program, Myanmar. Reporting Period January 2014 – December 2015. 15 June 2015 <http://aidsdatahub.org/myanmar-global-aids-response-progress-report-2015-national-aids-programme-2015>

9 Cambodia Country Progress Report. Monitoring Progress Towards the 2011 UN Political Declaration on HIV and AIDS, Reporting Period: January – December 2014, The National AIDS Authority, May 2015 http://www.aidsdatahub.org/sites/default/files/publication/Cambodia_narrative_report_2015.pdf

10 Latest available report shows the general prevalence rate in Cambodia is 0.6% according to National Aids Authority, UNAIDS, Cambodia Country Progress Report. May 2015; China at 0.037% according to 2015 China AIDS Response Progress Report, Myanmar at 0.54% according to Global Aids Response Progress 2015, and in Viet Nam at 0.26% according to Vietnam AIDS Response Progress Report 2014

discrimination against people living with HIV and key populations¹¹ as well as barriers to accessing health services for these populations. A survey, the People Living with Stigma Index, conducted in all four countries,¹² noted forms of discrimination against people living with HIV in each country, including in health care settings. The types of discrimination included disclosure of HIV status without consent, denial of services including sexual and reproductive health services to women living with HIV, advice against pregnancy and advice to terminate pregnancy or undergo permanent sterilization.¹³ Although, encouragingly, the second round of the survey conducted in Viet Nam in 2014 showed a statistically significant decrease from 2.9% to 1.8% in overall respondents that reported denial of services.¹⁴

Other studies conducted at country level also highlight discrimination against people living with HIV in health care settings. A cross sectional and descriptive study conducted in Cambodia in 2011 among urban and rural people living with HIV looked at degrees of discrimination and coping mechanisms often employed. It further compared the experiences of rural and urban residents and found a relationship between discrimination and the poverty status of people living with HIV. Interestingly, the study also found a higher degree of discrimination in health care centers in rural areas compared to urban areas, which may indicate discrimination occurs as a result of lack of awareness, fear, and misunderstanding of HIV, among other reasons.¹⁵ Similarly, a Gender Assessment workshop held in 2013 in Yangon¹⁶ raised concerns about the prevalence of sterilization of women living with HIV, highlighting the manifestation of HIV-related stigma within the health sector. The same workshop also highlighted discrimination against sex workers and men who have sex with men that impeded their access to antiretroviral therapy (ART).

Stigma, discrimination and other human rights violations are major barriers to effective national responses to HIV. Promoting and protecting rights not only reduces the personal suffering that can be associated with HIV, but also helps to create social and legal environments that encourage people to take up and use HIV service. Fear of stigma and discrimination reduces uptake of HIV testing, prevention and treatment programs. It also increases the reluctance of people to disclose their HIV status, consequently decreasing willingness, opportunities or advocacy to seek or obtain redress for HIV related violations.

11 "Key population" in this report refers to four key populations as identified by UNAIDS as populations that are key to the epidemic and its responses: sex workers and their clients, transgender persons, gay men and men who have sex with men, and people who inject drugs.

12 Cambodia 2010, China 2009, Myanmar 2010 and Vietnam in 2012 and 2014

13 CPN+ (2010). People living with HIV Stigma Index; The China Stigma Index Report (2009). UNAIDS, Institute of Social Development Research and Marie Stopes International; Myanmar Positive Group and MMRD Research Services. People Living with HIV Index, Myanmar. 2010; Vietnam Network of People living with HIV VNP + Council. (2012) Vietnam People Living with HIV Stigma Index. 2012. Retrieved from: <http://www.stigmaindex.org/sites/default/files/reports/Vietnam%20People%20Living%20with%20HIV%20Stigma%20Index%20Report%202012.pdf>

14 VNP + (2014) People Living with Stigma Index 2014 in Viet Nam, Ha Noi, Viet Nam

15 Srales, M (September, 2011). Stigma, Discrimination and Coping Mechanism; A Case Study of People Living with HIV/ AIDS in Urban and Rural Cambodia. A Thesis Presented to the Higher Degree Committee of Ritsumeikan Asia Pacific University in partial fulfillment of the requirements for the Degree of Master of Science in International Cooperation Policy (Public Health Management) <http://r-cube.ritsumei.ac.jp/bitstream/10367/3662/1/51209656.pdf>

16 UNAIDS. September 2014. Gender Assessment of the National HIV Response in Myanmar

Criminalization of people who are at higher risk of infection, such as men who have sex with men, sex workers, transgender people and people who use drugs, drives them underground and away from HIV services, which also increases their vulnerability to HIV, as well as to stigma, discrimination, marginalization and violence. Most people living with or vulnerable to HIV do not know their rights or the local laws that might protect them.

III. Methodology

Over a period of 18 months, starting in October 2014, Asia Catalyst worked with 8 community based organizations (CBOs) from Cambodia, China, Myanmar and Viet Nam to identify, analyze and document instances of discrimination against people living with HIV in healthcare settings across the region. The CBOs consulted widely within their organizations and communities to identify the priority issues within their constituencies and designed relevant and appropriate research frameworks to best capture testimony, information and analysis.

The eight organizations are:

In Cambodia:

ARV User's Association (AUA) – AUA based in Phnom Penh, currently works in six provinces in Cambodia and run Opportunistic Infection (OI) and Antiretroviral Therapy (ART) clinics. They also serve as a point of referral between health service seekers and other providers to grant greater access to treatment for people living with HIV.

Cambodian Community for Women Living with HIV/ AIDs (CCW) - CCW, based in Phnom Penh, is a network of women living with HIV in Cambodia advocating for sexual and reproductive health rights (SRHR) for this population.

In China:

Consultation Centre for AIDS and Health Services (Consultation Centre) - Consultation Centre, based in Shenyang works on the prevention of HIV among men who have sex with men and transgender populations in China.

Chengdu Tongle Health Counselling Service Centre (Chengdu Tongle) - Chengdu Tongle, based in Chengdu primarily works with men who have sex with men in China. They provide HIV testing and psychological support for community members, organize large-scale public education campaigns, and conduct HIV related trainings for health care workers.

In Myanmar:

Myanmar Positive Group National Network of PLHIV (MPG) - MPG is a national network of people living with HIV in Myanmar. The MPG secretariat is based in Yangon, with 15 sub-offices in various regions of the country. MPG carry out national level outreach and advocacy working with people living with HIV and key populations.

Aye Myanmar's Association, Sex Workers' Association (AMA) - AMA, based in Yangon, is a network of sex workers conducting advocacy to decriminalize sex work in Myanmar. The organization conducts activities to create an enabling environment for sex workers with HIV to access health care services.

In Viet Nam:

Kids Sun Group (KSG) - KSG is based in Hanoi. KSG works with people living with HIV, including women and youth. KSG provides training and advocacy around HIV and creates forums for effective dialogue between the community and service providers such as health care professionals and teachers.

Vietnam Youth Network of HIV AIDS Prevention (VYPN) – VYPN, based in Hanoi, works with young members of key populations, including transgender persons, men who have sex with men, and sex workers to organize social campaigns to address discrimination against young people living with HIV in Viet Nam.

The Research Areas

In consultation with community members living with HIV, the eight CBOs identified the following five major areas to concentrate their research:

1. Discrimination against women living with HIV when trying to access sexual and reproductive health services in Cambodia and Viet Nam;
2. Discrimination against transgender women living with HIV when trying to access breast augmentation procedures in China;
3. Discriminatory practices faced by men living with HIV who have sex with men as they seek access to general surgeries in China;
4. Extra fees charged to people living with HIV when accessing general health services in Myanmar; and
5. Discrimination against HIV-positive men who have sex with men when trying to access general health services in Viet Nam.

These issues were deemed the most pressing barriers to an adequate standard of health by the

communities represented by the 8 CBOs in the four countries.

Based on these issues identified by their communities, the CBOs developed research questionnaires which were finalized with technical input from Asia Catalyst, the UNAIDS Regional office in Bangkok and UNDP in Bangkok. Eight CBOs finalized five sets of questionnaires that directly related to each of the issues identified as most pressing for their communities. Two CBOs from Cambodia and one from Viet Nam finalized one joint questionnaire pertaining to discrimination against women living with HIV and their sexual and reproductive health rights. Two CBOs from Myanmar developed one joint questionnaire to address discrimination against people living with HIV and key populations in health care settings, specifically looking at discriminatory fees charged. The three other CBOs, one from Viet Nam and two from China, all developed individual questionnaires looking at discrimination against men who have sex with men (MSM) living with HIV, along with transgender persons living with HIV and their access to health services. All questionnaires were translated into local languages by the CBOs, and the CBOs trained additional researchers to carry out interviews in each country.

The CBOs conducted their field research and data collection from June 1st to August 15th, 2015 after six months of training by Asia Catalyst in human rights analysis and documentation. In Cambodia, women living with HIV were interviewed in Phnom Penh, Kampong Cham, Kampot, Battambang, Kep, and Siem Reap provinces. In China, interviews were conducted with men living with HIV who have sex with men in Chengdu, Mianyang, Deyang, and Yibin cities in Si Chuan province, and with transgender individuals living with HIV in Shenyang City, Liaoning Province. In Myanmar, interviews were conducted with people living with HIV including female sex workers and male sex workers who have sex with men, in Yangon, Bago, Mandalay, Dawei, and Mon States. In Viet Nam, all interviews were with residents of Hanoi, including women living with HIV and men living with HIV who have sex with men. All interviews were conducted in the local languages, recorded on audio recorders, and then transcribed and translated into English by the CBOs.

This qualitative study is based on a non-representative sample of 202 people living with HIV in four countries. There were two specific overarching criteria for selection of interviewees:

- People who are living with HIV and are aware of it; and
- People living with HIV who have sought health services in the last two years.
- Depending on the issue selected by each CBO, the interviews were conducted

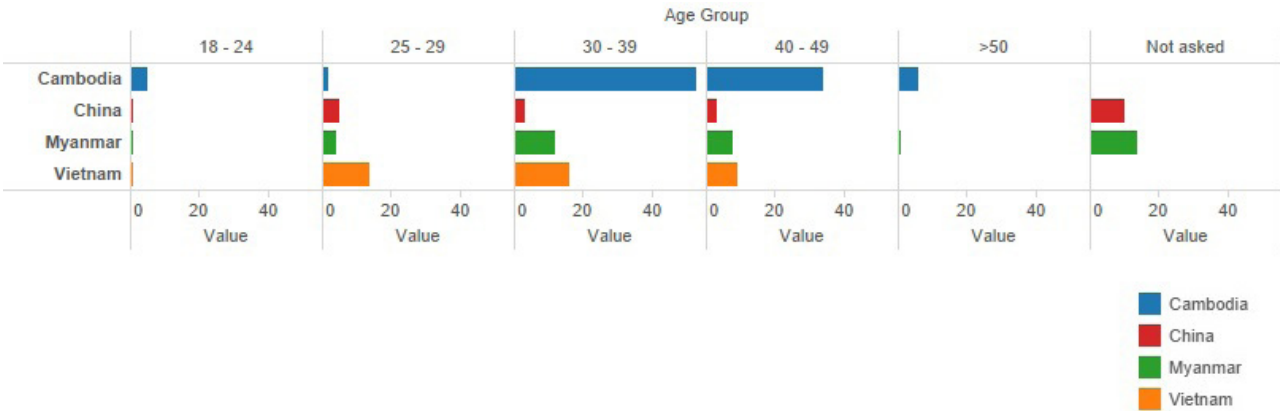
with the relevant communities of each CBO. CBOs applied a convenience sampling method to select interviewees who were identified from among their service recipients, members of their networks, as well as members of other CBOs working with people living with HIV and key populations.

The Interviewees

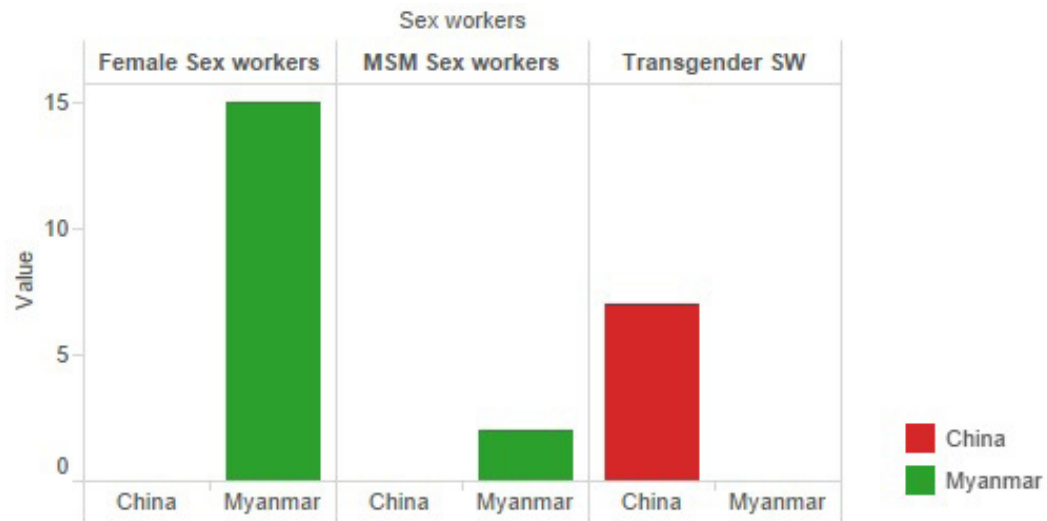
In total, the CBOs interviewed 202 people living with HIV across four countries in Asia, comprising: 149 women; 15 transgender individuals; and 38 men. One hundred interviews were conducted in Cambodia, 22 in China, and 40 each in Myanmar and Viet Nam.

Interviewee samples were selected in each country depending on the issues that were selected by each CBO. AUA and CCW interviewed 100 women living with HIV in Cambodia and explored women’s access to sexual and reproductive health rights. KSG in Viet Nam also interviewed 20 women living with HIV and explored the same issues. VYPN in Viet Nam interviewed 4 transgender individuals and 16 men who have sex with men, all of whom are living with HIV, to look at their access to health services. In Myanmar, AMA and MPG explored affordable access to healthcare for people living with HIV and key populations, and interviewed 11 men (of whom 2 identified as sex workers who have sex with men), 28 women (of whom 15 were sex workers) and 1 transgender woman. In China, Chengdu Tongle looked at access to surgery for 11 men living with HIV who identified as being men who have sex with men and 1 woman living with HIV. The Consultation Centre focused on access to breast surgery for 10 transgender women living with HIV (of whom 7 were sex workers).

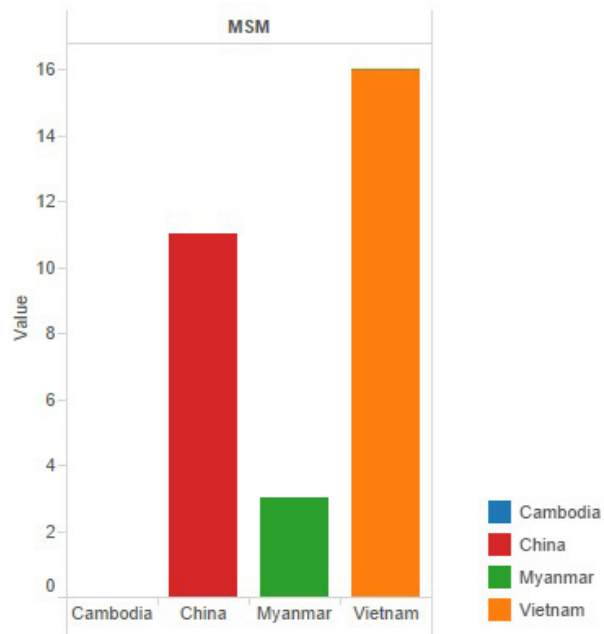
Total Number of Interviews in Cambodia, China, Myanmar and Viet Nam:



Total Number of Interviewees Who are Female, Male, or Transgender Sex Workers:

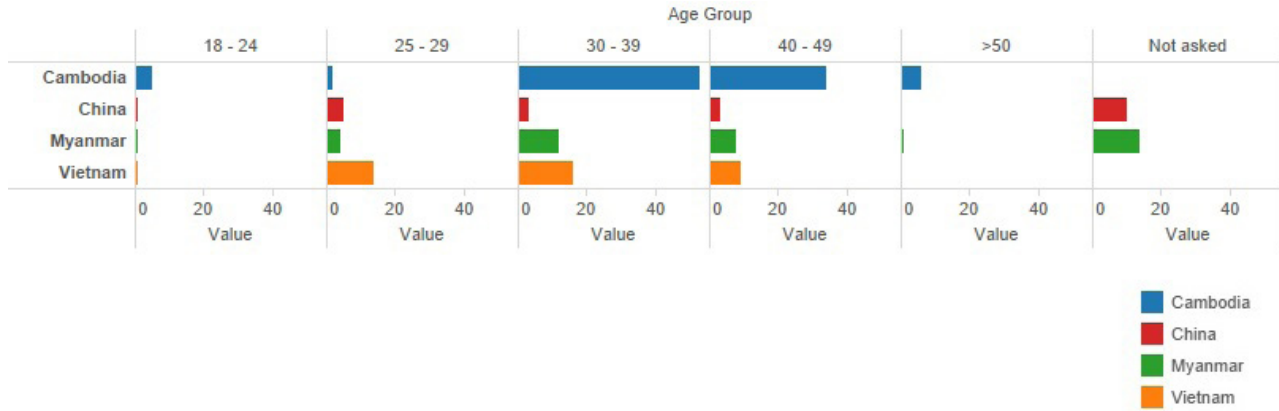


Total Number of Interviewees Who are Gay or Bi-sexual Men:



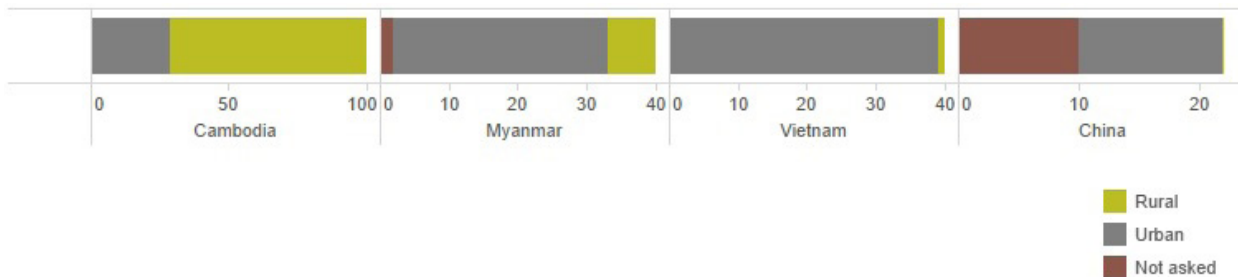
Age of the Interviewees

The majority of the interviewees were in the age range of 25 to 40 years old. In China, however, not all interviewees were asked questions related to age.



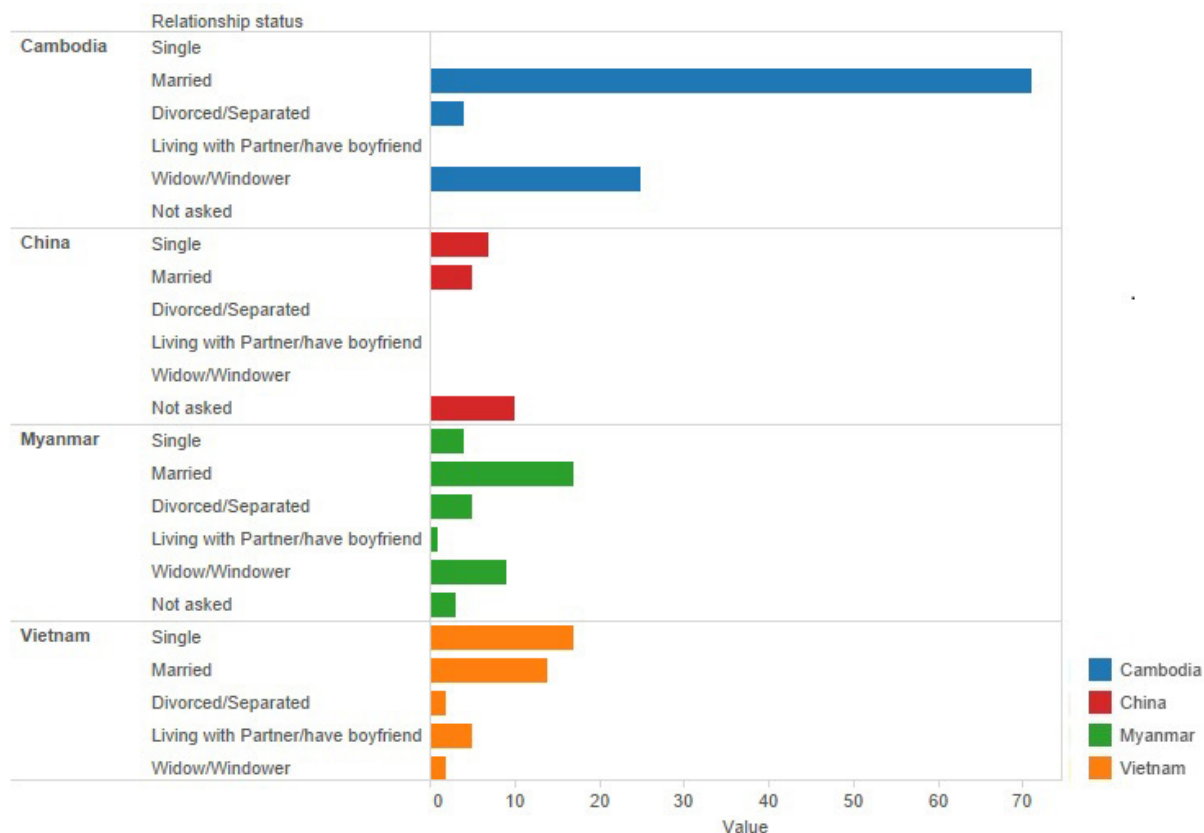
Residence

All interviewees from Viet Nam were residing in Hanoi at the time of the interview, although they may have originated from different provinces of the country. Similarly in Myanmar, although the majority of the interviewees were residing in Yangon, they may have migrated from different provinces. The majority of the interviews in Cambodia were conducted in rural areas, where the interviewees were residing at the time of the interview. Similarly, in China, interviews were conducted in the cities where respondents were residing and may have migrated from other parts of the country.



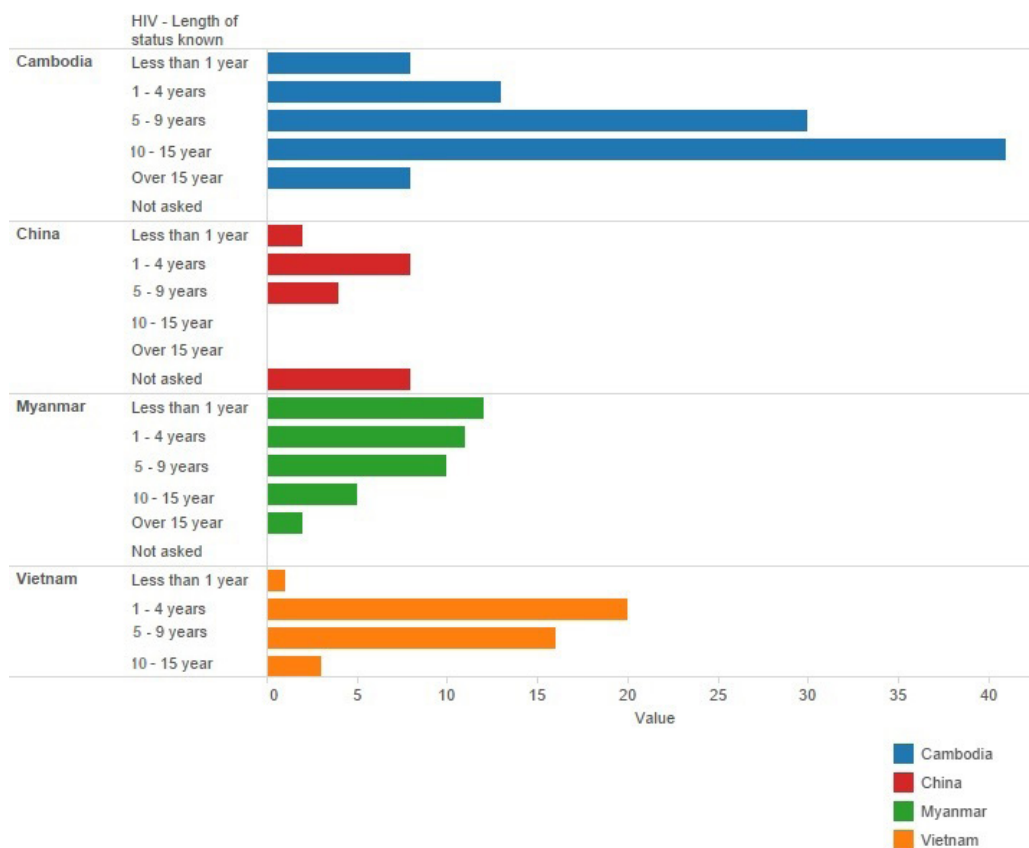
Relationship Status

The majority of interviewees in all four countries were married although this information could not be obtained from all of the interviewees in China. In Viet Nam, the majority of those who were single were men who have sex with men or people that identified as gay. Transgender persons in China were not asked about marital status. Among the men who have sex with men who interviewed in China, four were in a heterosexual marriage.



HIV Status

The majority of the interviewees in Cambodia had been living with HIV for more than nine years, but several of the interviewees (13) tested positive only in the preceding year. Similarly, in three other countries, there were many interviewees (5 in Viet Nam, 9 in China, and 17 in Myanmar) that were diagnosed with HIV less than a year before the interviews were conducted. Not all interviewees in China answered this question.



Ethics

The issues explored in this study were determined by the CBOs in consultation with wider communities. All interviews were conducted by CBOs or CBO-trained community members and were conducted in the local language. As such, a formal ethics approval committee was not formed. CBOs developed an informed consent form to disclose the nature and the purpose of the study before seeking consent for the interviews. All participants were informed of the objectives and risks of participating in this study and were guaranteed that their identities would be kept confidential. No names or any other form of identifying factors have been used in this report.

All participants were compensated for any travel or food expenses incurred to participate in this study, but were not otherwise paid. In most cases the researchers travelled to participants' communities to conduct the research, but some were interviewed in CBO offices.

Limitations

The findings of this study should be read in light of some limitations. The study was conducted among a small sample of respondents in limited geographical pockets in each country. They may not be representative of wider trends within each country or the region. Furthermore, this report neither quantifies the stigma and discrimination against people living with HIV and key populations in health care settings nor does it measure the impact of it. This report describes and documents the experiences of discrimination and the eventual direct or indirect consequences.

Efforts were made to include wide ranges of experiences of people living with HIV in seeking health services. No interviews were conducted with people who identified as using drugs as such the experiences of people living with HIV and who use drugs are not covered. Interviewees were contacted and recruited through local CBO networks as well as networks of community health service providers. Within these parameters, depending on the source of contact, the respondent may have had specific experiences.

No interviews were conducted with health care workers or government officials for this study. A study involving interviews with health care workers would be instructive in order to better understand their attitudes and perspectives. This would give a more complete picture of the environment in healthcare settings impacting on the experiences of people living with HIV.

And finally, as with all studies involving multiple languages and translations, some information may have been lost during the transcription and translation process. CBOs used part of sub-grants¹⁷ for translation services to minimize this limitation.

¹⁷ As part of the project, Asia Catalyst provided the 8 CBOs with small grants to cover the costs of their documentation and advocacy activities.

IV. Stigma and discrimination

UNAIDS defines HIV-related stigma as “the negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. the families of people living with HIV) and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people.”¹⁸

Manifestations of stigma may occur at various levels – including in informal settings like within the family and community – in the form of ostracization of individuals living with HIV, harassment or shunning and, in some cases, physical violence.¹⁹ It may also occur in institutional settings in the form of denial of services in health care settings, being barred from schools, denial of employment, or mandatory segregation in prison. At a national level it may manifest in laws and policies that can further stigmatize and discriminate against people living with HIV. Stigmatizing attitudes are based on thoughts, perceptions, and knowledge and can only be addressed through education and awareness of HIV. Discrimination, on the other hand, is more structural and is the responsibility of governments to address. It can be “institutionalized through existing laws, policies and practices that negatively focus on people living with HIV and marginalized groups, including criminalized populations,”²⁰ which is prohibited in international law and should be legislated against in national laws.

Discrimination resulting from stigma has been identified as one of the foremost barriers to HIV prevention, treatment, and care. UNAIDS noted in its guidance note in 2014 that stigma and discrimination undermine HIV prevention efforts by making people afraid to seek HIV information and services. Similarly, stigma and discrimination against people living with HIV and the resulting consequences inhibits their efforts to lead a healthier life²¹ and is directly linked with “delayed HIV testing, non-disclosure to partners and poor engagement with HIV services, including treatment retention.”²² Stigma, discrimination, and criminalization can also “block access to HIV services” for people living with HIV and “increase risk of violations of rights and vulnerability to HIV” for key populations.²³

UNAIDS guidance also notes that HIV-related discrimination refers to unfair and unjust treatment based on a person’s real or perceived HIV status; it extends to unfair treatment of other key populations and “is usually based on stigmatizing attitudes and beliefs about

18 UNAIDS (2014). Reduction of HIV-Related Stigma and Discrimination. Guidance Note 2014 - http://www.stopaidsnow.org/sites/stopaidsnow.org/files/2014unaidsguidancenote_HIVandsocialprotection_en.pdf

19 UNAIDS. (2005). HIV-related Stigma, Discrimination and Human Rights Violations: case Studies of successful programs. April 2005. http://data.unaids.org/Publications/IRC-pub06/jc999-humrightsviol_en.pdf

20 UNAIDS (2014). Reduction of HIV-Related Stigma and Discrimination. Guidance Note 2014, p.2

21 UNAIDS (2014). Reduction of HIV-Related Stigma and Discrimination. Guidance Note 2014, p.2

22 UNAIDS 2016 – 2021 Strategy. On the Fast-track to end AIDS http://aidsdatahub.org/sites/default/files/publication/UNAIDS_Strategy_2016-2021.pdf

23 UNAIDS 2016 – 2021 Strategy. On the Fast-track to end AIDS.

populations, behaviors, practices, sex, illness, and death.”²⁴ The UNAIDS Protocol of Identification of Discrimination against PLHIV²⁵ identifies the indicators of discrimination in health care settings as:

- Denial of Treatment – refusing to provide health services to people living with HIV because of their HIV status;
- Differential Treatment – treating patients with HIV differently than a non-HIV patient who have a similar condition, including coerced or forced sterilization;
- Testing without knowledge, or mandatory testing;
- Controls and segregation – segregation in hospitals, clinics, nursing homes, etc.;
- Disclosure of information, refusal to inform the person of the result of the HIV test, compulsory notification to sexual partners and/or disclosing information about HIV status to others without consent.

International Frameworks on Right to Health and Non-Discrimination for People Living with HIV and Key Populations

Discrimination in international human rights law is described as “any distinction, exclusion, restriction or preference which is based on any ground such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms.”²⁶ Resolutions adopted on human rights and HIV since 1990 have clarified that the term “or other status” used in the general non-discrimination clauses of international and regional human rights instruments (such as the International Covenant on Civil and Political Rights [ICCPR]) “should be interpreted to include health status, such as HIV and AIDS,”²⁷ thus prohibiting discrimination on the ground of HIV status. For example, UN Commission on Human Rights Resolution 1977/33 emphasized the “need for intensified efforts to ensure universal respect for and observance of human rights and fundamental freedoms for all to reduce vulnerability to HIV/AIDS and

24 UNAIDS (2014). Reduction of HIV-Related Stigma and Discrimination. Guidance Note 2014, p. 2

25 UNAIDS (2000). Protocol for the identification of discrimination against PLHIV http://data.unaids.org/Publications/IRC-pub01/jc295-protocol_en.pdf

26 Human Rights Committee, General Comment 18, Non-discrimination (Thirty-seventh session, 1989), Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/1/Rev.1 at 26 (1994)– http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCCPR%2fGEC%2f6622&Lang=en

27 UNAIDS. Protocol for Identification of Discrimination against people living with HIV. Geneva, 2000

to prevent HIV/AIDS-related discrimination and stigma.”²⁸ The same resolution in 1999/49 welcomed “the fact that many positive steps in implementing its previous resolutions have been taken, including the enactment of legislation in some countries to promote human rights in the context of HIV/AIDS and to prohibit discrimination against persons infected or presumed to be infected and members of vulnerable groups”²⁹ In addition, the “other status” terminology has also been interpreted to include the prohibition of discrimination on the basis of sexual orientation and gender identity.³⁰

Non-discrimination is recognized as an inherent human right, essential for ensuring the well-being, development, and dignity of a human being. UN member States have reaffirmed the full realization of human rights as an essential element in responding to HIV and effectively ending AIDS-related deaths through several non-binding Declarations and Resolutions. One such declaration was the Millennium Declaration (2000) where UN General Assembly members committed themselves to have “halted and begun to reverse, the spread of HIV and AIDS . . .” by 2015, and “to provide special assistance to children orphaned by HIV and AIDS.”³¹ The Millennium Declaration later coalesced into eight “Millennium Development Goals” that include combatting HIV and AIDS (as well as malaria and other diseases) as a major objective.³² Fourteen years later, in 2015, member states adopted 17 new Sustainable Development Goals, which included ending the AIDS

Select International Frameworks Referenced in this Report

The Universal Declaration of Human Rights

Article 2: Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status.

Article 7: All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

International Covenant on Civil and Political Rights

Article 2(1): Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Article 26: All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

International Covenant on Economic, Social and Cultural Rights

Article 2: The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

²⁸ The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), C.H.R. res. 1997/33, ESCOR Supp. (No. 3) at 115, U.N. Doc. E/CN.4/1997/33 (1997).

²⁹ The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). Commission of Human Rights Resolution 1999/49, 56th meeting, 27 April 1999. Retrieved on 11 Feb 2016 from: <http://www.un.org/en/terrorism/pdfs/2/G9914457.pdf>

³⁰ See more at UNOHCHR (2012). Born Free and Equal: Sexual Orientation and Gender Identity in International Law

³¹ United Nations Millennium Declaration, G.A. Res. 55/2, U.N. Doc. A/RES/55/2 (Sept. 18, 2000).

³² Millennium Project, What They Are, available at <http://www.unmillenniumproject.org/goals/> (last accessed August 6, 2015).

Select International Frameworks Referenced in this Report (continued)

The right to the highest attainable standard of health, 08/11/2000. E/C.12/2000/4. (General Comments)

Article 12 (special topics for broad application): 18. By virtue of article 2.2 and article 3, the Covenant proscribes any discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health.

19. With respect to the right to health, equality of access to health care and health services has to be emphasized.....

21.The realization of women's right to health requires the removal of all barriers interfering with access to health services, education and **information, including in the area of sexual and reproductive health.**

ESCAP Resolution 66/10: Regional call for action to achieve universal access to HIV prevention, treatment, care and support in Asia and the Pacific, 19 May 2010

1. Calls upon all members and associate members:
(b) To ground universal access in human rights and undertake measures to address stigma and discrimination, as well as policy and legal barriers to effective HIV responses, in particular with regard to key affected populations;

epidemic by 2030. Discrimination was identified as a primary barrier and a new fast-track strategy has been built based on the achievements already gained under the earlier Millennium Development Goals.

A second example was the Political Declaration on HIV and AIDS (2011)³³ where UN member states agreed to increase efforts for universal access to HIV prevention, treatment, care, and support and the ESCAP Resolutions³⁴ which call upon ESCAP nations to, among other things, review “national laws, policies, and practices to enable the full achievement of universal access targets with a view to eliminating all forms of discrimination against people at risk of infection or living with HIV, in particular key affected populations.”³⁵

The principle of non-discrimination is enshrined in international³⁶ and regional³⁷ human rights instruments and codified in national constitutions and laws. These human rights instruments provide a normative framework for a human rights approach to HIV which is based on the responsibility of the state to respect, protect, and promote human rights for all and has been outlined in the International Guidelines on HIV and AIDS and Human Rights.³⁸ States have an obligation to ensure non-discrimination, including for people living with HIV and key populations, in

the right for all to have the highest attainable standard of physical and mental health. Article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) calls

33 Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS, G.A.2011. http://safאים.net/files/HLM_AIDS_2011_Declaration.pdf

34 United Nations Economic and Social Commission for Asia Pacific's Resolutions 66-10: http://www.unescapsdd.org/files/documents/HIV_IGM1_INF4.pdf and 67-9 <http://www.unescap.org/resources/escap-resolution-679-asia-pacific-regional-review-progress-achieved-realizing-declaration>

35 United Nations Economic and Social Commission for Asia Pacific's Resolutions 66-10: http://www.unescapsdd.org/files/documents/HIV_IGM1_INF4.pdf and 67-9 <http://www.unescap.org/resources/escap-resolution-679-asia-pacific-regional-review-progress-achieved-realizing-declaration>

36 Universal Declaration of Human Rights, International Covenant on Civil and Political Rights, International Covenant on Economic, Social and Cultural Rights, Convention on the Elimination of All Forms of Discrimination Against Women, Convention on the Rights of the Child among others

37 African Charter of Human Rights, American Convention on Human Rights, European Convention on Human Rights and Fundamental Freedoms

38 OHCHR, UNAIDS (2006). International Guidelines on HIV and AIDS and Human Rights, 2006 Consolidated Version. Retrieved from: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

on states parties to act to prevent, treat, and control “epidemic, endemic, occupational and other diseases” and to create “conditions which would assure access to all medical service and medical attention in the event of sickness.”³⁹ The United Nations Committee on Economic, Social and Cultural Rights has supplied states parties with guidelines for access to health care and has noted, in a non-binding comment from 2000, that correct application of the ICESCR would prohibit “any discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of . . . health status (including HIV and AIDS) . . . , which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health.”⁴⁰

Focus on four study countries: Cambodia, China, Myanmar and Viet Nam

Cambodia, China, and Viet Nam are party to various international human rights instruments through UN treaty signature and ratification, and hence have obligations to fulfill their commitment to promoting human rights principles ensuring non-discriminatory policies for all persons within their respective territories. Although Myanmar has only signed a small number of major international treaties, and has so far not signed the ICCPR nor the ICESCR – which to a large degree regulate the right to health and the right to non-discrimination – the Universal Declaration on Human Rights (UDHR) is a basis for non-discriminatory treatment in accessing health care for people living with HIV and key populations and is now generally seen as customary international law and applicable to all UN member states.

All four countries have various national legal mechanisms to enforce non-discrimination and ensure the protection of the rights of people living with HIV and key populations. (Table 2) Additionally, although limited, Myanmar has national mechanisms to ensure people living with HIV and key populations have access to health services that are non-discriminatory, including in its constitution.

39 International Covenant on Economic, Social and Cultural Rights, adopted Dec. 16, 1966, 993 U.N.T.S. 3

40 CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12), Office of the High Commissioner for Human Rights, Aug. 11, 2000, E/C.12/2000/4

Table 1

Country	National HIV/ AIDS laws, policies and regulations promoting non-discrimination and protection of people living with HIV and key populations
Cambodia	<p><i>The Law on the Prevention and Control of HIV/AIDS (2002)</i> prohibits acts of discrimination against people living with HIV and their families in the following areas: health care, employment, education, housing, freedom of movement, credit, loans, insurance, and seeking public office.¹</p> <p><i>The Policy, Strategy and Guidelines for HIV Counseling and Testing 2002</i> prohibits hospitals and other health care providers from discriminating against people living with HIV and requires HIV test results to be confidential.²</p> <p><i>The Cambodian Criminal Code (2009)</i> identifies the following as prohibited grounds for discrimination: (1) membership or non-membership of a given ethnic group, nationality or race; (2) membership or non-membership of a given religion; (3) political affiliation; (4) union activities; (5) family situation; (6) gender; (7) state of health; and (8) disability</p>
China	<p><i>Regulations on AIDS Prevention and Treatment (2006)</i> provides a legal framework for the rights of people living with HIV and AIDS, including the right to marry, to access health care services, to enjoy equal employment opportunities and to receive an education. The Regulation contains a broadly worded right to non-discrimination.³</p> <p><i>The Notice on Further Strengthening the HIV Response (2010)</i> gives important guidance to courts when applying previous regulations relating to AIDS and other HIV-related laws.⁴</p> <p><i>“Four Free and One Care” policy (2003)</i>, provides for free antiretroviral drugs, free care around prevention of mother-to-child transmission, free voluntary counseling and testing, free schooling for children orphaned by AIDS, and care and economic assistance to people living with HIV.</p> <p><i>China’s Action Plan for Reducing and Preventing the Spread of HIV/AIDS for the 12th Five-Year National Plan in 2012</i>, strengthens the importance of HIV and AIDS education, scales up intervention measures, and enhances safe blood management.⁵</p>

Table 1 Footnotes

1 National Aids Authority Cambodia, Building an Enabling Legal Environment for Cambodia’s HIV Response: National Legal Review Report 14 (Nov. 2013), available at http://www.aidsdatahub.org/sites/default/files/publication/Cambodia_National_Legal_Review_2013.pdf; <http://www.ilo.org/public/english/protection/trav/aids/law/cambodia1.pdf>

2 National Aids Authority Cambodia, Building an Enabling Legal Environment for Cambodia’s HIV Response: National Legal Review Report 14 (Nov. 2013), available at http://www.aidsdatahub.org/sites/default/files/publication/Cambodia_National_Legal_Review_2013.pdf.

3 UNDP (2013). Legal protections against HIV-related human rights violations: Experiences and lessons learned from national HIV laws in Asia and the Pacific 69 (2013), available at <http://www.undp.org/content/dam/undp/library/hivaids/English/HIV-2013-legal-protections-against-hiv-related-human-rights-violations.pdf>

4 UNDP (2013). Legal protections against HIV-related human rights violations: Experiences and lessons learned from national HIV laws in Asia and the Pacific 69 (2013), available at <http://www.undp.org/content/dam/undp/library/hivaids/English/HIV-2013-legal-protections-against-hiv-related-human-rights-violations.pdf>

5 See Article 3 of the Document of General Office of the State Council, Guo Ban Fa [2012] No. 4. http://www.gov.cn/zwgc/2012-02/29/content_2079097.htm

<p>Myanmar</p>	<p>The Constitution of the Union of Myanmar forbids discriminating against “any citizen of the Republic of the Union of Myanmar, based on race, birth, religion, official position, status, culture, sex and wealth.” In regard to an individual’s right to health care, the Constitution notes that “every citizen shall, in accord with the health policy laid down by the Union, have the right to health care.”⁶</p> <p>Myanmar’s policy response to HIV and AIDS is contained in two national strategic plans on HIV and AIDS and “intends to guide the implementation and monitoring of all HIV-related activities and services in the country... [but] does not include specific activities, since it is intended to provide guidelines to the implementers.”⁷</p>
<p>Viet Nam</p>	<p>The Law on HIV/AIDS Prevention and Control No. 64/2006/QH11 (2006) includes the “elimination of stigma and discrimination against HIV-infected people and their family members.”⁸ The law creates certain rights (e.g., the right to enjoy medical treatment and health care, the right to refuse medical examination) and obligations (e.g., informing spouses of positive HIV tests) for people living with HIV, prohibits intentional transmission of HIV, requires improved education regarding HIV and AIDS, and creates a framework for confidentiality and protection for people living with HIV.</p> <p>Law on Medical Examination and Treatment No. 40/2009/QH12; Law on Child Protection, Care and Education No. 25/2004/QH11. Article 4 prohibits discrimination against children and requires that all children are “protected, cared for and educated, and enjoy lights prescribed by law.” Article 53 prohibits discrimination against children living with HIV and AIDS and stipulates that they are given proper medical care and the necessary assistance to allow them to be raised by their families or in child-support establishments.⁹</p> <p>Law on Gender Equality No. 73/2006/QH11 prohibits all forms of gender-based discrimination; Article 17 also specifically provides that men and women should have equal power to choose measures to prevent the transmission of HIV.¹⁰</p>

Table 1 Footnotes

6 Myanmar Constitution. Article 348 and 367, Myanmar, 2008. http://www.burmalibrary.org/docs5/Myanmar_Constitution-2008-en.pdf

7 Myanmar Health Sector Coordinating Committee, Myanmar National Strategic Plan on HIV and AIDS (2011-2015), note 9 at 9 http://www.myanmarhsc.org/images/stories/pdf/national_strategic/nsfinal.pdf

8 Law on HIV and AIDS Prevention and Control No. 64/2006/QH11 (2006). Viet Nam http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_113364.pdf

9 UNDP (2013). Legal Protections Against HIV-Related Human Rights Violations: Experiences and Lessons Learned from National HIV Laws in Asia and the Pacific. Supra Note 9 at 141

10 UNDP (2013). Legal Protections Against HIV-Related Human Rights Violations: Experiences and Lessons Learned from National HIV Laws in Asia and the Pacific. Supra Note 9 at 141

V. Findings

Testing and Counseling

The majority of people interviewed for this report had been living with HIV for longer than two years. This section covers the experiences of 44 interviewees that went for testing and only learned about their HIV status within the last two years (between 2013 and 2014).

Early HIV testing and diagnosis resulting in early treatment is crucial to successfully managing HIV. Authoritative guidance argues that confidential counseling both before and after testing is aimed to “increase knowledge of HIV prevention and enhance primary health care and positive prevention, as well as curative care when positive status is confirmed. The quality of counseling also shows itself in the quality of referrals, follow-ups, treatment adherence, and care, including nutritional, psychosocial and medical support to sustain the well-being of adults and children living with HIV.”⁴¹ For this study interviewees were therefore asked about their experiences of testing and the quality of counseling support they received following positive results.

The vast majority of the interviewees living with HIV across all four countries went for voluntary counseling and testing where their status was identified. Interviewees went for various reasons which included being sick for an extended period of time, spouses having tested positive, an emergency hospitalization due to an accident, regular pregnancy check-ups, or upon suggestion from a sibling or peer. Although the quality and level of pre-test counseling cannot be ascertained in this study, as those specific questions were not part of the interview, participant responses implied that pre-test counseling was carried out either by health care providers at Voluntary Confidential Counseling and Testing Centres (VCCT) in all four countries, by doctors at hospitals, by community organizations where the interviewees had some association, or by peers at work and, in one case, by a sibling who had previously tested positive.

A few interviewees – one in China, two in Myanmar, and two in Viet Nam – reported that HIV testing was done without their knowledge or consent when they visited health centers for check-ups. In the two cases in Viet Nam, the interviewees were tested for HIV after they were admitted for emergency care following an accident and were not in conducive physical condition to give consent for the testing, nor were there indications of legally entitled representatives being present to do this on their behalf.

41 UNICEF, FHI, WHO (2009). HIV Counseling Handbook for Asia Pacific. Retrieved from: http://www.wpro.who.int/hiv/documents/docs/HIVhandbook19Janfinal_C985.pdf?ua=1

“While treating this injury, the doctor ordered for blood tests. I did not know what kind of tests they were doing. The result of HIV positive was told by a nurse to both my wife and me.” – Interviewee in Mon State, Myanmar

“I was diagnosed with a perianal abscess and was transferred to the anorectal section for immediate operation and the doctor there said that I had to get operated immediately. They did 9 items of examination at that time. Two hours after the blood test, I got a call from the hospital that the doctor wanted a face to face talk with me. In that talk I was informed that I was infected with HIV and syphilis.”

– Interviewee in Chengdu, China

China has implemented a routine HIV screening program for high-risk groups.⁴² This program is similar to the Provider-Initiated HIV Testing and Counseling (PITC), but in reality and practice this may border on mandatory testing as those tested may not be informed what tests are being performed or know their rights for refusal.⁴³

Post-Test Counseling

Every HIV test, irrespective of results, should be accompanied by counseling. The aims of HIV test counseling is to prevent further HIV transmission or risk by providing information about transmission risks; to assist people in developing the personal skills needed to negotiate safer practices; to provide psychological support to people who are infected with and affected by HIV in improving their emotional, psychological, social, and spiritual well-being; and to support clients in treatment adherence.⁴⁴ In all four countries, interviewees found counseling effective and helpful when the providers gave ample time to explain the treatment procedures as well as provide psychological support. All of the women living with HIV interviewed in Cambodia who went for testing in the last two years were satisfied with the quality of their counseling support.

In other countries many interviewees who learned about their HIV status before 2013 also reflected on their post-test counselling. The majority of the interviewees in Viet Nam had negative experiences when receiving counseling which appeared to have been the result of inexperienced counselors and a lack of sensitivity when advising the client of the test result. The experiences of the interviewees from Viet Nam that were tested more recently, however, may reveal some improvement in the post-test counseling, particularly as several interviewees

42 Li, Li, Zunyou Wu, Sheng Wu, Sung-Jae Lee, Mary Jane Rotheram-Borus, Roger Detels, Manhong Jia, and Stephanie Sun. “Mandatory HIV testing in China: the perception of health-care providers.” *International journal of STD & AIDS* 18, no. 7 (2007): 476-481

43 Sullivan, Sheena G., Zunyou Wu, and Roger Detels. “Missed opportunities for HIV testing and counselling in Asia.” *AIDS Official Journal for the International AIDS Society* (2010) Volume 24 Issue: p S49-S53, doi: 10.1097/01.aids.0000390089.60682.26 http://journals.lww.com/aidsonline/Fulltext/2010/09003/Missed_opportunities_for_HIV_testing_and.7.aspx

44 UNICEF, FHI, WHO (2009). *HIV Counseling Handbook for the Asia-Pacific*. http://www.wpro.who.int/hiv/documents/docs/HIVhandbook19Janfinal_C985.pdf?ua=1

noted the involvement of peer educators who also provided them with psychological support.

“The counselors at the clinic and peer educators provided information. I’m satisfied with peer educators counseling. They are very helpful in giving me advice and provided support to overcome the crisis I was feeling” – Interviewee in Hanoi, Viet Nam

Notably, experiences of interviewees across countries show that the involvement of community members in counseling was more effective, understandable, and appreciated, as they provided timely guidance and information regarding access to treatment and psychological support.

Three of the interviewees from Myanmar also reported that, following testing, health care providers and counselors disclosed their HIV status to others without their consent – in two cases to extended family members and in one case of a woman who worked in the hospital herself, to her colleagues (See Case Study – Myanmar). It was not clear from the interviews what the intentions of the service providers might have been in these involuntary disclosures.

In Summary

Forced or involuntary testing and disclosure without consent are violations of the right to privacy for people living with HIV and may be regarded as discriminatory practices against them, also affecting their right to health.⁴⁵ One or both of these practices were found to have been employed by health care professionals in a few of the cases. Health care workers breached confidentiality by disclosing the status to others without the consent of the patient in Myanmar. In Myanmar and China, health care professionals conducted testing without the patient having knowledge of it. Protection of privacy and confidentiality is crucial in ensuring discrimination-free health services, giving people living with HIV confidence to seek services

Case Study : Myanmar

“ I tested positive less than a year ago. I was working as a cleaner in a private hospital. Four months ago, I got sick and rested at home after taking leave from work. The owner of the hospital came and asked me to have a check up at the hospital. When I reached the hospital, they conducted blood tests, twice. They did not inform me anything about the testing. And then, one of the doctors from the hospital came to my room and told me that I have HIV. My colleagues at the hospital also seemed to know even though I had not known yet. After testing positive I was dismissed from my job. I didn’t get any counseling. After that, I came to the general hospital for antiretroviral treatment where I met with an Outreach Worker from MPG’s Sub office. She explained to me about antiretroviral drugs. Counselors from MPG provided proper counseling and psychosocial support. They explained to me about ART and drugs in detail which helped me understand my health status. I also met with peers and I got a lot of psychosocial support from them.”

45 Indicators of discrimination as identified in the UNAIDS Protocol for the identification of discrimination against people living with HIV includes testing without consent and disclosure without consent http://data.unaids.org/Publications/IRC-pub01/jc295-protocol_en.pdf

as well as encouraging voluntary testing in the broader community. To address discrimination, effective policies that target inappropriate practices need to be drafted. Service providers must be made aware of these policies and understand the right of people living with HIV to decide when and to whom to disclose their HIV status

Accessing Health Services for People Living with HIV

Following testing, people living with HIV should be referred for treatment, care, and support services. They have specific health care needs and may need immediate treatment, regular check-ups for viral load and CD 4 count, and treatment of opportunistic infections and other communicable diseases. Initiating treatment may vary according to the stage of diagnosis and country treatment guidelines. ART can be a complex treatment and clients may need to take multiple medications over a long period of time. For those on treatment, adherence to ART is vital for an optimal response to controlling viral load. In addition, people living with HIV may need a wide range of other health services that are accessed by the general population, and treatment may also include medications for Tuberculosis (TB), Hepatitis B, other Opportunistic Infections or Sexually Transmitted Infections with complex regimes of doses, including treatment for any side effects that may occur. People living with HIV are also as prone as the general population to a wide variety of unrelated illnesses, such as cancer and heart disease, while key populations such as sex workers also have high incidence of cervical cancer and other sexual and reproductive health needs. Having access to discrimination-free health services and availability of quality affordable services is vital for people living with HIV to have a longer and healthier life and reduce the chance of transmission of HIV to others.

Health Needs

Interviewees across all four countries said they visited health care centers to receive ART services related to opportunistic infections and side effects of HIV treatments. Women living with HIV sought services related to sexual and reproductive health, including pregnancy related services, advice on safer pregnancy, post-natal care and Prevention of Mother to Child Transmission (PMTCT) services, sexual health, or all of these. Other treatments included Tuberculosis (TB), Hepatitis C virus (HCV), Hepatitis B virus (HBV) related testing and treatments, kidney and lung function testing and treatment, STI tests and treatments, dental care, dermatology related treatments, hormonal treatments for men who have sex with men and transgender interviewees, treatment that required surgery such as appendicitis and

bone related diseases, as well as general sickness and emergency services for accident-related injuries. In addition, transgender persons interviewed in China were seeking breast enhancement surgery.

Government-run general hospitals are the most common facilities where interviewees sought health services. Others went to private clinics or clinics run by non-governmental organizations (NGOs). All of the interviewees from Viet Nam were residing in Hanoi at the time of the interview and reported availability of all required services in public hospitals in Hanoi. Interviewees in Myanmar sought services at NGO clinics, public hospitals, and private clinics. Six of the women from Myanmar that were seeking pregnancy-related services all went to public hospitals. In Cambodia, women went to public hospitals and health centers for information as well as services.

Interviewees in China who sought services at public or private health institutions reported two major reasons that influenced their decision to select a particular hospital for services. The first reason was the physical accessibility of the hospital and the convenience it offered in regard to commuting. A second major influencing factor was the reputation of the institution as being one of the finest for the services required. Respondents believed the hospitals would have the finest quality equipment and technical capacity to treat their ailments.

“This hospital is the first choice for anyone because of their world-class medical technology (also for non-HIV). As a native from Chengdu, I know the importance of this hospital and know that they have the capacity to perform surgery for people living with HIV.” – Interviewee in Chengdu, China

Disclosure to service providers

The specialized services required by the interviewees in the four countries may be denied in the health centers they frequent when health service providers are aware of their HIV status. A majority of the interviewees across countries said they would not want to disclose their HIV status to health service providers who were not already aware of their HIV status. A total of 72 interviewees (12 in China, 20 in Viet Nam, and 40 in Myanmar) were asked and responded to what considerations they make before deciding to disclose their status or not. A significant number of these interviewees in Myanmar (26) said that they voluntarily disclosed their status. In China, despite the Regulation on AIDS Prevention and Treatment (2006) which obligates people living with HIV to “inform the fact of being infected or suffering the disease to their

medical doctors,”⁴⁶ only four of the interviewees said they disclosed their status voluntarily.

Interviewees who decided to reveal their HIV status voluntarily cited two main reasons for doing so. First, they hoped that revealing their status would help to achieve an accurate diagnosis and appropriate treatment. Secondly, they hoped the health service providers would take all necessary precautions to protect themselves from occupational infections and that the doctors would consider their HIV status when deciding on appropriate services.

“I disclosed my status so they [healthcare worker] can prevent themselves too.”

– Interviewee in Yangon, Myanmar

“I told the doctor because it is our duty to inform them so that medical personnel can avoid infection during operations” – Interviewee in Chengdu, China

Over half of the 72 interviewees asked – 8 in China, 14 in Myanmar, and 20 in Viet Nam – did not disclose their HIV status voluntarily. An assumption of being treated negatively may widely exist within the community of people living with HIV and key populations even though they may not have experienced it directly. One of the interviewees in Viet Nam said he completely avoids treatment because he is scared of being discriminated against.

“I have not been denied services because I have not sought services. I am scared of going to hospital. I am scared that the doctors will know about my status and discriminate against me” – Interviewee in Hanoi, Viet Nam

In addition, two specific considerations were made when interviewees decided not to disclose their HIV status to health care providers. Fear of rejection of services by the service providers was the foremost reason interviewees chose not to disclose their HIV status to health care providers.

“I did not inform the doctor because I am afraid the doctor will discriminate against me and not provide me with services.” – Interviewee in Hanoi, Viet Nam

“Actually, when I go to the clinic, I want to inform the doctor that I have HIV. But I don’t tell them because I worry that I would face stigma and discrimination.”

– Interviewee in Yangon, Myanmar

“I did not tell them I have HIV because I was worried they will not agree to serve me.”

– Interviewee in Chengdu, China

46 UNDP (2013). Legal Protections against HIV-related human rights violations: Experiences and lessons learned from national HIV laws in Asia Pacific, p 70

Another reason for not disclosing their status upfront was because interviewees said they did not believe they would get an accurate diagnosis if their HIV status was known to service providers.

“The reason is simple, I want to get the correct diagnosis about my disease. I want them to tell me the truth.” – Interviewee in Chengdu, China

Discrimination in accessing quality health services for people living with HIV and key populations

The study found that a majority of the interviewees in all four countries reported some form of discrimination as they sought health services and that the discrimination was based on their status as persons living with HIV. Interviewees reported negative experiences at private hospitals and clinics, government-run facilities and, in at least one case in Myanmar, at an NGO clinic. Patients reported that staff in health care centers at all levels had observable negative attitudes, from non-medical staff including receptionists and cleaners to nurses and senior health professionals. In some cases, even staff members at the highest levels of hospital administrations were found to be engaging in discriminating behavior against people living with HIV.

Denial of Services

Many of the interviewees from all four countries (51), reported a denial of some form of required health care service following the disclosure of their HIV status, either by voluntary means or otherwise. This included pregnancy-related services for women living with HIV in Cambodia, surgery for men who have sex with men and transgender persons living with HIV in China, and other general health services for sex workers, men who have sex with men, and other people living with HIV in Myanmar and Viet Nam.

In Myanmar six of the interviewees also reported denial of services in the course of accessing ART and regular follow-up tests, including refusal for testing by lab support staff.

“I had difficulties in getting blood tests. Laboratory staff at the hospital said that they don’t want to collect blood from HIV positive people”
– Interviewee in Mandalay, Myanmar

Accessing HIV treatment and opportunistic infections treatments and adhering to those medication regimes depends on access to service providers, both in terms of physical access and access to treatment. Denial of such critical and regular health services may discourage people living with HIV from adhering to the prescribed course and may result in ineffective treatment.

The majority of the denial of health services occurred in accessing non-HIV related services, particularly when invasive treatments such as surgery were required. However, even when treatment was non-surgical, people living with HIV still faced denial of certain services. Interviewees in Myanmar and Viet Nam reported that they were asked to find different service providers, citing a lack of infrastructure or specialization to treat patients with HIV.

“I went for a rectal examination because I suspected I had warts. The doctor first led me to the lab but, after knowing my status, he refused to treat me”

– Interviewee in Hanoi, Viet Nam

One other interviewee reported having had a cough and shortness of breath, but upon arrival at a health service center, she was asked to go to an OI/ART hospital.

“I went to the doctor because I had a cough and was short of breath. I told the doctor about my HIV status. They didn’t check my health. The doctor just said I should go to the OI/ART hospital.”

– Interviewee in Phnom Penh, Cambodia

Another interviewee from Myanmar was diagnosed with a tumor and was told that a surgical operation would be required, but she was unable to get it after her HIV status was revealed. After refusal from the first hospital, she attempted to access this surgery from two other private hospitals and was also denied. She was finally forced against her wishes to go to a government hospital where she was concerned about the possibility of a breach of confidentiality.

“The gynecologist told me that this tumor should be removed and scheduled the surgery for the 13th July. When I arrived at the hospital, the doctor took my medical record and told me that they cannot do this surgery because I am on ART. So, I returned home and inquired at other private hospitals. They also replied that they cannot operate on people living with HIV. Although I was worried that other people will know about my status, I decided to go to a Government Hospital.”

– Interviewee in Dawei, Myanmar

She was not clearly informed whether the hospital lacked the technical capacity to perform surgery on a patient living with HIV, or if there were other specific health concerns for her. The only reasons she was given to explain the refusal of service was either that she was on ART or that she was HIV positive.

A further eight interviewees from Viet Nam and two from Myanmar were asked to find different service providers after disclosing their HIV status. Interviewees from Viet Nam reported they were asked to go to “public hospitals” which may have meant government hospitals that are designated to provide HIV-related services, or go to “bigger hospitals” which may have meant hospitals with better technical capacity. Others were simply asked to go to “other service providers” while some were told the hospital could not treat people with HIV. Similarly, interviewees in China were asked to go to infectious disease hospitals instead.

“The doctor told me to go to other service providers. Because of the STI in my rectum, health staff knew that I’m an HIV positive man who has sex with men, so they refused to treat me” – Interviewee in Hanoi, Viet Nam

“Because I am living with HIV, he said he could not extract [my tooth] and suggested for me to go to the General Hospital.” – Interviewee in Yangon, Myanmar

Many male interviewees who have sex with men who were seeking surgery said they were refused treatment because the hospital feared that treating them would put the doctors at risk. One of these male interviewees in China, who was at the hospital for gastritis and proctitis, was told that the service could not be provided for him because the hospital feared that treating him may put doctors at risk of infection.

“He [the doctor] was very surprised when I told him I am HIV positive. At that time there was not much reaction. But, the second day, I was told by the director of the section that I cannot be treated because they fear it might hurt the doctors.”
– Interviewee in Chengdu, China

A 2010 literature review found that some health professionals, especially surgical staff, have concern over occupational exposure to HIV, and that these concerns are compounded by a lack of systematic training around occupational exposure.⁴⁷ However, interviewees in China also reported going to some of the best-equipped and reputed institutions in the country hence, when the interviewees were told that the hospital “lacked equipment” to perform

47 ILO, The STD and AIDs Prevention and Control Centre of the Chinese Centre for Disease Control and Prevention. Discrimination against people living with HIV within health care settings in China. The HIV Program. 2010. Retrieved on 8 July 2015: http://www.ilo.org/wcmsp5/groups/public/@ed_protect/@protrav/@ilo_aids/documents/publication/wcms_155950.pdf

surgeries, they believed it was a direct result of having disclosed their HIV status.

“They told me that some equipment was damaged and they asked me to find another hospital for the operation. I think it is just because of my HIV status. How can it be a coincidence? They had already asked me to pay for the surgery. But when I told them I have HIV then their equipment got dysfunctional?”

– Interviewee in Chengdu, China

All ten of the transgender persons interviewed in China who were seeking breast surgery were denied the surgery.

“Before the surgery, they tested me and found that I am HIV positive. So then they told me they could not provide breast surgery for people living with HIV.”

– Interviewee in Shenyang, China

Among the 127 women living with HIV who were interviewed, 59 of them accessed pregnancy-related services during the period covered by the study. A few of them from Cambodia and Myanmar were denied much-needed health services and assistance at the time of labor and had to give birth without assistance at the hospital because they were living with HIV.

“After going through 5 days of labor pain, the first hospital was unable to help me and referred me to this hospital. They did not help. Fortunately, I delivered [the baby] on my own in the waiting room” – Interviewee in Kampot Province, Cambodia

Prevention of HIV transmission from mother to child requires a continuum of care from before pregnancy to post-natal care. Information and services related to safer pregnancy and PMTCT is critical for women living with HIV in order to prevent transmission to the newborn and to ensure the future health of the mother. Denial of services during pregnancy, child-birth, and post-natal care may lead to long-term consequences.

One of the interviewees from China opined that she was refused care over concerns that the service providers would lose other clients and suffer financial losses if it were known that they provide care to patients living with HIV. Qualitative research conducted in 2010 in China found that the profit-driven model of health care facilities was a factor driving discrimination against people living with HIV, along with the fear of HIV itself and the fear of HIV transmission resulting from occupational exposure.⁴⁸

48 ILO, The STD and AIDs Prevention and Control Centre of the Chinese Centre for Disease Control and Prevention. Discrimination against people living with HIV within health care settings in China. The HIV Program. 2010. Retrieved on 8 July 2015: http://www.ilo.org/wcmsp5/groups/public/@ed_protect/@protrav/@ilo_aids/documents/publication/wcms_155950.pdf

“I think the number one reason that they refuse to conduct surgery on HIV-positive people is because they are afraid of losing their “clients” or patients. If they carried out the surgeries for us, then maybe many other clients will choose another hospital for surgeries in the future.” – Interviewee in Shenyang, China

In some cases, denials may also have been due to a genuine lack of technical capacity to treat patients living with HIV, particularly when surgery was required.

All surgery, regardless of the diagnosis of the patient, requires surgeons to adhere to universal precautions to prevent infection caused by exposure to blood and bodily fluids during surgery. The Ministry of Health in China issued a directive called Occupational Exposure Prevention Guideline for Health Care Providers Working in HIV/ AIDS Care in 2004.⁴⁹ Also, the Guidelines for the Clinical Management of HIV Infection in Adults and Adolescents for Myanmar⁵⁰ outlines proper training of employees and the necessary equipment for prevention and control of infections. Despite these formal instructions, health institutions where interviewees sought services may not have been fully equipped or trained to follow the guidelines.

“They told me they were not allowed to perform such a surgery on HIV patients no matter how much money I was willing to pay, or they would be punished and even closed down by the Center for Disease Control.” – Interviewee in Shenyang, China

However, the lack of capacity to implement standard procedures and universal precautions should not be grounds for denial of services to people living with HIV. Nor is it the responsibility of the patient to enforce adherence. Exposure to HIV and communicable diseases should be considered workplace hazards within health care settings and should be addressed as part of an occupational health and safety program.⁵¹ All workers have the right to access necessary equipment and protocols for universal precautions and reduce the risk of occupational exposure to HIV transmission. It is the responsibility of workers and management, at all times to comply with universal precautions. Medical professionals should consistently employ universal precautions with all patients to protect themselves from infection.⁵²

It was clear from the experiences of interviewees that services were denied to them because of their HIV status. Under principles of non-discrimination within an international human rights framework, discriminatory refusal of treatment is a violation of the rights of people living with

49 Guideline for diagnosis and treatment for HIV/AIDS in China (2005). Chinese Medical Association and Chinese Centre for Disease Control and Prevention. Chinese Medical Journal 2006; 119 (19):1589-1608. Retrieved on 28 October 2015 from: http://www.who.int/hiv/pub/guidelines/china_art.pdf

50 Guidelines for the Clinical Management of HIV Infection in Adults and Adolescents. (2007). National AIDS ST Control Program, Department of Health, Ministry of Health, Myanmar, Second Edition, July 2007. Retrieved 10 December 2015 from: http://www.who.int/hiv/pub/guidelines/myanmar_art.pdf

51 ILO. Joint ILO/WHO Guidelines on health services and HIV and AIDS, Geneva 2005

52 Centre for Disease Control. Recommendations for Prevention of HIV Transmission in Health Care Settings. MMWR 1987;96 (suppl No 2S) James O. Mason M.D. Dr. Ph <http://www.cdc.gov/mmwr//preview/mmwrhtml/00023587.htm>

HIV; however, health services providers do retain the right to refuse treatment if they lack specialization and full qualifications. A study to ascertain whether there was genuine lack of qualification among service providers in these countries may shed further light on instances where treatment is refused. Such a study should also assess the attitudes, beliefs, and structural factors that determine behaviors of health care workers towards people living with HIV.

Differential Treatment

Following the disclosure of HIV status, interviewees reported several forms of treatment that may have been discriminatory towards people living with HIV and key populations because of their HIV status. These differential treatments included changing treatment from surgical to topical, forced additional expenses, and forced early discharge from hospitals which prevented patients from accessing complete care. Interviewees across countries reported types of these occurrences following their HIV status disclosure. In addition, women living with HIV who sought pregnancy-related services in Cambodia also reported, in some cases, that their treatment was conditional to being sterilized.

Change of treatment from surgery to topical treatment

Four of the interviewees from China and Viet Nam reported that, following the disclosure of their HIV status, the health care providers changed their intervention from surgical to topical treatments. This change in treatment advice occurred after doctors became aware of the HIV-status of their patient, despite having already declared that surgery was the best course. While in some cases physicians may have determined that specific factors relating to the patient's health may have necessitated an alternate treatment, one interviewee's experiences revealed that health service providers made little attempt to ascertain the status of the patient's health, implying that the change in treatment was based solely on the patient's HIV status.

“After they knew I have HIV, they changed the treatment from surgery into observance and treatment directly. As a professional doctor and hospital should, they did not check my medical information. They did not check my CD4 count and make conclusions. It's obvious they are refusing me because I have HIV” – Interviewee in Chengdu, China

Additional fees and expenses

Many interviewees from Myanmar (14) reported that they were forced to pay additional fees or incur extra expenses for the services they received because of their HIV status, at both private

and government-run hospitals and health service centers. The justification for these fees was to cover the costs of medical supplies such as gloves, masks, gowns used by surgeons and patients, and spirits and cotton swabs, but these costs were not charged to other patients.

“Everyone pays the specific operation fee. But there are extra charges for HIV patients where they are asked to buy long gloves, apron, spirit, cotton and things like that.”

– Interviewee in Dawei, Myanmar

These additional expenditures appear to have been forced upon patients due to their HIV status. Some of the interviewees reported having enquired with other patients about these additional charges or had seen patients ahead of them in the queue receiving the same services but being charged lower prices. Others reported that they had collected information prior to accessing services or saw free-of-cost signage at the hospital for the particular services being accessed, yet being charged more after their HIV status was known.

“I know because before going there I looked up the information and it was about 7,000 [approx.. US\$ 6] to 8,000 [approx.. US\$ 7] kyats. But I had to spend 1, 5000 to 20,000 kyats.” – Interviewee in Yangon, Myanmar

“My family noticed there was a thermometer in the nurses’ room and everyone was using that. The one I bought they [the nurses] just used for reading my illness, then they put it on the table and I kept it with me”. – Interviewee in Yangon, Myanmar

Although HIV-related treatment costs are subsidized by the state,⁵³ non-HIV related treatment costs are borne by individuals out of pocket in Myanmar. As such, if people living with HIV are charged more than other people for the same procedures and treatments this is discriminatory. It also places a unnecessary financial burden that may result in reduced access to treatment as well as other essentials, such as food and clothing, for the individual or their family. Furthermore, several of the interviewees did not receive receipts for these extra charges. This may imply that, in addition to discriminatory fees, staff at health care centers may have been, for individual gain, exercising circumstantial power over people living with HIV who were seeking much needed health services.

This study did not attempt to ascertain whether patients with other communicable diseases also incurred these same ancillary costs; however, standardized, transparent pricing mechanisms and adequate financing of government-funded public health care services would

53 Myanmar Positive Group, Department of Medical Research and UNAIDS (2014). A Study on the Role of HIV Positive Community in Providing Antiretroviral Therapy in Myanmar

help to ensure equal treatment of all patients irrespective of their diagnosis or health care needs. A further study comparing health care expenses and the experiences of both people living with HIV and other patients may shed further light on practices in health care settings.

Forced Discharge

Some of the interviewees from China (2), Myanmar (2), and Cambodia (3) reported that they were forced to leave the hospital after their HIV status became known to service providers which ultimately denied them the right to access quality health services with potentially adverse future health consequences. An interviewee in China reported that he was forced to leave after the hospital refused him an operation and only provided him with oral treatment. The hospital then recommended that he go to a specialized hospital, and he was provided with a document stating that he had requested to leave.

“I was required to leave the hospital and pay a total of 430 Yuan (approximately \$65 USD) to settle the costs. I then had to leave with a notification that stated the reason for leaving was because the patient asked to leave.” – Interviewee in Chengdu, China

A pregnant woman from Cambodia reported that due to a lack of care from service providers because of her HIV status, she was forced to leave the hospital before being able to access the necessary support for preventing mother to child transmission of HIV, which may have had a negative impact on the well-being of both the mother and the infant. She was later supported by a CBO that referred her to another hospital where she was able to receive PMTCT support.

“Doctors did not come near me and they told other doctors in their group that I have HIV. After the delivery, within one day, I was asked to leave the hospital and my family had to take care [post-natal care] of me at home.”
– Interviewee in Phnom Penh, Cambodia

Differential provision of services in public and private health facilities

Eleven interviewees in Myanmar and two in Cambodia reported segregated waiting areas and bed spaces for people living with HIV away from general patients, and markers identifying case files of HIV patients at both government and private run health care facilities.

“We had to wait in a separate area from others.”
– Interviewee in Yangon, Myanmar

“I noticed that our history files’ [patient files’] colors are different.”

– Interviewed in Yangon, Myanmar

One interviewee from Myanmar reported she was flatly denied a bed in the hospital even though she was admitted and was receiving treatment. She was told she could not be allocated a bed according to the instructions of physicians.

“When I was admitted in the hospital I did not get a bed. I asked why I didn’t get a bed. They replied that I was HIV positive and they did not give me a bed as instructed by the physicians from the medical ward of the General Hospital. So, I was admitted for 2 days and 1 night, but I slept in the barracks for the guards”

– Interviewee in Mandalay, Myanmar

These publicly observable segregation practices were clearly a form of discrimination and a violation of the patient’s right to privacy.

Denial of child-birth-related information and services based on discrimination against women living with HIV

Sexual and reproductive health rights are prescribed in international human rights law as part of the right to health and in accordance with the principle of non-discrimination. Sexual and reproductive rights derive from the rights of every person to found a family and the right to decide freely and responsibly the number, spacing, and timing of their children and to have the information and means to do so without discrimination, including on the basis of health status.⁵⁴ According to the World Health Organization, this includes information on the prevention of unwanted pregnancy, information and help for planned pregnancy that reduces the risk of HIV transmission to the child, antiretroviral treatment and health services during pregnancy and throughout their life, and safer abortion services if a woman so decides.⁵⁵ The Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) further emphasizes the rights of women by requiring that “States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.”⁵⁶

Stigma and discrimination experienced by women living with HIV have been noted in previous studies. For example, the 2012 study carried out by the Women of Asia Pacific Network

54 Program of Action, Adopted at The International Conference on Population and Development, Cairo 5 – 13 September 1994, 20th Anniversary Edition retrieved on 4 November 2015 from: http://www.unfpa.org/sites/default/files/pub-pdf/programme_of_action_Web%20ENGLISH.pdf; CEDAW Article 16 (e); ICCPR Art 23 (2), ICESCR

55 WHO (2010). Antiretroviral drugs for treating pregnant women and preventing HIV infections in infants: recommendations for public health approach. 2010 version http://apps.who.int/iris/bitstream/10665/75236/1/9789241599818_eng.pdf

56 CEDAW Article 12

of People Living with HIV that documented positive women's experiences in accessing reproductive and maternal health rights in six Asian countries noted that the ability of women living with HIV to make informed decisions may be further limited or severely impacted when this attitude is interspersed with highly patriarchal social structures that have little regard for women's sexual and reproductive needs.⁵⁷ The report found that during a complete reproductive cycle, beginning from the decision to get pregnant to post-natal status, women living with HIV experienced multiple rights violations, including various levels of discrimination and lack of accurate information on reproductive and maternal health. Based on the experiences of several women living with HIV interviewed for this study that chose to have children or were thinking about having children, show that discrimination against women living with HIV still continues.

Ten of the women living with HIV reported seeking information in Cambodia and Viet Nam and were unsatisfied with the advice and the attitude of the service providers. Only one Vietnamese woman who received advice from a doctor, a long-term acquaintance, reported being satisfied about the advice she received which included precautions that are required to prevent transmission to the child, and PMTCT was explained to her.

Women living with HIV were discouraged from becoming pregnant and were counseled to not have children by the doctors they consulted. They found the information confusing and unsupportive, or health care providers actively discouraged them from having children. Women from both Cambodia and Viet Nam said the doctors questioned their decision and asked them to reconsider their desire to have children.

“I went to see a doctor to get advice on having a child. The doctor asked me: How old are you? I said I am 38. Then she said why at 38 do I still not have a child? I said I want to have two children. And then I also informed her I am living with HIV. She was very surprised and said “why do you want to have a child if you are HIV positive?” She said “have you considered it carefully? Why do you want a child even if you are HIV positive?” She asked me who will take care of my child if I got sick and died. She said there will be no one to take care of my child so I should reconsider.”

– Interviewee in Hanoi, Viet Nam

Some of the women interviewed also felt that perhaps the doctors were concerned about their health and hence were advising them against pregnancy.

57 APN + (2012). Positive and Pregnant: How dare you. A study on access to reproductive and maternal health care for women living with HIV in Asia. This study was conducted in Bangladesh, Cambodia, India, Indonesia, Nepal and Vietnam.

“I don’t know why she said I should reconsider, maybe she wants the best for me as my health and our financial status is weak. But I have seen some women living with HIV who have had babies after consulting with a doctor.”

– Interviewee in Hanoi, Viet Nam

“My doctor at the OI/ART clinic recommended that I do not have a baby because I have HIV and he was afraid that I would transmit it to the child. He also said I may not be able to bring up the child. So I agreed with the doctor.”

– Interviewee in Phnom Penh, Cambodia

Denying critical and medically accurate information to women that will enable them to make informed decisions on whether to and when to have children violates women’s sexual and reproductive rights. None of these women reported receiving information on lowering the risk of HIV transmission to the child. Furthermore, the power imbalance between doctor and patient, exacerbated by the doctors’ negative approach, likely made it extremely difficult for the patients to insist on being supplied with information about safer motherhood for women living with HIV.

“I want to know how to have a healthy child. My husband is HIV negative but no one provides me counseling on how to do it. I feel very sad because we are young and we need to have a child.”

– Interviewee in Hanoi, Viet Nam

PMTCT services in Cambodia, China, Myanmar and Viet Nam

Transmission of HIV from mother to child during pregnancy, labor, delivery, and breastfeeding are the most common ways of children being infected by HIV.¹ Prevention of Mother-to-Child Transmission requires multiple levels of interventions before and during pregnancy and after childbirth. Adherence to an anti-HIV medication regime before and during pregnancy, safe practices during labor and delivery, and continued medication both for the mother and her infant after childbirth may reduce the risk of infection to the newborn.² All four countries included in this study have adopted the UN Declaration of Commitment on HIV/ AIDS to provide 80% of pregnant women with access to PMTCT by 2010.³ PMTCT services started in Cambodia in 2001 with a pilot project under the National Maternal Child Health Center. It was scaled up to eight sites by 2003 and was available in 19 provinces and cities by 2006.⁴ The 2004 Directive of the Ministry of Health in Viet Nam included a comprehensive program on PMTCT, as did the National Plan on Prevention of Mother to Child Transmission of HIV (2006–2012) and the National Strategy on Population and Reproductive Health (2011–2012). PMTCT services are now integrated into reproductive health systems with services available at community health stations providing Ante-natal Care (ANC) services.⁵ The latest available report from China (2015) states that prevention of mother to child transmission of HIV, syphilis and hepatitis B has expanded to 1638 counties, covering 55% of all counties.⁶ The National Strategy Plan of the National AIDS Program in Myanmar aims to reduce mother-to-child transmission of HIV by 80% by 2016, and the latest available report shows that 79.8% of pregnant women received antiretroviral prophylaxis to reduce the risk of transmission.⁷

1 HIV Prevention: Preventing Mother to Child Transmission of HIV. (Last updated 8/25/2015; last reviewed 8/25/2015). AIDS Info. Available at: <https://aidsinfo.nih.gov/education-materials/fact-sheets/20/50/prevention-of-mother-to-child-transmission-of-hiv>
2 HIV and Pregnancy – HIV Testing and Pregnancy. AIDS Info. Reviewed February 2012. Available at: https://aidsinfo.nih.gov/contentfiles/hivtestingandpregnancy_fs_en.pdf
3 UNGASS (2001). Declaration of Commitment on HIV and AIDS. Retrieved on 18 Nov 2015 from: http://www.unaids.org/sites/default/files/sub_landing/files/aidsdeclaration_en_0.pdf
4 PMTCT Program Cambodia Joint Program Report, 26 August – 3 September 2007, National Maternal and Child Health Centre, Ministry of Health. Cambodia. October 2007. Retrieved on 18 Nov from: http://www.hiscambodia.org/public/fileupload/PMTCT_EXTERNAL_JOINT_REVIEW_E_15_1_08.pdf
5 Vietnam AIDS Response Progress Report 2014. http://www.unaids.org/sites/default/files/country/documents/VNM_narrative_report_2014.pdf
6 2015 China AIDS response progress report, National Health and Planning Commission of the People’s Republic of China, May 2015
7 Global AIDS Response Progress Report Myanmar. National AIDS Programme, 15 June 2015

This discrimination against women living with HIV continued even as they accessed services during pregnancy. Several women from both Cambodia and Viet Nam (10) said that they were chastised by health service providers for being pregnant and were reprimanded for having a baby.

“I received medicine at the hospital to prevent HIV transmission to my baby. The doctor said to me “If you are HIV positive, you should not have a baby.” I felt they were not happy to see me pregnant.”

– Interviewee in Siem Reap, Cambodia

“I went to access PMTCT at the hospital and after I gave my document to the doctor, the doctor said, “There is no need to check your pregnancy because you have HIV.” He scolded me, questioning why I needed to have a baby when I have HIV, and he said that I will transmit my HIV to my child. I was very angry with the bad words of the doctor and I stopped receiving PMTCT and OI/ART treatment there and went to an OI/ART service at another referral hospital.” – Interviewee in KEP Province, Cambodia

In addition, one woman in China was asked to terminate her pregnancy and the hospital told her they “do not have the capacity to treat her.” Albeit the hospital may have lacked the technical skills for treating pregnant women living with HIV, but the decision to have a child remains solely with a woman, irrespective of her HIV status. The aforementioned patient later received services from the Infectious Disease Hospital, which also provided her with PMTCT advice and services.

However, many women from Cambodia (67) and Viet Nam (5), where specific questions related to information on PMTCT were asked during interviews, also reported receiving extensive PMTCT-related information which included explanations on modes of transmission of HIV, the need for adherence to medication regimes to lower the risk of transmission to the child, risks associated with breast feeding, the importance of delivering in a hospital, maintaining hygiene, and the importance of drug adherence and accessing ante-natal care. Sources of information on PMTCT were doctors, health staff at OI/ ART clinics, CBO outreach workers, friends, religious figures, and village community leaders. This may reflect the progress that has been made since the PMTCT services to women living with HIV were included in national plans to end HIV. It may also reflect the effectiveness of collaboration between government programs, health care workers, and communities.

Sterilization

Forced and coerced sterilization is established in international human rights law as a human rights violation. CEDAW General Recommendation 19 states “Compulsory sterilization or abortion adversely affects women’s physical and mental health, and infringes the right of women to decide on the number and spacing of their children”.⁵⁸ The World Health Organization has stated that “sterilization without full, free and informed consent has been variously described by international, regional, and national human rights bodies as an involuntary, coercive and/or forced practice, and as a violation of fundamental human rights, including the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to found a family and the right to be free from discrimination.”⁵⁹ A study conducted in 2012 in six countries in Asia found that 30% of 757 HIV-positive women were asked to undergo sterilization, and the majority (60%) were asked to do so by an obstetrician-gynecologist and/or HIV clinician.⁶⁰

The experiences of some women living with HIV (Cambodia 4, Myanmar 2) interviewed for this report, who were seeking pregnancy-related services, and did not receive adequate information in order to make informed decisions regarding sterilization and its consequences suggest that women continue to face similar discriminatory experiences.

“My baby is now one year old. I have already undergone sterilization and now I am filled with sorrow that I cannot have another baby. I decided to have sterilization because I was afraid I will transmit HIV to another baby if I have more.”

– Interviewee in Siem Reap, Cambodia

Moreover, it also appeared that some service providers may have made sterilization a condition of providing pregnancy-related services to women living with HIV, and a refusal of the sterilization procedure resulted in those women being forced to find other service providers.

“I decided not to have the delivery of my baby there and go to another referral hospital because I did not want to undergo sterilization.” – Interviewee in Siem Reap, Cambodia

One interviewee explained how the hospital tried to force him and his wife to agree to undergo sterilization until he threatened to sue them if a sterilization procedure was performed.

58 CEDAW General Recommendation 19, para 22 <http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm>

59 WHO, 2014. Eliminating forced, coercive and other involuntary sterilization: An Inter Agency Statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1

60 APN + (2012). Positive and Pregnant: How dare you. A study on access to reproductive and maternal health care for women living with HIV in Asia. This study was conducted in Bangladesh, Cambodia, India, Indonesia, Nepal and Vietnam.

“When we registered we needed to fill a form and nurses asked us to go for sterilization. We did not agree. They kept forcing us till my wife was about to enter the operation theater because they said they had to do the surgery for delivery. Before the delivery I quarreled with the doctors and told them not to perform sterilization on my wife. I told them I will sue them if they do it without the agreement of the patient.”

– Interviewee in Yangon, Myanmar

Another woman was sterilized by the hospital without her knowledge and consent. It was not clear from the interview how much information she was provided before the procedure took place, but she maintained she did not give consent.

“I have two children. They resolutely told me not to give birth another time. I was sterilized without my consent.” – Interviewee in Yangon, Myanmar

The principle of informed consent incorporates a patient’s right to choose from among the options presented by the physicians with full understanding of the consequences. This right was clearly violated in the cases of some of the women who went through a sterilization process without adequate information and understanding of the consequences. Women have the right to clear and complete reproductive health information, and providing them with inadequate information and making some health services contingent upon the acceptance of others is tantamount to coercion, and it prevents women living with HIV from enjoying their full reproductive rights.

Breach of Privacy and Confidentiality

Discussing diagnosis and treatment is a private issue between a patient and their doctor and should not be shared with anyone not directly involved in the treatment procedure. Given the stigma often associated with HIV, it is even more important to respect the privacy and confidentiality of patients living with HIV. Several interviewees (27), a majority from Myanmar (21), Viet Nam (1), and Cambodia (5) reported that health service providers engaged in activities that led to a breach of privacy and confidentiality of HIV patients. This involved sharing information with unauthorized staff, publicly humiliating patients by calling them out, segregating them from other patients, and other practices that breach confidentiality. The Regional Analysis of Stigma index survey conducted in nine countries in Asia between 2008 and 2010 found that the majority of the survey participants believed that their medical records were not kept confidential in health care settings, and breaches of confidentiality were

identified in several countries.⁶¹

Deliberate sharing of information that was not medically necessary

Several interviewees from Myanmar, Cambodia, and Viet Nam recounted experiences that highlighted prohibitively discriminatory attitudes of health service providers towards patients living with HIV. These attitudes violated the patients' rights to privacy and confidentiality, as well as potentially causing other follow-on rights violations. A woman in Cambodia recounted that the doctor announced her HIV status to other health care providers, all of whom then refused to provide service to her.

“During my delivery the doctors used bad words saying, “This is a woman with HIV and we should be careful. We are afraid that we will get HIV from her.” The doctor did not attend to me during that time. And then other doctors also did not come to me, because the others also knew about my status because of his behavior.”

– Interviewee in Phnom Penh, Cambodia

Some of the interviewees in Myanmar reported being informed of their HIV status in public areas. In two cases, hospital staff deliberately shared the HIV status of the interviewee with other people in the hospital. One of the interviewees said she experienced this at the hands of both nurses and doctors.

“The nurses shouted loudly to other people, ‘She has HIV. Don’t eat any food with her! Don’t go to her! You will be infected too.’ She asked me, ‘You are HIV positive, what is your job?’ I didn’t tell her I am a sex worker. Then the doctor also told other patients about my HIV status. The other doctors and other patients were looking at me. And then, they stayed away from me” – Interviewee in Yangon, Myanmar

Interviewees in Myanmar reported that their HIV status was disclosed to hospital support staff who had no need to know. One of the interviewees reported that the support staff at the hospital knew of his and his child’s HIV status and refused to clean the area where they were placed.

“The cleaners in this hospital loudly said that we are HIV positive and also my baby. So, they didn’t want to do clean the area near us.” – Interviewee in Yangon, Myanmar

“Cleaners shouted at us saying, “They are HIV positive,” like that. Every time, the

61 People Living with HIV Stigma Index: Asia Pacific Regional Analysis. UNAIDS, 2011

cleaners reminded the physicians to use gloves because “this patient has HIV.” They would say that very loudly in the ward.” – Interviewee in Mandalay, Myanmar

Practices that breach privacy

As mentioned earlier, some of the practices that treat people living with HIV differently often also result in a breach of the privacy of those patients. This includes segregated waiting areas and markers identifying HIV patients.

“The hospital has a sign for the room for pregnant women with HIV, and so other people will know we are people living with HIV.”
– Interviewee in Phnom Penh, Cambodia

Other forms of barriers in accessing health services

Publicly humiliating treatment

Several interviewees (35) from all four countries felt that they did not receive a similar level of care and support extended to other patients. They reported being left unattended for extended periods, having service staff refuse to touch them, and being shouted at in public areas of the facilities. Interviewees described these encounters, which may be interpreted as discriminatory towards people living with HIV, as discouraging them from continuing to access services.

“The lab technician berated us when we went to the lab for testing. She did not touch me but [stuck] my finger with a needle.” – Interviewee in Dawei, Myanmar

“Although I was the first patient, they checked all the other patients who were behind me and had taken the token after me. I was serviced the last. So, I asked the nurse why I was checked last and she shouted at me, ‘You do not know your status. You should be satisfied that you were at least checked even if it was last. That is the regulation we lay down here. If you are not satisfied, you can go to a private hospital. You become like that yourself. We check these kinds of patients last. If you are not satisfied, don’t come here again. Do you know the bed and the place you are kept? Hussy!’ She was very rude.” – Interviewee in Dawei, Myanmar

Several of the interviewees (16) from Cambodia, Myanmar, and Viet Nam reported being treated inappropriately by staff at hospitals and clinics. One interviewee said she faced this every time she visited hospitals for treatment.

“They used to shout and scold us. We are used to it.”

– Interviewee in Yangon, Myanmar

Another interviewee from Myanmar said she discontinued treatment at the hospital where she felt humiliated. She later found support from one of the CBOs who referred her to another hospital where she continued her treatment.

“I went to Public Hospital to get ART. Health care staff from the hospital behaved rudely and scolded me loudly. They blamed me in front of other patients for infecting my baby with HIV.” – Interviewee in Yangon, Myanmar

Another interviewee from China recounted that after disclosing his HIV status the doctor set down the medical file he was studying and washed his hands.

“But after hearing that I am a person living with HIV, the doctor put down my medical record and washed his hands right there in front of me! He then forced me to leave his office. After knowing that I am a person living with HIV, he acted as if even the seat in his consulting room that I was sitting on will transmit HIV to him.”

– Interviewee in Chengdu, China

Service providers may have fear of occupational exposure to HIV. A study on adherence to universal precautions among health care providers in China showed that health care providers believe extra protections are necessary to treat people living with HIV, comparing the level of protection to SARS, a disease that can be spread through casual contact.⁶² The experience of one interviewee highlights this complex relationship between fear, genuine lack of understanding of HIV transmission, and the manifestation of inappropriate and sometimes discriminatory responses from health care providers.

“The doctor and the hospital staff did not know much about HIV and transmission of HIV. I explained to the doctor. The doctor was scared, very scared especially about the open wound of the operation. I talked with the doctor as I am trained and have studied a lot from the internet about HIV. I had a scientific study for the doctor about HIV transmission. Even then, he [the doctor] could not believe it. While we were talking, he cried twice. I felt no discrimination from him but I felt fear, great fear in him. We know this disease but he didn’t. In that short time, he could not accept the fact. He told me he had a family and been preparing to get married. He also said that he would resign. I

62 Sheng, Li, Zunyou, Haijun, Chunqing, Zhihua, Manhong, Haixia (2009). Universal precaution in the Era of HIV and AIDS: Perception of Health Service Providers in Yunnan, China. HHS Public Access. AIDS Behavior. Available in PMC 2009 November 02. Retrieved on 27 Oct 2015 from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2736060/pdf/nihms-123270.pdf>

am not clear whether his plan of resignation was just caused by this issue or others, but if it was this issue then he must have been really scared.”

– Interviewee in Chengdu, China

Barriers in ART access and adherence

Interviewees from Myanmar, Viet Nam, and China reported going to referral hospitals, community health centers, and to private hospitals to access antiretroviral treatment.

A number of interviewees in Myanmar and in Cambodia (12) reported two main difficulties in accessing services. Firstly, although ART was available at health centers, the distance and cost of the journey to those centers posed some difficulty in accessing care. Interviewees who were not residing in city centers reported having to take time off from work to travel for treatment. This resulted in the loss of one or more days’ income, depending on whether or not the patients were able to receive the doses all on the same day or were required to attend on subsequent days.

Interviewees also reported that staff at health centers were not sensitive to this difficulty faced by their clients. They reported routinely being asked to return the following day and being asked to wait for long hours.

“I live outside of Yangon and have to travel to Yangon to see the doctor. If I am a little late, they give me a later date or ask me to come next day. I have difficulty to return home and come back again. I do not have enough money. I do not have friends in Yangon to stay with. Even when I explain my difficulty, the nurses don’t accept it. If I arrive during their lunch time I can stay inside. If I go out during their lunch time, I cannot come in. I have to spend the whole day waiting for ART.”

– Interviewee in Yangon, Myanmar

Secondly, a lack of integrated services for people living with HIV creates barriers to them seeking health services. Interviewees said that apart from the logistical difficulties of going to multiple health service centers, attending multiple sites also meant they had to disclose their status to many different people.

“I am taking antiretroviral drugs and it is not easy to disclose my HIV status. But my clinic only has services for HIV and TB, and they refer us to go to other places for services such as regular sickness. I just wish to cure such common sickness by myself.” – Interviewee in Yangon, Myanmar

Stigma against key populations

In addition to stigma associated with HIV, people living with HIV who are also part of key populations may face increased stigma and discrimination because of their profession, sexual orientation or gender identity. This is particularly true for sex workers, men who have sex with men, and transgender individuals. In an online consultation with 517 people living with HIV and an additional semi-structured interview with 19 people living with HIV conducted in 2010, participants reported that their association with a “high risk community” was an important contributor that attracted discrimination against people living with HIV.⁶³ UNAIDS noted in 2013 the link between discrimination associated with key populations and increased HIV prevalence among key populations.⁶⁴ Global prevalence of HIV has been estimated to be “28 times higher among people who inject drugs, 12 times higher among sex workers and up to 49 times higher among transgender woman than the rest of the adult population”.⁶⁵

For this study, transgender and male interviewees who have sex with men in both China and Viet Nam reported they were denied service because of their gender and sexual orientation. One transgender interviewee in Viet Nam who was seeking STI testing was told “services are not available for transgender persons” before she had disclosed her HIV status, implying that she was discriminated against on the basis of her gender identity and/or expression.

“The doctor told me that I am a female transgender and that services are not available for me. They asked me to find another service provider. I was denied by the public hospital...They told me to go to another provider. They don’t provide services for transgender.”

– Interviewee in Hanoi, Viet Nam

Similarly sex workers interviewed in China (2) and Myanmar (1) said they were discriminated against because of their work.

“I could also feel that they are treating me differently because they know about my sex work.”

– Interviewee in Shenyang, China

Inconsistent messaging in relation to HIV

Commonly available HIV informational materials may also be inadvertently perpetuating

63 Global Network of People Living with HIV (GNP+). (2010). HIV Related Stigma Measures and Measurement tools; Consultation with people living with HIV to contribute to development of common indicators, July to September 2010

64 UNAIDS (2013). HIV in Asia and the Pacific. p.15

65 UNAIDS Report shows that 19million of the 35million PLHIV today do not know they have the virus. UNAIDS Press Release, 16 July 2014, Geneva. http://www.unodc.org/documents/ungass2016/Contributions/UN/UNAIDS/20140716_PR_GapReport_en.pdf

negative and discriminatory behaviors towards people living with HIV. People living with HIV in Myanmar pointed towards informational materials in hospitals that broadcasted HIV as an untreatable, fatal disease, and it is possible that these materials further reinforce negative attitudes and behaviors towards people living with HIV in both health workers and the wider community.

“The billboards in this hospital and many places announced that AIDS is incurable, there’s a lack of treatment available, and people are sure to die.”

– Interviewee in Yangon, Myanmar

Positive experiences in accessing health services

Significant numbers of women living with HIV interviewed in Cambodia (40), some in Viet Nam (5), and a few men who have sex with men interviewed in Viet Nam (3) reported satisfactory experiences in seeking health services. The majority of the women sought pregnancy-related services and accessed services at public hospitals, health centers, as well as private clinics. The male interviewees who have sex with men accessed services either at public hospitals or community health centers, and said they had not been refused any services they required.

Knowledge of HIV prevention, awareness among health care providers of issues related to people living with HIV, and increased collaboration between community based organizations and health care centers may have resulted in patients receiving quality health services. In Viet Nam, interviewees felt that when health service providers were aware of issues related to people living with HIV, they were treated just the same as other patients and also received guidance on prevention.

“When they found out about my HIV status, they treated us just the same as before because this was a big and central hospital.”

– Interviewee in Hanoi, Viet Nam

Similarly, in Cambodia, women received community home-based care⁶⁶ services and went to hospitals that were referred to them by their counselors. In some cases, women were also

66 Community Home-Based Care (HBC) in Cambodia is a team comprised of health staff, NGOs, and people living with HIV created under the National Centre for HIV/AIDS, Dermatology and STDs (NCHAD) under the Ministry of Health. It was set up to address the challenges of access to health services for people living with HIV posed by widespread stigma and discrimination and limited capacity of health service providers to cope with the increasing needs for HIV/AIDS care and manage severe opportunistic infections (OI). Since the development of the Continuum of Care approach, HBC’s role is to ensure people living with HIV get appropriate physical care and treatment, including home-based treatment of mild symptoms by family members; at home support to ensure adherence to OI and ART treatments and referrals when required, psychosocial counseling as appropriate, including individual, family or group counseling. This also includes counseling pregnant women on ante-natal care and PMTCT services. Their role also includes awareness raising on HIV and AIDS and care and support needs of people living with HIV. Standard Operating Procedure for Implementing Community Home-Based Care Activities in Cambodia. National Centre for HIV/AIDS, Dermatology and STDs <http://www.nchads.org/SOPs/SOP%20for%20HBC%20%20%28ENG%29.pdf>

accompanied by their counselors who acted as liaison with the service providers. Furthermore, the quality of services received by women living with HIV was greatly improved when peers and community members were present at health care facilities, helping the women navigate the services available.

VI. Consequences of discrimination and other barriers in accessing health services

The consistent use of globally relevant scales of stigma and discrimination such as the Stigma Index are critical to understanding changing trends in relation to stigma and discrimination. We know stigma and discrimination drive reluctance to test for HIV, disclose HIV status as well as detrimentally affect treatment, care, and support efforts. However there are other possible consequences of HIV-related stigma including negative economic consequences and negative impacts on psychological well-being as well as self-stigma, or internalized stigma

One of the most concerning consequences of negative attitudes faced at health care centers is non-adherence to treatment and a loss to follow-up. At least two of the interviewees from Myanmar said they discontinued treatment as a direct result of the negative behaviors they felt they experienced at the hands of health workers.

“I feel so depressed to take treatment.....I will not go back to the NGO clinic because they treated me badly.” – Interviewee in Yangon, Myanmar

“I missed one day of drugs. When I arrived at the clinic, the nurse did not explain well about the extra drugs [left after missing doses] and she shouted loudly at me in front of all the other patients for missing the doses. So, I am not taking any ART now and it has been nearly six months. Currently, I don’t take ART and am not getting treatment. I do not know my CD4 count.” – Interviewee in Dawei, Myanmar

Lack of adherence to medication may lead to treatment failure and possible drug resistance and hence it is very important that people living with HIV adhere to their ART regimen. In this case in particular, the health staff may have been concerned over the interviewee missing the assigned drug that may lead to failure of treatment. However, counseling on adherence, the importance of regular testing, and information on treatment failure and the consequences that may ensue must be provided with respect to the privacy and confidentiality of the person living with HIV. Mistreatment at the hands of health care workers may discourage people living with HIV from continuing to receive treatment and seek necessary health services.

Apart from ART adherence, interviewees reported several consequences of discriminatory behavior or other forms of barriers they faced in accessing health services. Such consequences as those listed below can also indirectly reduce treatment adherence and

treatment success,⁶⁷ as well as other important factors including willingness and ability of people living with HIV to implement measures to prevent onward transmission of HIV and to disclose HIV status.

i. Discrimination in health care settings may result in substandard health for people living with HIV

Interviewees across countries reported long-term deterioration of health due to refusal of treatment, delayed treatment, or mal-treatment by health service providers.

One interviewee from China who is now living with a cyst in his ear said he feels desperate. Following the initial refusal, he was referred to another hospital by a CBO where the doctor advised him against surgery and said that the cyst will cure itself. It was not clear how malignant or benign the cyst was.

“The doctor said it was only a small operation however people with HIV and AIDS may die even with a little cut. So it is better not to do the operation. After all my ear will cure itself in one or two years” – Interviewee in Chengdu, China

Refusal of services also meant interviewees were forced to suffer the pain and unease caused by their ailment for extended periods of time until alternatives could be found. Yet for others, not getting treatment for extended periods may lead to permanent damage.

“Even though sudden deafness is just a complication of HIV, if I don’t get medical attention soon I will be deaf. Now I have to tolerate this pain and at the same time need to tolerate this unfair event. So I am very sad about that.” – Interviewee in Chengdu, China

“My condition was getting worse, I had to spend more time to find other service providers.” – Interviewee in Hanoi, Viet Nam

Denial from legitimate institutions to provide surgeries that fit with the needs of the patient may force them to undergo procedures at facilities that have inadequate or no safety standards or find their own alternatives, which all may have negative impacts on their health.

67 Katz, T. I, Ryu, A. E, Onuegbu, A.G, Psaros, C, Weiser, S. D, Bangsberg, D. R, Tsai, A. C (2013). Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society*. Published online 2013 Nov 13. doi: 10.7448/IAS.16.3.18640. Retrieved on 5 Feb from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3833107/>

“I heard that there’s a hospital that could do the surgery, but it is not a regular hospital. I am not confident about their medical expertise as well as the technical level.”

– Interviewee in Shenyang, China

“I do not go for health check ups anymore. I usually buy medicine by myself.”

– Interviewee in Hanoi, Viet Nam

Denying health services in specialized hospitals and forcing people living with HIV to find other solutions leads to denial of best available quality health services. For example, the majority of the male interviewees in China living with HIV who have sex with men were asked to go to the Designated Infectious Disease Center by the health care providers where they initially sought services. Interviewees found that the infectious disease hospitals did not have the required specialization to treat their conditions. Designated hospitals provide ART and OI treatment, PMTCT treatment, and Chinese Traditional as well as Western Integrated therapy for HIV treatment but may not be specialized on non-HIV related medical treatments. Another interviewee said receiving treatment at an infectious disease hospital was akin to making his HIV-status public. He emphatically stated that, even if it meant loss of life, he would not access service at an infectious disease hospital to protect the confidentiality of his status.

“I’m married. If I go to the hospital for infectious diseases and then my friends and relatives come to see me, it is easy for them to know about my HIV. So I can’t go to hospital for infectious diseases. I need to have surgery sooner or later. If my disease is worse than before, then I will go to this hospital again. If they still do not want to treat me, then I have to go to the hospital for infectious diseases, This choice I will never choose, and I would rather die” – Interviewee in Chengdu, China

ii. Discrimination in health care settings may have negative economic consequences for people living with HIV

In addition to extra supplies and treatment expenses reported mainly by interviewees in Myanmar, denial of treatment may also have further economic consequences for people living with HIV in all four countries. Interviewees reported incurring expenses at hospitals for services which eventually they were not able to access satisfactorily, and then forced to access required services and treatments at private hospitals. Apart from the obvious direct financial burdens, this situation resulted in protracted treatment and a further deterioration in health, which then in turn had an adverse impact on the person’s ability to work and earn.

“Once I had a problem in my genitals after surgery, I had to go to Thailand for an

examination. I had to spend a lot of time and money to do that.”

– Interviewee in Hanoi, Viet Nam

“If they cancel the appointment and give me another date, I lose another day of work.”

– Interviewee in Yangon, Myanmar

“I have many debts to pay. I have to go out to work but I am unable to because of this pain.” – Interviewee in Chengdu, China

The experiences of transgender sex workers interviewed in China further illustrate the impact of discrimination in accessing health services on their ability to earn money. The majority of the transgender persons interviewed in China worked as sex workers and appeared to have a client base of primarily heterosexual males. They believed having a “female-like body” and “real breasts” will help them attract more clients and negotiate better prices.

“Most of the clients in the park hope to find a woman with real breasts. Even for us trans people, if you have “real” breasts, the clients would rather pay much more for you than for others who don’t have breasts.” – Interviewee in Shenyang, China

iii. Discrimination in health care settings may negatively impact the psychological well-being of people living with HIV

People living with HIV need to have regular interaction with health care providers to ensure better health, and consistent inappropriate attitudes and discriminatory behavior, including extra financial burdens, may lead to poorer psychological well-being.

Interviewees across countries described continuously feeling apprehensive and worried about their health, fearing their status will be disclosed to others as they access services, and feeling desperate when they are denied services.

“I do not feel confident about going for health care services, I feel angry and upset. I am always scared that they will have a stigmatizing attitude. Because of this apprehension, I don’t want to go to hospital where I feel doctors are unfriendly.”

– Interviewee in Hanoi, Viet Nam

“I just get depressed with these experiences. I told my family I do not want to go there again.” – Interviewee in Yangon, Myanmar

And one interviewee said it has led him to a suicide attempt.

“I tried to kill myself by taking 20 antiretroviral tablets.”
– Interviewee in Mandalay, Myanmar

Discriminatory attitudes and the inability to access health services, either because of denial, lack of access, or as a measure to avoid negative treatment, may have profound effects on the psychological well being of people living with HIV. A recent study conducted in Cambodia found discrimination faced by people living with HIV may have an impact on their mental health condition.⁶⁸ The interviewees in this study reported feeling distressed, depressed, sad, and having fear of imminent death and suicidal thoughts because of the negative experiences they faced.

iv. Discrimination in health care settings may result in denial of gender identity and can have further legal consequences

All of the transgender persons living with HIV interviewed in China regarded breast surgery as a crucial step to being closer to the person they identify as. All of the interviewees reported having to live with the permanent psychological stress of “pretending” to be someone they do not identify with.

“If I have real breasts, I can dress as a woman during the daytime, and I don’t need to pretend to be a man. It will make me more self-confident. I can dress as a woman day and night. But now it is impossible.” – Interviewee in China

According to Chinese law, transgender persons can change their gender marker in official documents only after sexual reassignment surgery (SRS).⁶⁹ This includes household registration permits and identity cards, alteration of school rolls and academic records. Additionally, the legal requirements for marriage registration for transgender people require completion of SRS and an altered ID card.

SRS is a series of complex processes with multiple procedures and, for transgender women, breast augmentation surgery may be a part of this procedure. If refusal of breast surgery is indicative of reluctance to conduct SRS for people living with HIV, this may ultimately deprive transgender women of the right to have legal identity in the gender they identify with, which could lead to extended denial of civil and political rights.

68 Yi, S, Chhoun, P, Suong, S, Thin, K and Tuot, S. (2015). Prevalence of Aids Related Stigma and discrimination in association with mental disorder among people living with HIV in Cambodia. Research Centre, KHANA, February 2015, Phnom Penh, Cambodia

69 Asia Catalyst, ZUO YOU & SCMC (2015) “My Life is Too Dark to See the Light” A survey of living conditions of transgender female sex workers in Beijing and Shanghai, January 2015

VII. Actions Taken

Complaints

Very few interviewees across all four countries attempted to take any form of action against barriers they faced in accessing health services. Women living with HIV interviewed in Cambodia and Viet Nam said they did not make any formal complaints to anyone at the health care centers about the negative experiences they faced. Women in Cambodia (5) and Viet Nam (2) reported their experiences to the CBOs and people living with HIV networks who then helped them receive services in different facilities.

“I complained to the people living with HIV network in the province and they helped me to get service.” – Interviewee in Kampong Cham Province, Cambodia

One interviewee in Myanmar complained to the Medical Superintendent of the hospital. Although the Medical Superintendent apologized for the behavior of the nurse, they did not take any action to prevent similar behavior in the future. The interviewee said she believed the Medical Superintendent apologized only because she told him she is associated with a community-based organization.

“The Medical Superintendent told me he would replace doctors for follow up if I don’t want to deal with her. And, he invited me to come to him if I have any complaint. But, I was worried that they will be annoyed because of me and I went private for biopsy testing. I did not go again.” – Interviewee in Dawei, Myanmar

Another interviewee in China contacted the Centre for Disease Control who supported him and attempted to force the doctor to provide services to him. The patient later relented, however, because he did not believe a doctor under pressure would provide quality treatment.

“I contacted the doctor from the CDC, and they supported me and contacted the director of the infection section... They used an administrative way to force the doctor to provide the treatment for me. But the doctor will just undergo the procedure because of the pressure but, deep in his mind, he will still be unwilling and have fear which cannot be eliminated. Under that condition, even though he accepted to treat me, he would still be in much fear” – Interviewee in Chengdu, China

Interviewees in Myanmar and Cambodia cited the lack of a complaint mechanism or their lack of knowledge of one as the reason for not raising any complaints. Women in Cambodia and

transgender persons from China also reported that fear of repercussions and fear of disclosure of their HIV status as reasons for not making formal complaints. An interviewee from China did not seek advice from relevant organizations due to the fear of further disclosure of their HIV status.

“I have not made any complaints because I don’t want anybody to know my HIV status. Besides, I don’t want people to know my HIV status, so I don’t dare to ask for advice or help from others or some relevant organizations.” – Interviewee in Shenyang, China

Furthermore, interviewees’ lack of trust in the available system also discouraged interviewees from making formal complaints. Seven interviewees in China said they did not make any complaints because they did not believe there would be positive outcomes for them. Four who did make formal complaints to a higher level at the hospitals they attended did not receive a favorable response and the denial of services was further reinforced. This endorsement of service denials on the basis of a person’s HIV status by a higher-level authority may indicate systemic discrimination against people living with HIV in these institutions.

“I tried to make a complaint to their [doctors’] supervisors, but they treated me like I am a monster and was also rejected. In the end they refused to even meet with me when I went to their office” – Interviewee in Shenyang, China

“I tried to communicate with that doctor’s supervisor, but he told me that there was no fault on the part of that doctor.” – Interviewee in Shenyang, China

Change of medical record

One of the interviewees from China took the extreme measure of altering his medical record, removing references to his HIV status to acquire the required medical services. The interviewee needed surgery for appendicitis and reported successful surgery after removing the reference to HIV. It was not clear in the interviews how he was able to change the record, nor was it clear if universal precautions were taken during the surgery.

VIII. Support Systems for People Living with HIV and Key Populations

Support from Community-Based Organizations and people living with HIV networks were reported as the most accessible and useful by interviewees in all four countries.

First, interviewees from Cambodia, Myanmar, and Viet Nam reported receiving financial and material support from CBOs. This assistance facilitated continued access and adherence to ART and supported living costs through financial and material support such as rice, hygiene materials, and nutritious food. Women living with HIV received regular counseling support, information on health and hygiene and advice on referral hospitals for smooth access to health. Some women also received support for start-up businesses.

“I got support from NGOs. They provided me transport support and facilitated for me to meet a doctor.” – Interviewee in Phnom Penh, Cambodia

“I get support from the people living with HIV network for travel allowance, nutrition support and psychosocial support. All staff from MPG support me as their family.”
– Interviewee in Mandalay, Myanmar

At least three women from Cambodia reported that the material support they had been receiving had been discontinued. It is not clear from the interviews why this support was discontinued, nor what the impact would be for women living with HIV. The termination of this support may be an indication of a reduction in international funding for HIV programs in the country and thus a direct impact on people living with HIV and key populations.

“I used to get support in the last two years. Not anymore.”
– Interviewee in Phnom Penh, Cambodia

Secondly, interviewees reported the importance of psychological support and counseling provided by the communities.

“A CBO provided information on treatment and the importance of antiretroviral treatment, support for treatment and psychological support.”
– Interviewee in Hanoi, Viet Nam

Interviewees in Viet Nam found psychological support during counseling by CBOs as the most

important, particularly since they also reported poor quality in post-test counseling that lacked psychological support from health service providers.

“They were very friendly, made it easy to understand and are close with us. They are also women living with HIV and it’s easy to understand each other.”

– Interviewee in Hanoi, Viet Nam

Third, interviewees found the referrals from CBOs to health services that are friendly to people living with HIV to be imperative. In China, many of the interviewees were able to access much-needed surgery services at the health service providers referred by CBOs.

“I was referred to another hospital by the CBO where I got the treatment and I got better.” – Interviewee in Chengdu, China

“If we have any problem, the groups would offer me detailed solutions or help, such as how to deal with the drug allergy, how to relieve our mental stress, and so on. If we have difficulties in life, the groups will even provide some subsidies for us.”

– Interviewee in Shenyang, China

Following the negative experiences from the initial hospitals, seven of the interviewees from China then found different medical institutes where they were able to access required medical surgeries. Four of the interviewees said they were referred to these institutes by CBO workers.

After CBO intervention, one of the interviewees received the required services in the same hospital where he was initially refused.

“Through the CBO I could talk to the CDC and talk to the surgeon. ... the CDC also knows this hospital is a fixed HIV treatment hospital and they have worked with them before. So the CDC succeeded in arranging this surgery for me”

- Interviewee in Chengdu, China

In addition to making referrals, CBOs also provided peer support to people living with HIV.

“The CBO introduced me to another service provider and accompanied me to the health center.” – Interviewee in Hanoi, Viet Nam

“They recommend a lot of HIV-friendly doctors to conduct some useful counseling. And they are also always patiently answering a lot of questions for us.”

– Interviewee in Shenyang, China

Finally, interviewees also reported the importance of capacity building and knowledge building support from the CBOs. CBO outreach workers and CBO networks were the largest source of information on sexual health for women living with HIV in Cambodia and Viet Nam. Women living with HIV were visited by outreach workers, attended activities organized by CBOs, including health and rights trainings where sexual and health-related information was provided. At the CBO-organized events, interviewees were able to meet with their peers and found space for sharing experiences and learning from their peers.

“I got more information in terms of treatment. I’m finding the treatment easier. My friends helped me to be more confident and live my life more positively.” – Interviewee in Hanoi, Viet Nam

“The organization calls regular meetings. Life is unpredictable. That’s why I want to get more knowledge from them for me. I go for regular meetings of CBOs.” – Interviewee in Yangon, Myanmar

IX. Discussions and Conclusion

On 25 September 2015, 17 Sustainable Development Goals (SDGs) were adopted by member states of the United Nations, including a target of ending the AIDS epidemic by 2030.⁷⁰ Recognizing discrimination as the foremost barrier, UNAIDS in celebrating early achievement of reaching the target of 15 million people having access to treatment, also noted “a strong relationship between increased HIV treatment coverage and reduced prevalence of HIV- related stigma.”⁷¹ A new fast-track strategy that built on the achievements of the earlier targets set by the Millenium Development Goals, and emphasizing zero discrimination, which was adopted by all four countries in this study, has now been unveiled. Achieving these targets will further advance progress towards the third SDG goal on health and other related goals such as eradicating inequality, ending poverty, hunger, and education.

Elimination of discrimination in health care settings is ultimately best determined by the communities and individuals who face it. The data in this report highlight and give voice to stigma and discrimination in healthcare settings as experienced by communities and individuals living with HIV. A clear understanding of this is fundamental to the success of broader efforts to end AIDS. If there is discrimination on the frontline, barriers will continue to exist for people living with HIV and key populations in accessing high quality health services.

Indicators of Discrimination against people living with HIV and its impact on the lives of people living with HIV and key populations

Consistent with other studies, this study found several indicators of discrimination faced by people living with HIV and key populations as a result of their HIV status as they sought health services. Indicators of discriminations were found when accessing HIV-related services as well as non-HIV-related services and both at private- and government-run health facilities, and sometimes also at community-run health facilities.

The study indicated that voluntary counseling and testing encouraged more people to seek testing, resulting in early diagnosis. However, **involuntary testing, or testing without consent**, was also found in some cases in Myanmar and China. Coerced or involuntary testing violates rights of physical integrity and autonomy over one’s body. Additionally, due to the serious nature of HIV, the lack of pre- and post-test counseling in an involuntary testing scenario may result in a longer-term health impact for people living with HIV and their families. For example,

70 Sustainable Development Goal 3, Target 3.3: By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>

71UNAIDS. “15 by 15” A Global Target Achieved. (2015) <http://aidsdatahub.org/%E2%80%9C15-15%E2%80%9D-global-target-achieved-unaids-2015>

although all of the interviewees in Viet Nam eventually received counseling, some of them reported that they have not disclosed their status to anyone, including to a close partner in one case. The study also documented that **breach of privacy and confidentiality** by counselors, doctors, and other health support staff continues to take place in health care settings. While in some cases there were deliberate actions taken by health care providers to inform others about the HIV status of the patients, in other cases inappropriate actions by service providers and problematic practices at health centers such as **segregated waiting areas** made their status known to others. Testing without knowledge and consent along with disclosure without consent was reported in the People Living with HIV Stigma Index conducted in Cambodia in 2010, China in 2009, Myanmar in 2010, and Viet Nam in 2011. The findings of this study indicate the continuation of this practice, although some improvement has been noted, particularly in Cambodia where all interviewees reported voluntary testing.

Denial of treatment and services, including for surgery and delivery services for pregnant women living with HIV, was reported in all four countries which led to avoidable lengthening of ailments. Moreover, the study found health institutions and health care staff were found to have employed **differential treatment**, both in terms of medical options for people living with HIV and facilities at the service centers. These treatments, such as segregated spaces and oral medication where surgery was clearly required, denied people living with HIV of the highest quality of health care services available in each country.

Prejudice against women living with HIV influenced advice given to them as they sought information on safer pregnancy. **Information related to sexual health and reproductive health were lacking** for women living with HIV who wished to bear children, denying them the right to freely and responsibly make informed decisions on the matter. Women in Cambodia, Myanmar, and Viet Nam were found to have been subjected to these violations of rights. It appeared from these women's experiences that doctors or health service providers do not focus on providing information on safer pregnancy and necessary precautions including health consequences for the women living with HIV, but instead further encouraged fear surrounding the virus, for example, by telling women they would pass on their disease to their babies or asking them who would care for their children when they die. This continued fear further perpetuated stigma surrounding HIV.

Apart from China where universal health insurance coverage allows some economic reprieve to people living with HIV, in the other three countries, health care costs are covered by governments, donors, and patient's out-of-pocket expenditure. People living with HIV across all four countries face additional challenges in accessing quality health care in the form of

transport costs, loss of earnings, and other informal costs due to the lack of widespread availability of health services. The economic burden was further exacerbated when additional costs were directly imposed on patients living with HIV.

Among the four countries where this study was conducted, Myanmar is the only country that does not have an explicit law on non-discrimination or rights of people living with HIV. However, even in the other three countries where explicit laws exist, the **enforcement of laws ensuring access to the highest attainable health without discrimination for people living with HIV have not been effective**. For example, enforcement of the AIDS Law by prosecutors or court actions to penalize people for discrimination have not yet occurred in Cambodia.⁷² Similarly, in China, by the end of 2014, only six cases of HIV related discrimination were filed, two were refused by the court, one's claim was overruled, one were ruled against people living with HIV, and two got compensation through court mediation.⁷³ An HIV patient who sued the hospital for cancer operation refusal also got compensation through mediation.⁷⁴

Although many participants indicated having knowledge of their legal rights as people living with HIV through their engagement with CBOs, fear of reprisals from health service providers and lack of information on complaint procedures discouraged them from taking any actions against inappropriate treatment. A majority of people living with HIV decided not to make formal complaints for these reasons, as well as general skepticism that the complaints would not eventuate in positive outcomes. Considering that those who did file complaints did not get satisfactory responses, such mistrust in the system was not unfounded. The failure to adhere to non-disclosure and non-discrimination by health care workers also indicates that the existing laws, policies, and regulations may not have been well disseminated or monitored for compliance.

Government and non-government efforts in promoting information about HIV and safer practices for prevention that do not reflect developments made in the last decades may result in the unintended consequence of further discrimination towards the communities. Information that is ambiguous can further stigmatize and encourage discrimination against people living HIV through inaccurate interpretations, and it must be improved to reflect the developments that have been made in living with HIV in the last decades. The public health messages at the hospitals in Myanmar that explained HIV and AIDS as a dangerous fatal disease may have instilled fear among health care staff, resulting in discriminatory behaviors towards people living

72 UNDP (2013). Legal protections against HIV-related human rights violations: Experiences and lessons learned from national HIV laws in Asia and the Pacific., p. 66, May 2013, Bangkok, UNDP

73 Xu Mengna, "The sixth AIDS employment discrimination case was refused, no favorable ruling for the previous five cases". [????????????????????????????????????]. The Paper. November 12, 2014. http://www.thepaper.cn/newsDetail_forward_1277316.

74 First AIDS penitent anti-discrimination case got compensation of 100,000 RMB after mediation [????????????????????????????????????10?]. April 15,2015. http://news.medilive.cn/all/info-news/show-77156_97.html

with HIV who were seeking services.

Finally, the interplay of poverty, gender, and minority group membership was also a factor in discrimination faced by some of the people living with HIV in accessing health services. The link between HIV and poverty, stigma, and discrimination – including based on gender identity and sexual orientation – has been widely acknowledged. This study also suggests that discrimination in health care settings may also be exacerbated by existing stigma and discrimination against key populations across socio-economic and cultural lines. The study in Myanmar, for example, found that people living with HIV with lower economic status might face increased discrimination (or more negative impact due to discrimination) compared to others who may be able to influence behaviors by providing monetary or other benefits to health service providers. Assumptions made by health care workers about linkages of HIV with sex work was clear in the experience of some of the people living with HIV who were interviewed. Several sex workers felt the need to hide their work to be able to receive treatment. Similarly, several men who have sex with men and transgender persons interviewed in China, Myanmar, and Viet Nam felt they were discriminated against because of their gender identity or same-sex relationships. Additionally, mobile communities, including migrant workers, have difficulty in accessing ART and in seeking care for regular health needs.

Role of communities in addressing discrimination in health care settings

A disproportionate burden of HIV is borne by key populations in all four countries. Stigma and discrimination are fundamental barriers to creating an environment where key populations are enabled to achieve the highest possible health standards. The abilities of the community are extremely important to ensure prevention, testing, care, and treatment of HIV. This study shows many people living with HIV, especially sex workers and men who have sex with men, decided to have testing following counseling support and advice from their peers. Furthermore, the quality of post-test counseling was higher when CBOs or peers were involved. People living with HIV felt they not only received information on the treatment regimen but found psychological support that helped them understand living with HIV. The psychological support was important in addressing internalized stigma and also to have a forward-looking approach to life. Quality counseling has an important impact in prevention, particularly in disclosing HIV status with intimate partners.

Home-based care services provided to women living with HIV in Cambodia shaped their experiences in accessing reproductive health advices and services. The majority of the

women interviewed expressed satisfaction on the advice and services they received. Women were advised on the use of condoms for prevention and received mother-to-child prevention advice and support. Community facilitators eased the link between service providers and seekers. In Cambodia where the health services sector suffers from being under-resourced and is characterized by “low level of salaries and incentive for staff impacting service delivery,”⁷⁵ the additional resources from the communities may contribute towards much-needed human resources, build stronger links between community and service providers, increase understanding among health service providers on issues related to HIV, and reduce discriminatory attitudes that may have been an outcome of lack of knowledge and understanding.

In accessing non-ART-related health services, the support of CBOs was even more important. Community groups were regarded as the support pillar for people living with HIV when they needed health-related advice. People living with HIV turned to CBOs for support when they were refused services. In all four countries, interviewees reported that after refusal, they turned to the CBOs who then referred them to hospitals that provided the required services. CBO workers were also instrumental in facilitating links between people living with HIV and health service providers.

Equally important is the role of CBOs in strengthening the knowledge and capacity of the community. This includes information on prevention of and protection from transmission, leading a healthy life, and knowledge of the rights of people living with HIV.

75 RHAC, ARROW, SIDA. On Access to Sexual and Reproductive Rights: Cambodia, 2013. Retrieved on December 2015 from: <http://arrow.org.my/wp-content/uploads/2015/04/Country-Profile-SRR-Cambodia.pdf>

XII. Recommendations

The findings of this study strongly indicate that discrimination in health care settings can be a considerable barrier for people living with HIV to access critical health services. Discrimination in health care settings against PLHIV limits effective implementation of national HIV plans and the global HIV targets of zero new HIV infections and zero HIV related deaths. A strong collaboration between government agencies, hospital administrations, international development partners, and community-based organizations to address discrimination at all levels is required.

The CBOs that are part of this project jointly provided the following recommendations to all stakeholders as steps in the right direction to create universal protections for all.

To National Governments

- **Effectively implement existing laws that prohibit all forms of discrimination against people living with HIV and key populations:** Conduct nationwide stigma and discrimination prevalence surveys among health care workers and in health care settings. Ensure that further actions on addressing stigma and discrimination address the findings of the survey. This type of data can be triangulated with the information of experiences of community members to form a more comprehensive picture of the drivers of discrimination in health care settings and provide clear direction in terms of areas to address through interventions.
- **Reinforce the implementation of rights-based HIV laws and monitor their implementation:** Increased efforts must be made in all four countries to promote HIV- and AIDS-related laws to reduce stigma and discrimination by promoting non-discriminatory attitudes. Conduct qualitative evaluation of prevention programs and information materials on HIV and AIDS. Ensure that public information materials are sensitive to stigmatizing interpretations, and that they should provide unambiguous and factual information on HIV and AIDS. Governments should also amend laws that criminalize minority groups and perpetuate discrimination against said groups.
- **Promote and strengthen the implementation of laws on non-discrimination and ensure access to justice for people living with HIV and key populations:** Government programs should include providing legal empowerment programs for people living with HIV and key populations. Governments should collaborate with community-based organizations, peer educators, and self help groups at local levels to provide community legal education so that people living with HIV and key populations can self-advocate for their rights, protection of their rights to include rights to health, as well as negotiating resolutions for grievances.
- **Raise awareness of HIV issues to medical students:** Governments, through their

ministries overseeing education, should consider embedding HIV and AIDS education and human rights education in the medical curricula of all students in medical fields. This would include doctors, nurses, as well as lab technicians and other support staff.

- **Strengthen collaboration with community-based organizations:** Governments, through their ministries of health and implementing agencies at local, district, and national levels, should promote more dialogue between community members and government-run facilities. Governments should establish an “HIV focal point” at hospitals that incorporates all levels of staff, including higher-level officials. These staff should be trained regularly on issues relating to people living with HIV and key populations, including human rights and legal rights. The focal point persons should foster greater collaboration and coordination with CBOs. CBOs should be represented in the implementation of HIV-treatment, care, and support programs, and regularly consulted for advice and feedback. Government hospitals at local, district, and national levels should recruit community members to provide psychosocial support and facilitate services at hospitals.

To Health Care Service Administrations:

- **Promote awareness among health care providers at all levels on human rights and legal rights of people living with HIV and key populations:** Health care administrations should ensure service providers at all levels undergo minimum ethics and human rights training related to HIV and sexual orientation and gender identity, which should include issues around confidentiality and duty to provide treatment.⁷⁶ Regular training sessions should be provided for health service providers, including both medical professionals as well as other non-medical staff, on policies around HIV, non-discrimination, confidentiality, and reproductive rights. Ensure health care centers and hospitals have written policies and procedures for protecting privacy and providing appropriate and non-discriminatory services and advice. Develop a code of conduct for health care settings that includes a clear and comprehensive outline of conduct that constitutes unlawful discrimination against people living with HIV which is prohibited and may be punishable by law. Provide regular training to service providers on the policies and code of conduct, and ensure that they are implemented and regularly monitored.

- **Provide comprehensive sexual and reproductive health training, including HIV and AIDS, for health care workers:** Health care administrations should ensure understanding of the particular physical and psychological needs of women living with HIV, including the specific problems they face with respect to reproductive and child health. It should also address barriers to HIV status disclosure, such as fear of stigma, discrimination, or violence.⁷⁷

- **Thoroughly investigate and take action against breaches of confidentiality, denial of treatment, or any other forms of discriminatory attitudes amongst health care workers:** Health care administrations should establish anonymous complaint mechanisms for all of their clients to register their grievances. The complaints should be thoroughly investigated and appropriate actions should

⁷⁶ OHCHR, UNAIDS (2006). International Guidelines on HIV and AIDS and Human Rights, 2006 Consolidated Version. Retrieved from: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

⁷⁷ Joint ILO/WHO Guidelines on health services and HIV/AIDS, ILO/WHO, Geneva, 2005, http://www.who.int/occupational_health/activities/2ilowho.pdf

be taken. Create committees that include senior representatives from hospital administrations and community groups to address the grievances of the communities.

- **Invest in, apply, and strengthen practice of standard procedures and universal precautions:** Integrate sensitization of health care providers at all levels on work place issues concerning communicable disease, including HIV, as regular workplace training.⁷⁸ Ensure full implementation of universal precautions to raise occupational health and safety standards, which will better protect the rights of health care workers as well as minimize the grounds for discrimination against people living with HIV and key populations.
- **Develop strong collaborations with community-based organizations:** Governments, particularly representatives from health departments at local and district levels, should establish strong relationships with community-based organizations. CBOs should be represented in the implementation of HIV-treatment, care, and support programs, and CBO advice and feedback should be regularly sought. Government hospitals at local, district, and national levels should recruit community members to provide psychosocial support and facilitate services at the hospitals.

To International Development Partners

- **Increase capacity of CBOs to strengthening their human and legal rights knowledge and advocacy:** International partners should support capacity building of CBOs on human and legal rights knowledge so that people living with HIV and key populations can self-advocate for their rights, protection of their rights including the right to health, as well as negotiating resolutions for grievances.
- **Supply technical support for human rights documentation:** Support CBOs through training and other technical support to conduct qualitative documentation with health care providers to understand the knowledge, attitudes, and perspectives of health care providers. This understanding will help CBOs to conduct effective advocacy as well as forge better alliances to address discrimination.
- **Provide financial and technical support for the continuation of program, documentation, and advocacy activities:** Support funds to implement the activities within CBO strategies that include human rights, stigma, and discrimination trainings and non-discrimination and advocacy that reach wider networks of the communities.
- **Facilitate linking resources:** Partners should coordinate between CBOs to facilitate information sharing, collective advocacy efforts, and establishment of good practices on voluntary, evidence-informed, and community and rights-based programs for people who use drugs and those who engage in sex work. International partners can also support to establish multisectoral collaboration⁷⁹ among CBOs, law enforcement, health, judiciary, human rights, social welfare, and legal service providers to assist in developing frameworks for eliminating

⁷⁸ Joint ILO/WHO Guidelines on health services and HIV/AIDS, ILO/WHO, Geneva, 2005, http://www.who.int/occupational_health/activities/2ilowho.pdf
⁷⁹ UNDP (2015). HIV and the law in South East Asia

discrimination against people living with HIV and key populations at all levels.

To Community-Based Organizations

- **Strengthen networks and collaboration:** With the reduction of international funding in middle-income countries, governments are being expected to bridge the funding gap for prevention, treatment, care, and support of people living with HIV and key populations. However, in light of competing priorities within national budgets, CBOs must be more creative in advocating for the needs of their community members. CBOs working with HIV should explore, reach out, and network with other wider networks of communities that provide health services, legal support, and advocacy around respecting, protecting, and promoting human rights at all levels. Coordination and collaboration between CBOs across all issues should be strengthened. A regular platform for sharing information and collective advocacy efforts between CBOs across all issues should be established and CBOs should actively engage and participate in such a forum.
- **Increase awareness of human rights and existing legal frameworks:** Community members should take active steps towards better informing themselves and wider communities about human rights, sexual and reproductive rights, awareness of stigma and discrimination, and the existing laws that are protecting or hindering achievement of their rights. CBOs should create space to conduct regular legal literacy activities for communities in order to strengthen knowledge of the communities about their rights and legal recourse that can be taken in event of the violation of their rights.
- **Strengthen and continue documentation of human rights violations:** Community documentation of violation of human rights is the strong basis for evidence-informed programming and advocacy. CBOs should routinely document experiences of people living with HIV and key populations in accessing health services. The findings of the documentation should be shared with health care providers, government partners, and other stakeholders to improve services and advocate for equal rights and non-discrimination of people living with HIV and key populations.
- **Collaborate with government partners and health care providers at all levels, from local to national:** CBOs should strengthen relationships and conduct collaborative activities with government partners and health care providers at all levels to increase knowledge and awareness of government partners and health care providers on issues of people living with HIV and key populations, including human and legal rights of people living with HIV and key populations. In collaboration, communities can support the delivery of health services such as counseling and referrals, activities that have been proven to reduce discrimination and increase access to quality health care for people living with HIV and key populations.
- **Increase knowledge and awareness of the communities on regular HIV treatment:** CBOs should ensure regular training and outreach within their communities through peer educators, self help groups, and other community mechanisms to educate the community on HIV treatment regimes, the importance of regular testing, and treatment failure and its consequences. CBOs, through engagement with peer educators and self help groups, should also regularly inform communities about what services are available at local health care facilities and gather information on how and where other health needs of the communities can be met.

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