



# THE PEOPLE LIVING STIGMA INDEX 2.0

# Cambodia

# **Research Report**

A Survey on Stigma and Discrimination among People Living with HIV in Cambodia













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# Foreword

At the global level, millions of people have been lost over the last three decades and too many are still facing a daily life-or-death struggle for treatment and care, adequate food, housing, and income, often in the face of pervasive HIV related stigma, discrimination and violence.

Since the beginning of the 1990s, more than 100,000 people lost their lives due to HIV and AIDS in Cambodia. With the deep understanding of the shame, anger, hopelessness, or despairthat people living with HIV (PLHIV) might experience while seeking emotional and social support and employment, Cambodia promulgated the Law on Prevention and Control of HIV and AIDS and made antiretroviral therapy publicly available in 2002. In addition, with support of development partners and local institutions, nutrition support has been provided to more than one third of HIV affected families from 2002 to 2012.

To achieve the Royal Government of Cambodia's commitment to end AIDS as a public health threat by 2025, the National AIDS Authority (NAA) has a mandate to end stigma and discrimination towards people living with, or at risk of HIV inside and outside health-care settings. With the Cambodia People Living with HIV Stigma Index 2.0 (PLHIV Stigma Index 2.0), the NAA intends to improve access to health across the whole continuum of care, not just HIV services, of the approximately 73,000 people who are currently living with this disease including key populations.

- The PLHIV Stigma Index 2.0 helps advance an understanding of the causes, extent and impact of stigma and discrimination experienced by PLHIV in Cambodia. The PLHIV Stigma Index 2.0 improves upon the first version of the PLHIV Stigma Index, initially developed in 2008 and implemented in over 90 countries, including in Cambodia in 2010. The PLHIV Stigma Index 2.0 was implemented in 2018–19 in Cambodia under leadership of the Cambodian People Living with HIV Network, with technical support and guidance of the NAA, Population Council, and the National Advisory Committee comprising members from government, non-governmental organizations civil society, bilateral and multilateral agencies, and PLHIV and key population networks. The survey received funding from FHI360 LINKAGES Project / United States Agency for International Development (USAID) and Joint United Nations Programme on HIV/AIDS (UNAIDS).
- Following the standard PLHIV Stigma Index 2.0 questionnaire, this report includes information on: HIV status disclosure; external stigma and discrimination; internalized stigma and resilience; HIV testing, care, and treatment; viral suppression; general health status and other health conditions; healthcare stigma, human rights and affecting change; and stigma and discrimination experienced for reasons other than HIV status. In addition to these topics, the report includes Cambodia-specific information on PLHIV's access to social protection schemes and other topics of relevance.



 The study was conducted following the Greater Involvement of People living with HIV/AIDS (GIPA) principle and provides voice to the PLHIV population to advocate for them to live full and productive lives free of stigma and discrimination.

The findings and the recommendations of the Stigma Index 2.0 will help us to end public stigma and self-stigma and change the behaviors of individuals or institutions who unjustly deprive others of their rights and life opportunities due to stigma and discrimination. The NAA believes that the 95-95-95 targets for 2025 can be achieved when PLHIV and at-risk people feel at ease to join those public services without fear or negative beliefs while providers adopt friendly attitudes to all public services they provide to their beneficiaries.

With this Stigma Index 2.0 report, the NAA is calling on health care and social workers and relevant institutions both at national and sub-national level to end the exclusion or marginalization of PLHIV and key populations that deprive them of their civil rights, such as access to equitable health and social services, opportunities for employment, education, and full participation in civic life. This combined effort will uphold the quality of lives of PLHIV and key populations enabling them to actively participate in country socio-economic development generating the return of the investment on the HIV and AIDS response.

Lastly, I would like to thank USAID Cambodia, FHI360 LINKAGES Project and UNAIDS for financial support and NAA, Population Council and all members of the National Advisory Committee for their technical guidance and assistance. I express my sincere thanks to all persons involved in the implementation of this PHLIV Stigma Index 2.0 Cambodia and special thanks to all PHIV who both implemented and participated in the survey.

#### H.E. leng Mouly

Senior Minister in charge of special mission and Chairman of the National AIDS Authority



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We are extremely grateful for the financial support from the United States Agency for International Development (USAID) through FHI360's LINKAGES Project and the Joint United Nations Programme on HIV/AIDS (UNAIDS), who also provided technical guidance during the implementation of the survey. The National Advisory Committee, comprising members from government, civil society, bilateral and multilateral agencies, and PLHIV and key population networks, provided technical inputs and guidance to the survey implementation and helped ensure that the survey was inclusive and technically sound. We are thankful for their engagement throughout the planning phases of the survey as well as during the interpretation phase.

For the implementation of data collection, we received kind facilitation from Catholic Relief Services, the National Center for HIV/AIDS, Dermatology and STD, Phnom Penh Municipal Health Department, and Provincial Health Departments of Siem Reap, Battambang, Banteay Meanchey, Kampong Cham and Kandal. The survey could not have been implemented without their support.

The survey was managed, advised and supported by a team of individuals whose contributions deserve special mention. Special thanks go to Dr. Ashish Bajracharya and Dr. Heng Molyaneth from the Population Council for their technical leadership in research design, development of research protocols, finalization of sampling methodologies, training of data collection team, data collection activities, data analysis and report writing. We are also deeply indebted to H.E. Dr. Tia Phalla, Dr. Tep Navuth, and Dr. Sim Sophay from the NAA for their leadership, support and guidance throughout all stages of the survey, and in particular for the NAA's patronage of this survey in support of the PLHIV population. The survey team received significant technical and coordination support from Dr. Steve Wignall, Ms. Seng Sopheap, Mr. Im Chanry, and Mr. Rang Chandary from the FHI360 LINKAGES Project, Mr. Ung Polin from UNAIDS, Ms. Yat Bunmey and Ms. Barbara Friedland from the Population Council, and Mr. Noy Prorphea from Catholic Relief Services. Thanks also go to Ms. Vong Rylida and Ms. Tracy McClair from the Population Council for their analysis and technical writing support respectively.



Heartfelt thanks go to all members of the PLHIV community who contributed in the survey, both as interviewers and as participants of the survey and our various interpretation workshops. Despite not being experienced interviewers, facing challenges with the use of tablets for data entry, traveling far distances to remote areas to interview respondents, the data collection team members, fully comprising members of the PLHIV community, worked diligently and did a highly commendable job of collecting high quality data. Similarly, we extend our thanks to all PLHIV respondents who provided their valuable time to participate in interviews and provincial interpretation workshops and provide unique insights on their experiences.

Finally, our thanks go to the implementation team from Cambodian People Living with HIV Network, Mr. Seum Sophal and Ms. Leap Sreyluch, and other individuals who contributed to the successful completion of the survey but whose names could not all be mentioned.

**Sorn Sothearidh** National Coordinator Cambodian People Living with HIV Network (CPN+)



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# Acronyms

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
CAA	Community Action Approach
CPN+	Cambodian People Living with HIV Network
CRS	Catholic Relief Services
GIPA	Greater Involvement of People living with HIV
GNP+	Global Network of People living with HIV
HIV	human immunodeficiency virus
ICW	International Community of Women Living with HIV
LINKAGES	Linkages across the Continuum of HIV Services for Key Populations Affected by HIV
MSM	men who have sex with men
NAA	National AIDS Authority
NAC	National Advisory Committee
NCHADS	National Center for HIV/AIDS, Dermatology and STD
ODK	Open Data Kit
PLHIV	people living with HIV
Project SOAR	Project Strengthening Operational AIDS Research
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development



# **Executive Summary**

### BACKGROUND

Cambodia was one of the fastest growing HIV epidemics in Asia in the mid-1990s; however, the country has been successful in reducing its HIV prevalence and incidence over the last decade. Despite this success, Cambodia still needs additional efforts to address disparities at the subnational level, special needs among key populations, and general stigma and attitudes associated with HIV/AIDS. HIV-related discrimination is not only a human rights violation, but it also has an impact on people's ability to access HIV testing, care, and treatment. The United Nations' 2016 High-Level Meeting on Ending AIDS included "elimination of HIV-related discrimination" as one of three critical targets to achieve by 2020, along with reducing the number of new HIV infections and people dying from AIDS-related causes to under half a million.

To understand the causes, extent, and effects of stigma and discrimination experienced by people living with HIV (PLHIV) in Cambodia, the People Living with HIV Stigma Index 2.0 (PLHIV Stigma Index 2.0) was implemented in Cambodia under leadership of the Cambodian People Living with HIV Network. The survey received technical support and guidance from the Population Council, National AIDS Authority, and a National Advisory Committee (NAC), comprising members from government, civil society, bilateral and multilateral agencies, and PLHIV and key population networks. The survey received funding from FHI360 LINKAGES Project/ United States Agency for International Development (USAID) and Joint United Nations Programme on HIV/ AIDS (UNAIDS).

#### **RESEARCH METHODOLOGY**

The implementation of the PLHIV Stigma Index 2.0 in Cambodia was carried out through a series of consultative activities of the NAC, which drew participation from a range of stakeholders, including members of the PLHIV community, leading up to development of the research protocol, obtaining ethical approvals, and the implementation of the survey tool among PLHIV. Consultative activities, engaging stakeholders including members from the PLHIV community, were also conducted after completion of the data collection for interpretation of results.

The targeted sample size was 1,200 PLHIV in six provinces in Cambodia: Phnom Penh, Siem Reap, Battambang, Banteay Meanchey, Kandal, and Kampong Cham. The sample size in each province was determined by employing probability proportional to size methodology to the known population of PLHIV in each respective province. The survey employed three sampling strategies: antiretroviral therapy (ART) client list-based sampling, ART clinic/site-based sampling and snowball sampling in order to reach diverse groups of PLHIV, including those who were



potentially difficult to reach, had been lost to follow up, or were not members of the HIV support network. PLHIV were eligible to participate in the survey if they were 18 years of age or older, had known their HIV positive status for at least 12 months, were mentally sound and capable of giving consent, had provided informed consent to participate in the survey and speak Khmer. Upon completion of the data collection, the survey collected information from a total sample of 1,222 PLHIV: 391 respondents through ART client list-based sampling, 727 respondents through ART clinic/site-based sampling, and 104 respondents through snowball sampling. Data were collected using the updated version of the PLHIV Stigma Index questionnaire loaded on Android tablets running an Open Data Kit application. The data collection team comprised of 36 members of the PLHIV community who received training on how to conduct interviews with PLHIV in an ethical manner. The survey received ethical approvals from the Population Council Institutional Review Board and the National Ethics Committee for Health Research in Cambodia.

#### **KEY FINDINGS**

Respondents in the survey have some distinctive characteristics. Overall, around 60 percent of them were women, with some variation among provinces. The mean age of respondents was 45 years old. Fifty-two percent of respondents were currently in an intimate relationship, and slightly more than half of those had a partner also living with HIV. Less than 5 percent of respondents were from key population groups. Almost 67 percent of respondents had only primary or less education, while another 33 percent had secondary education or higher. Respondents came from diverse economic backgrounds: 32 percent unemployed, 32 percent doing casual or part-time job, 23 percent full-time self-employed, 2 percent part-time self-employed, and 11 percent full-time employee.

#### Below are key findings of the survey:

- **HIV status known and disclosure:** The average duration that respondents had known of their positive HIV status is 10 years. Disclosure of HIV positive status was less common to unknown people than to family and friends (65 percent disclosed to partner vs. 7 percent disclosed to employers). Generally, disclosure got easier over time for the majority of respondents.
- **External stigma and discrimination:** Most respondents across provinces reported having never experienced or minimally experiencing external discrimination.
- **Internalized stigma:** Report of internalized stigma was high across provinces. Generally, women reported higher levels of shame and feelings of worthlessness, while men reported higher levels of guilt.
- HIV testing, care and treatment: A majority of respondents tested for HIV by their own choice and due to their self-perception of risk and / or feeling sick. Not everyone received treatment right after the positive result of their HIV testing. The top reported reasons for this were "not being ready to cope with their HIV infection" and "worried that other people would find out". A small proportion of respondents reported "bad experiences with health workers" as the reason.



- Viral load detection and suppression: Around 40 percent of respondents had a viral load that was undetectable at the time of the survey, while 12 percent had a viral load that was detectable. Twenty three percent had had a viral load test but were still waiting for results of the test at the time of the survey. Another 5 percent had not had a viral load test in the past 12 months prior to the survey. Nearly 20 percent of the sample did not know what viral load or suppression meant.
- **General health condition:** A majority of respondents self-assessed their health to be generally good or fair. However, almost 30 percent reported an experience of having tuberculosis, hepatitis, STIs, or a mental health issue. Among these respondents, only 29 percent had received treatment.
- Anxiety and depressive symptoms: Three-fourths of respondents (74 percent) reported anxiety and depressive symptoms during the two weeks prior to the survey, with women having greater proportions than men. Among those reporting this problem, 76 percent did not receive any type of support.
- **Healthcare stigma:** Instances of disclosing client's HIV status to others, speaking badly about clients, and avoiding physical contact with clients remain problems when PLHIV accessed both HIV and non-HIV care and treatment services. There were relatively low reports of stigma when accessing sexual and reproductive healthcare across gender and provinces.
- **Human rights and effecting change:** One-third of respondents did not know there are laws for protecting PLHIV from discrimination in Cambodia, while another 4 percent said there are no laws at all.
- **Social protection scheme:** Slightly less than half of respondents in the survey or their family members were covered by a social protection scheme, including Health Equity Fund and ID Poor programs.

### ADDITIONAL ANALYSIS ON STIGMA

Comparison of results from Stigma Index 1.0 (2010) vs. Stigma Index 2.0 (2019)

- Results of the Stigma Index 1.0 and 2.0 on external and internalized stigma are not directly comparable due to design differences in the questionnaires between the surveys in terms of topics of the questions and how the questions were asked.
- Report of external discrimination in the Stigma Index 2.0 study was very low, particularly on indicators for refused employment and verbal abuse or harassment. Reports on similar questions on external discrimination, including employment and lost income and verbal harassment were high in Stigma Index 1.0.
- Reports of internalized stigma in Stigma Index 2.0, in particular on feelings of worthlessness, guilt and shame about being HIV positive were considerably high. On a similar set of measures in the 2010 survey, reports of experience of internalized stigma was significantly high on five measures including those related to feeling of worthless, guilt, shame about being HIV positive, and desire to have children or low self-confidence.



#### Stigma by Different Characteristics of Sample

- Additive indices for external stigma, resilience and internalized stigma were generated using corresponding questions from the survey. Differences in each index score were analyzed by various sample characteristics.
- Reported levels of external stigma and discrimination were different among respondents recruited through differing sampling approaches, showing higher levels for clinic based and snowball sampling.
- Resilience/abilities to cope with HIV positive status vary depending on education level and duration of known HIV positive status of respondents.
- Reported levels of internalized-stigma vary among respondents depending on their age, duration of known HIV positive status, education level, intimate relationship status, perceived ease of disclosing HIV status, knowledge of laws for protecting PLHIV from discrimination, and access to social protection scheme.

## DISCUSSION

- **External stigma and discrimination:** Reports of external discrimination is observed to be very low in the Stigma Index 2.0 study. However, at the same time, reports of HIV status disclosure to non-family members in the 2019 survey are observed to be low as well. The changing support environment for PLHIV may make disclosure to non-family members unnecessary. Therefore, the low rate of disclosure to non-family members may provide an alternative explanation for the low report of external discrimination.
- Internalized stigma: The reports of internalized stigma in the 2019 survey is observed to be significantly high. Some potential reasons for high internalized stigma include fewer communitybased HIV sensitization activities and self-help/peer support groups and reduced home-based care support and lack of understanding on viral load and on detectability and transmissibility. Results of bivariate analyses suggest that continued prevalence of self-stigma among PLHIV is a complex issue that depends on many socio-demographic factors. Therefore, the issue of internalized stigma will require further rigorous quantitative and qualitative analyses.
- Viral load detection and suppression: There is continued lack of clear understanding of viral load testing and viral load suppression. One-fifth of respondents participating in the survey did not know the meaning of viral load suppression. In addition to this lack of understanding, there is a common misunderstanding that undetectable viral load means being cured of HIV, which may lead to PLHIV dropping out of treatment and disconnecting from HIV support networks, raising risks of elevated viral loads after having left treatment, rising incidence of STIs, unwanted pregnancy, and potentially new HIV infections as a result of risky sexual behaviors. The lack of understanding that undetectable viral load means it is untransmissible may lead to negative implications on perceptions of self-stigma and guilt and external stigma towards PLHIV.



#### **RECOMMENDATIONS AND CONCLUSION**

Based on the results of the PLHIV Stigma Index 2.0 study and discussions among the NAC and at the six provincial interpretation workshops, several actions were identified as potential strategies to address persistent issues related to stigma and discrimination against PLHIV in Cambodia. These recommendations are discussed below:

- Promoting HIV/AIDS education: HIV/AIDS education should expand its scope beyond basic information about HIV transmission and prevention. Target audiences of HIV/AIDS education should include both PLHIV and the general public in order to reduce stigma and discrimination. Educational activities need to be held in various settings, including communities, health facilities, social and mass media platforms, medical training systems, and formal education systems.
- Improving client-provider interaction and health service coverage: HIV healthcare providers may need to use more innovative approaches to explain the concepts of viral load detection and suppression, as well as the importance of receiving and adhering to regular ART care and treatment clearly. In addition, more training might be needed for service providers to provide improved levels of confidentiality as well as ethical and non-judgmental care at facilities. Providers should continue to communicate with clients at risk of migration during appointments about how they can plan their ART treatment. Combining opportunistic infection, mental health, and ART services together could potentially encourage visits to ART sites and reduce internalized stigma and other health issues beyond HIV.
- Providing community-based social support: Although some PLHIV continue to choose to not disclose their status and not use any social support or connection with HIV support networks, providing community support in various forms was repeatedly recommended by stakeholders as a potentially important strategy to reduce internalized stigma. The practice of home-based care or peer support groups from the past (e.g., "Friends Helping Friends") were highly appreciated as an effective way to provide needed social and emotional support to PLHIV. These support networks do not exist anymore in Cambodia and a desire for their return was expressed by the PLHIV community and other stakeholders.
- **Expanding social health protection support:** Granting Equity Cards through the ID poor program to PLHIV could potentially help improve their lives in various aspects and could have the potential effect of reducing internalized stigma, enabling PLHIV to lead more normal lives.

In conclusion, the study was successfully implemented under the leadership of the PLHIV community and with close collaboration among stakeholders from various sectors and the government. The updated questionnaire has provided a much-needed update to the knowledge and understanding of the state of stigma and discrimination faced by the PLHIV community in Cambodia. Due to the participatory nature of the study, the evidence that has been generated from the study has been readily actionable, both from a programmatic and advocacy standpoint.



# 1. Background

## People Living with HIV Stigma Index 2.0

People living with HIV (PLHIV) often experience stigma and discrimination that can affect their well-being in significant ways. HIV-related discrimination is not only a human rights violation, but also has an impact on people's ability to access HIV testing, care, and treatment. The United Nations' 2016 High-Level Meeting on Ending AIDS included "elimination of HIV-related discrimination" as one of three critical targets to achieve by 2020, along with reducing the number of new HIV infections and people dying from AIDS-related causes to under half a million (UNAIDS, 2015).

The PLHIV Stigma Index was developed by the Global Network of People living with HIV (GNP+), the International Community of Women Living with HIV (ICW), International Planned Parenthood Federation, and the Joint United Nations Programme on HIV/AIDS (UNAIDS) to provide evidence on stigma and discrimination that could be used to advocate for the rights of PLHIV. In keeping with the Greater Involvement of PLHIV (GIPA) principle, the Stigma Index is designed to be implemented by PLHIV to measure and detect changing trends in stigma and discrimination experienced by PLHIV, and to develop evidence-informed action to address this stigma. The Index was launched in 2008, and as of October 2017, over 100,000 PLHIV had been interviewed from nearly 90 countries around the world, more than 2,000 PLHIV had been trained as interviewers, and the survey had been translated into more than 50 languages (the PLHIV Stigma Index International Partnership of GNP+, ICW, and UNAIDS, 2018).

Shifts in the HIV epidemic, the increased evidence on the epidemic and the population groups it affects, and changes in global responses to HIV suggested that the Stigma Index needed to be updated and strengthened to be a better measurement and advocacy tool. In October 2015, a global group of experts working in the field of HIV and AIDS established a small working group comprised of representatives from GNP+, ICW, UNAIDS, United States Agency for International Development (USAID), experts from the Population Council's Project Supporting Operational AIDS Research (Project SOAR) and other leaders in the field to begin the process of assessing, updating, and pilot testing a strengthened PLHIV Stigma Index. The small working group implemented a process for evaluating and updating the Stigma Index that would be transparent and incorporate as many perspectives as possible, developing the PLHIV Stigma Index 2.0 tool. This updated tool was pilot tested in Uganda, Cameroon and Senegal in 2017 and the questionnaire was finalized in December 2017.



#### HIV/AIDS and its associated stigma and attitudes in Cambodia

Cambodia had one of the fastest growing HIV epidemics in Asia in the mid-1990s; however, the country has been successful in reducing its HIV prevalence over the last decade (NCHADS, 2016). The National HIV prevalence rate among adults aged 15–49 years old was 1.6 percent in 1998 and only 0.6 percent in 2017. The rate is projected to remain at 0.5 percent by 2020. New HIV infections also have remarkably decreased from 2,300 cases in 2010 to 880 cases in 2018. In terms of population size, the number of PLHIV in Cambodia was 73,000 people estimated in 2018. Moreover, the country achieved a high coverage of antiretroviral therapy (ART) of 81 percent in 2018 among all PLHIV.

Despite these successes, Cambodia still needs additional efforts to address disparities at the subnational level, special needs among key populations, and general stigma and attitudes associated with HIV. Phnom Penh, the capital city, and two other provinces (Battambang and Siem Reap) have the highest rates of HIV prevalence, new HIV infections, and AIDS related-death cases (NCHADS, 2016). The population groups in Cambodia that are most vulnerable to HIV and related stigma and discrimination include entertainment workers, people who use/inject drugs, transgender people, and gay men and other men who have sex with men (MSM). On average, less than 30 percent of general population reportedly expressed accepting attitudes towards PLHIV in the 2014 Cambodia Demographic Health Survey (NIS, DG for Health, and ICF International, 2015).<sup>1</sup>

The Cambodian People Living with HIV Network (CPN+), in collaboration with Khmer HIV/AIDS NGO Alliance, conducted the first ever PLHIV Stigma Index in Cambodia in 2010 with support from UNAIDS. The survey was implemented under the guidance of an Advisory Committee chaired by the National AIDS Authority (NAA) and comprised of representatives from government, civil society, bilateral and multilateral agencies and PLHIV and key population networks. This assessment targeted a total sample size of 400 PLHIV in four provinces and one municipality with a high prevalence of HIV and concentration of PLHIV: Kampong Cham, Battambang, Takeo, Kampong Thom and Phnom Penh. Data were collected using a multi-stage cluster sampling procedure from 40 health center catchment areas, with probability proportional to population size methods utilized to determine the number of PLHIV interviewed from each cluster. The National Ethics Committee for Health Research of Cambodia approved the survey.

Four indicators were included in the 2014 Cambodia Demographic Health Survey to measure attitudes of general population towards PLHIV, including their willingness 1) to buy vegetables from an infected shopkeeper, 2) to let other knows the HIV status of family members, 3) to take care of relatives who have the AIDS virus in their own households, and 4) to allow an HIV-positive female teacher who is not sick to continue teaching.



### **PLHIV Stigma Index 2.0 in Cambodia**

The PLHIV Stigma Index 2.0 was implemented in Cambodia in 2018–19 by CPN+ with technical support from the Population Council and the NAA, and with funding from FHI360 LINKAGES/ USAID and UNAIDS. This survey was implemented in close partnership with community-based organizations working with PLHIV and key populations in Cambodia and represents the CPN+ and Cambodian stakeholders' second national implementation of the Stigma Index. The Population Council served in a technical advisory capacity and facilitated the implementation of the survey as well as research utilization and advocacy. The survey was advised by a National Advisory Committee (NAC) which was composed of representatives from government, civil society, bilateral and multilateral agencies, and PLHIV and key population networks through consultative and participatory processes, providing technical, advocacy, and practical guidance on the implementation of the Stigma Index 2.0 in Cambodia and interpretation of survey results. Survey findings will enhance the contemporary knowledge on the situation of stigma and discrimination experienced by PLHIV in Cambodia and enhance evidence-based advocacy to improve programs and policies to better address the PLHIV needs in priority areas in Cambodia. The implementation of the updated PLHIV Stigma Index 2.0 in Cambodia is also among the first of these updated versions to be conducted in the world and the first in Asia.

# 2. Survey Objectives

The overarching goal of this survey was to advance the understanding of the causes, extent, manifestation, and impact on care and service uptake, of stigma and discrimination experienced by PLHIV in select provinces in Cambodia utilizing the PLHIV Stigma Index 2.0 survey.

Specific objectives of this survey follow:

- Objective 1: Provide an updated situational analysis of HIV related stigma and discrimination in Cambodia utilizing the Stigma Index 2.0 survey to provide an evidence base for improving policies, programs, and to better meet the needs of PLHIV in priority provinces.
- Objective 2: Improve evidence-based advocacy on HIV related stigma and discrimination and to ensure that research utilization and evidence-based programming and policymaking practices are systematically improved and documented.
- Objective 3: Continue to improve and model the best practice of GIPA within the survey to empower and develop capacities of PLHIV.



# 3. Methodology of the Survey

# 3.1 Survey Design

CPN+, with technical support from the Population Council and the NAA, led the implementation of a cross sectional quantitative survey of stigma and discrimination among PLHIV in six priority provinces in Cambodia: Phnom Penh, Battambang, Siem Reap, and Banteay Meanchey, Kandal and Kampong Cham with support from FHI360 LINKAGES/USAID and UNAIDS Cambodia. CPN+ and Population Council utilized the recently finalized PLHIV Stigma Index 2.0 tool.

#### **Consultative mechanisms**

The implementation of the PLHIV Stigma Index 2.0 in Cambodia was carried out through a series of consultative mechanisms that drew participation from a range of stakeholders, including members of the PLHIV community, leading up to development of the research protocol, obtaining ethical approvals, and the implementation of the survey tool among PLHIV. Consultative activities were also conducted after the completion of the data collection for interpretation of results engaging stakeholders including members from the PLHIV community.

#### National Advisory Committee

As a first step in the preparation process, a NAC was formed to provide technical, advocacy, and practical guidance to the implementation of the Stigma Index 2.0 in Cambodia. The NAC was formed under the leadership of the National AIDS Authority and the National Center for HIV AIDS Dermatology and STI (NCHADS). The primary function of this advisory committee was to provide guidance and support to the research design, sampling, and field implementation of the Stigma Index. It also provided guidance on the inclusion of several Cambodia-specific questions to the standard Stigma Index 2.0 tool in a separate section at the end of the standard tool. Furthermore, the NAC provided specific inputs on the interpretation of survey findings and on draft survey reports, facilitating the contextualization of the evidence generated. It also advised on research utilization and policy advocacy plans following the completion of the survey. The NAC met three times in Phnom Penh, twice before data collection, and once after data collection:

- 1. The first meeting, held in August 2018, introduced the PLHIV Stigma Index 2.0 tool and a consultation was held on the implementation plan for the Stigma Index 2.0 survey in Cambodia.
- 2. The second meeting, held in November 2018, focused on survey design, specifically on finalizing the research protocol and tools, sample size determination, sampling methodologies and field implementation planning.
- 3. The third meeting, held in June 2019, brought together NAC members to consult on the findings from the survey and interpretation of results, discussing key issues to highlight in the dissemination of survey results.



The Population Council also led the formation of a smaller Technical Advisory Group for research design and implementation specific issues that met more frequently. (See Appendix for Terms of Reference of the NAC).

#### **Provincial Interpretation Workshops**

Upon completion of data collection and analysis of data, the survey team organized interpretation workshops in each of the six survey provinces in May 2019. The key objectives of the workshops were to share and discuss preliminary research findings of each province with relevant local stakeholders, including the PLHIV community from each province, and to collect input from local stakeholders that can provide context to results and generate recommendations to address outstanding issues faced by PLHIV communities in respective provinces. A total of 162 participants attended and participated in the six workshops. They comprised of representatives from PLHIV communities, community-based organizations, health providers from ART clinics, management of provincial/municipal health departments, and staff and representatives from NAA, CPN+, FHI360 LINKAGES, Population Council and data collection team members. The interpretation workshops were highly participatory in nature. In addition to the presentation of results from each respective province to the local audience, the agenda featured participatory feedback sessions from participants through group discussion. Groups were divided to feature diversity amongst stakeholders and were asked to respond to questions related to improving loss to follow-up outcomes as well as on interpreting and reducing high levels of internal stigma observed in the survey results.

Province	Number of Participants	
Siem Reap (SR)	19 persons (10 males, 9 females)	
Banteay Meanchey (BMC)	30 persons (16 males, 14 females)	
Battambang (BTB)	32 persons (13 males, 19 females)	
Kampong Cham (Kg.C)	29 persons (11 males, 18 females)	
Kandal (KD)	19 persons (5 males, 14 females)	
Phnom Penh (PP)	33 persons (11 males, 22 females)	

#### Table 1. Participation in the six provincial interpretation workshops

Insights from these consultative processes in the interpretation of results are further discussed in the Discussion section below.



### **Research protocol development and ethical approval**

The Population Council worked closely with CPN+, in consultation with the NAC, to develop a research protocol and finalize translation of the Stigma Index 2.0 tool to implement the survey for ethical approval. In accordance with the policies of the Population Council, the research protocol was submitted to both an international Institutional Review Board as well as the national ethical review board of Cambodia. Ethical approval was received from the following ethical review bodies after rigorous review of the protocol, and after recommended modifications where required were made:

- Population Council's Institutional Review Board, New York, USA-Approved October 2018.
- Cambodian National Ethics Committee for Health Research—Approved August 2018.

# **Eligibility criteria**

PLHIV with following criteria were eligible to participate in the survey:

- 18 years of age or older
- Self-reported knowledge of HIV status for at least 12 months
- Mentally sound and capable of giving consent
- Has provided informed consent to participate in the survey
- Speaks Khmer

### Population and sample size

The targeted sample size was 1,200 PLHIV in six provinces in Cambodia: Phnom Penh, Siem Reap, Battambang, Banteay Meanchey, Kandal, and Kampong Cham aiming to expand on the 2010 Stigma Index survey sample size, which reached 394 PLHIV participants. The sample size in each province was determined by employing probability proportional to size methodology to the known population of PLHIV in each respective province. Details of the targeted sample sizes are shown below in Table 2.

Survey Provinces	Population Size of PLHIV* 2018 Estimate	Sample Size (Probability Proportional to Size) (Total=1,200 PLHIV)
Phnom Penh	14,312	451
Siem Reap	5,746	181
Battambang	6,150	194
Banteay Meanchey	4,421	139
Kandal	3,794	120
Kampong Cham	3,638	115
TOTAL	38,061	1,200

#### Table 2. Target sample size, by province

Note: \*Population estimate based on PLHIV aged 15 and over (NCHADS, 2016)



# Sampling methodology

The selection of the sample for the survey utilized a combination of both a stratified random sampling strategy and a snowball sampling strategy to recruit a target of 1,200 PLHIV for the survey. Under the stratified random sampling strategy, participants were recruited through two sub approaches:

- **1.** ART client list-based selection
- 2. ART clinic-based (site) selection

A snowball sampling approach was employed to reach PLHIV who were potentially difficult to reach, had been lost to follow up, or were not members of networks.

In total, a final sample size of 1,222 PLHIV respondents in six provinces was reached upon completion of data collection. Table 3 details the targeted sample sizes and actual recruited sample size by sampling strategy stratified by list-based selection, clinic-based selection, and snowball sampling selection. Some adjustments were made in sampling strategies based on challenges encountered in the field. All decisions related to sampling were taken in close consultation with the NAC.

Research Sites	Sti	atified Rar Sampling		Snowball Selection	Required Sample Size	List-based Sample Recruited	Clinic walk-in Sample	Snowball Sample Recruited	Total Sample Recruited
	Total (a+b)	(a) List- based Selection (50%)	(b) Clinic- based Selection (50%)		5126	Kecrolled	Recruited	Kectolled	Keci ulieu
Phnom Penh	376	188	188	75	451	74	378	2	454
Siem Reap	151	75.5	75.5	30	181	76	84	30	190
Battambang	161	80.5	80.5	33	194	80	82	33	195
Banteay Meanchey	116	58	58	23	139	62	61	16	139
Kandal	100	50	50	20	120	51	69	5	125
Kampong Cham	96	48	48	19	115	48	53	18	119
TOTAL	1000	500	500	200	1200	391	727	104	1222

#### Table 3. Targeted and achieved sample size by sampling strategy and province

Details of each of the sampling strategies are presented below:



#### Two-Stage Stratified Random Sampling (N=1118):

Approximately 1,000 of the 1,200 PLHIV participants were aimed to be selected utilizing the two-stage stratified random sampling procedure, with roughly equal sample sizes sought between the two methods. PLHIV interviewers invited potential participants in person at selected ART clinics or by phone by collaborating with the Catholic Relief Services who facilitated the initiation of contact based on contact information for ART users lists available to Catholic Relief Services (CRS). In total, the survey reached 1,118 PLHIV participants through the two-stage stratified random sampling methods, slightly higher than the anticipated target. As noted above, the survey utilized two approaches under this method:

#### 1. ART client list-based selection:

The survey collaborated with the Catholic Relief Services Cambodia to employ the client listbased selection procedure. CRS, as the principal ART service delivery partner for care and support in Cambodia facilitated contacts between the survey team and PLHIV under this procedure utilizing the ART user client lists that they have compiled for all survey provinces. In order to ensure that proper procedures and protocols were followed in utilizing these lists, the NAA, on behalf of the survey, made an official request to CRS for ART client lists which contained only information on names, addresses, and contact information of clients. All other information was removed prior to utilization for sample selection. In collaboration with CRS, NAA provided the six randomized client lists to Community Action Approach (CAA) workers, who are non-medical health service providers that stationed in selected ART clinics in each province, who made initial contacts to PLHIV regarding the survey. CAA workers made initial phone calls to randomly selected clients from the ART client lists facilitated by CRS. If contacted PLHIV agreed to participate in the survey, a contact was then facilitated with a survey team member for an interview. This procedure was repeated until desired sample sizes in each province, in conjunction with clinicbased selection, was reached. Involvement of CAA workers, who have official/mandated authority in the public health system to have direct communication with ART clients, helped ensure confidentiality and privacy for ART clients before they decided to join the survey. A total of 391 PLHIV were recruited using this methodology.

#### 2. ART clinic-based selection:

In conjunction with the selection based on ART client lists, ART-clinic based (or site-based) selection was also employed to reach targeted sample sizes in the six survey provinces. ART clinics were considered to have an environment where PLHIV feel relatively at ease to disclose their eligibility to participate in the survey. CAA workers, who had established relationships with ART clients had initial face-to-face interactions with walk-in clients to explore their interest in the survey. If clients expressed interest in participation in the survey, clients were referred to the research team on site, who then explained details of the survey and set up interview appointments. CAA workers continued to interact with walk-in ART clients for a period of one month or until the desired sample size was reached under this methodology. A total of 727 PLHIV were recruited for the survey using this methodology.



#### Snowball Sampling (N=104):

To ensure that a broader range of PLHIV were reached beyond those who are on treatment or are members of networks and support groups, the survey utilized a snow-ball sampling technique for a smaller proportion of the total sample size, initially aiming to reach approximately 200 PLHIV participants. The snowball sampling technique involved research team members and CAA workers who were involved in recruitment of the sample utilizing the site-based and list-based sampling methodologies asking participants to refer the survey team to peers who may meet the aforementioned criteria, including those who had been lost to follow up. In total, the survey reached a smaller proportion of PLHIV using this technique than anticipated, with a total of 104 PLHIV participants being recruited through snowball sampling.

# 3.2 Data Collection

### **Recruitment and training of data collectors**

The data collection team of 36 PLHIV was recruited by CPN+ to conduct the data collection for the survey, which were divided into six teams and included six supervisors. Data collection teams participated in a 4-day training session in two batches. The first was conducted in Siem Reap province for the three northern provinces of Siem Reap, Battambang and Banteay Meanchey and the second for the provinces adjacent to the capital in Phnom Penh for three provinces of Phnom Penh, Kandal and Kampong Cham. The research team participated in training that comprised of research ethics, data collection techniques, gender, sexuality, and other sensitive topics, as well as working with PLHIV and key populations. The survey team were trained on the Stigma Index 2.0 tool itself. Trainings were held between December 2018 and January 2019 and led by the Population Council, NAA, CPN+, and FHI360 LINKAGES.

### **Data collection**

A cross-sectional quantitative data collection methodology was used to implement the updated PLHIV Stigma Index questionnaire including single-choice and multiple-choice questions covering the following domains: 1) Socio-demographic information; 2) Experience of stigma and discrimination due to living with HIV; 3) Experience of stigma and discrimination due to identity, sexual orientation, or behavior; 4) Disclosure of HIV status; 5) Internalized stigma and resilience due to living with HIV; 6) Interactions with healthcare services; and 7) Human rights and effecting change.

Limited qualitative data was also collected in the form of a single open-ended question at the end of the PLHIV Stigma Index 2.0 questionnaire. This question asked all respondents to describe a scenario in which s/he or a spouse/partner, family member, or friend experienced stigma or discrimination related to living with HIV.



### **Translations**

All data collection instruments were translated into Khmer before conducting the survey. In order to ensure the accuracy of translation, translated Khmer tools were back translated into English, and pre-tested prior to being utilized in the target population. The National Advisory Group, the Population Council, NAA and CPN+ ensured that the translation was accurate. The PLHIV Stigma Index 2.0 tool and informed consent form (ICF) was translated into Khmer by local translators who have extensive experience translating HIV/AIDS related materials and questionnaires. The Khmer versions of the Stigma Index 2.0 tool and ICF were also reviewed by the Population Council research team together with technical staff of CPN+, NAA, FHI360 LINKAGES, and UNAIDS Cambodia to ensure cultural appropriateness of questions and accuracy of translation.

#### **Interview procedures**

Each participant completed an approximately one hour-long Stigma Index interview. Informed consent procedures were implemented prior to the interview and only participants who provided consent participated in the survey. Participants completed the interview in sites that were identified prior to data collection and where privacy was ensured. The peer-interviewers administered the survey questionnaire with each participant individually. Participants could pause or stop the interview and leave the interview room at any time for any reason. The "side-by-side" interviewing technique was used in the data collection with the interviewer and the respondent sitting next to each other.

### Use of mobile electronic devices in data collection

Data were collected on the finalized version of the Stigma Index 2.0 questionnaire, loaded on an electronic mobile device—an Android tablet—using the Open Data Kit (ODK) platform. The use of mobile devices for data collection enabled data collectors to directly enter data into Android tablets in the field. Data were transmitted to a secure server over a cellular or Wi-Fi network. The questionnaire was administered by the peer-interviewers who recorded answers and took notes of the narratives on the electronic forms. CPN+, as well as the Population Council research team and FHI360 LINKAGES based in Phnom Penh, provided ongoing data monitoring and quality assurance jointly.

# 3.3 Risks and Benefits

The questions in the Stigma Index 2.0 involved participants' personal experiences related to stigma and discrimination. During the interview, participants may have felt uncomfortable or distressed while discussing some of the survey topics such as stigma, harassment, sexual assault, and HIV status. There was some risk of involuntary HIV status disclosure if participant confidentiality and privacy was breached (if, for example, a participant was seen participating in this survey). To minimize the potential psychological risk, all interviewers (who are also PLHIV) were provided



with sensitivity training on these topics. If any participant required additional counseling, s/he was referred to health care, social support, and/or legal services available in the community. Each of the interviewers were given a list of agencies available in the municipalities in which they are conducting interviews to refer participants, as needed.

There were no direct benefits to the participants; however, being provided with referrals may have been helpful for participants who needed support but were not been accessing services. As mentioned, to minimize risks a list of providers including physical addresses, contact information, and telephone numbers for health services, legal services, counseling, or support groups was created and given to interviewers to provide referrals to participants who requested a referral during the interview. Participants may have felt a sense of pride participating in a survey that has the potential to improve policies and practices to reduce stigma and discrimination among PLHIV in Cambodia and elsewhere. Interviewers benefited from the training and experience conducting the research.

# **3.4 Confidentiality**

In order to ensure confidentiality for participants in the survey, no personal identifiers were collected during recruitment or participation. In addition, potential participants' contact information was not recorded. Data were kept on a secure server with no personal identifiers. To reduce the potential breach of privacy and confidentiality, all survey staff were required to receive ethics training and be committed to maintaining the confidentiality throughout and after their interaction with the potential participants. Similarly, all survey locations were in private settings. In the preparatory process of the research project, PLHIV interviewers and community members identified appropriate locations where interviews could be conducted with visual and auditory privacy.

# 3.5 Informed Consent Process

All participants went through an informed consent process before participating in the Stigma Index 2.0 and were only interviewed if they provided consent. As part of the informed consent process, PLHIV interviewers introduced the survey and clearly explained the details of the procedure, risks, benefits and assurances related to privacy and confidentiality and other ethical concerns. Interviewers also answered any questions raised by potential survey participants. The consent script, translated to Khmer from English by translators with extensive knowledge of HIV/AIDS, was utilized to ensure appropriateness of the descriptions of and ethical considerations of the survey. Participants who agreed to participate in the survey provided written consent by signing the informed consent form.



# 4. Research Findings

# 4.1 Respondent Characteristics

## Socio-demographic characteristics

The average age of the 1,222 total respondents was 45 years (Table 4). Sixty-one percent were female (n=746) and 39 percent were male (n=476). Kampong Cham had the highest proportion of women (71 percent) and Banteay Meanchey had the lowest proportion of women (55 percent). Only one respondent identified as transgender. Thirty-seven percent of respondents were from Phnom Penh (n=454), 16 percent were from Siem Reap (n=190), 16 percent were from Battambang (n=195), 11 percent were from Banteay Meanchey (n=139), 10 percent were from Kandal (n=125) and 10 percent were from Kampong Cham (n=119).

	% (n)
Average age (Range, Std. Dev.)	45 (18-80; 10)
Sex at birth	
Female	61 (746)
Male	39 (476)
Gender Identity	
Female	61 (744)
Male	39 (474)
Transgender	0.08 (1)
Do not identify	0.16 (2)
Prefer not to answer	0.08 (1)
Province	
Phnom Penh	37 (454)
Siem Reap	16 (190)
Battambang	16 (195)
Banteay Meanchey	11 (139)
Kandal	10 (125)
Kampong Cham	10 (119)

#### Table 4. Socio-demographic characteristics (N=1222)



# **Relationships and children**

Approximately half of all respondents reported currently being in an intimate relationship (52 percent; n=637) (Table 5). Of those, 57 percent reported that their partner was living with HIV (n=363). Forty percent of all respondents reported currently not taking care of any children (n=490), 31 percent reported currently taking care of one child (n=374), and 29 percent reported currently taking care of two or more children (n=358).

#### Table 5. Couples and children (N=1222)

	% (n)
Currently in an intimate relationship	52 (637)
Partner living with HIV	57 (363)
Number of children currently taking care of (under 18 years old) 0 1 2+	40 (490) 31 (374) 29 (358)

### **Education and employment**

One third of all respondents had secondary education or more (n=408) compared to two-thirds who had primary education or less (n=814) (Table 6). Thirty-two percent of respondents were unemployed (n=386). Thirty-three percent of respondents were doing casual or part-time work, and 34 percent were employed full time (11 percent were employees and 23 percent were self-employed).

#### Table 6. Education and employment status (N=1222)

	% (n)
Highest level of formal education	
Primary or less	66.6 (814)
Secondary or more	33.4 (408)
Employment status	
Full time (as an employee)	10.6 (129)
Part time (as an employee)	1.8 (22)
Full time (self-employed)	23.3 (285)
Doing casual or part-time	32.7 (400)
Unemployed	31.6 (386)



## **Identities**

Among those whose gender identity was male (n=474), 2 percent identified as MSM (n=9), less than 1 percent identified as gay/homosexual (n=3), and less than 1 percent identified as bisexual (n=3).

Six percent of respondents identified as a member of a racial, ethnic, or religious minority (n=70), six percent identified as migrant workers (n=72), and five percent identified as living with a disability (n=66). Smaller percentages of respondents identified as members of an indigenous/aboriginal group, refugees or asylum seekers, internally displaced persons, or experienced incarceration/in prison before.

	% (n)
Member of a racial, ethnic, or religious minority	5.7 (70)
Member of an Indigenous/ Aboriginal group	2.6 (32)
Living with a disability	5.4 (66)
Refugee or asylum seeker	3.2 (39)
Migrant worker	5.9 (72)
Internally displaced person	3 (36)
Experienced incarceration/in prison before	1.4 (17)

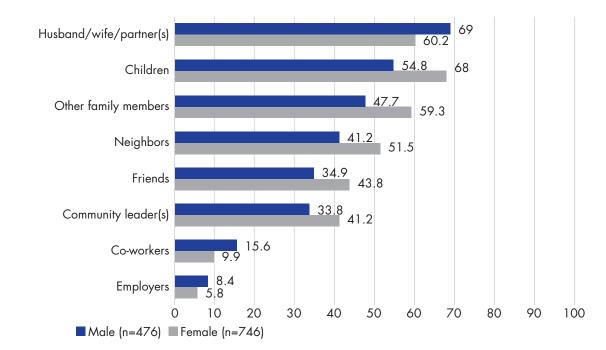
#### Table 7. Group identity (N=1222)

# 4.2 HIV Status Disclosure

Among those who could remember how long they have known their HIV status (68 percent of the total), respondents reported knowing their HIV status for 10 years, on average. Female respondents have known their HIV status for slightly longer than male respondents (11.3 vs. 10.1 years). Respondents in Phnom Penh reported knowing their status for relatively longer than respondents from other provinces. In Siem Reap, respondents knew of their status for 5 years, on average.

Overall, disclosure was most common to husband/wife/partners, children, and other family members, and disclosure was more common among women than men (Figure 1). Across the six provinces, more than 50 percent of respondents disclosed their status to their partner and children. Kandal had the highest rate of disclosure to partners (78 percent) and children (82 percent). Disclosure was least common to employers, coworkers, community leaders, friends, and neighbors. Disclosure was reported to have become easier over time for 70 percent of the sample, with similar findings by sex and across provinces.



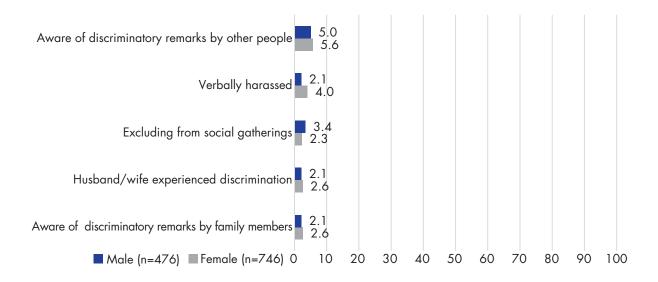


#### Figure 1. Disclosure of HIV status (N=1222)

# 4.3 External Stigma and Discrimination

Most respondents across provinces reported having never or minimally experienced external stigma and discrimination. The most common experience of external stigma was discriminatory remarks by other people—5 percent for men and 6 percent for women (Figure 2). Across provinces, respondents from Kandal reported relatively higher levels of stigma and discrimination, although overall stigma and discrimination in the province remained low.

Figure 2. Experiences of external stigma and discrimination (N=1222)



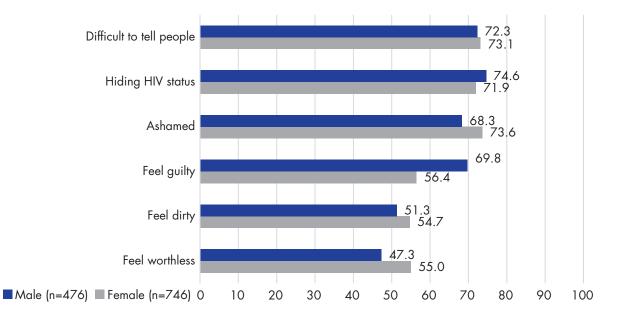


# 4.4 Internalized Stigma and Resilience

### Internalized stigma

Internalized stigma was very high among respondents from all six provinces. Seventy-five percent of men and 72 percent of women reported that they hide their HIV status from others (Figure 3). Seventy-two percent of men and 73 percent of women reported that it is difficult to tell people about their HIV infection. Women reported higher levels of shame and feelings of worthlessness, while men reported higher levels of guilt.

There were some differences in internalized stigma by province. Respondents from Siem Reap reported the highest proportions of internalized stigma followed by Battambang. For example, 82 percent of respondents from Siem Reap found it difficult to disclose their status compared to the average of 73 percent across all six provinces. Also, 86 percent of respondents from Battambang felt ashamed that they are HIV positive compared to the average of 72 percent across all six provinces.



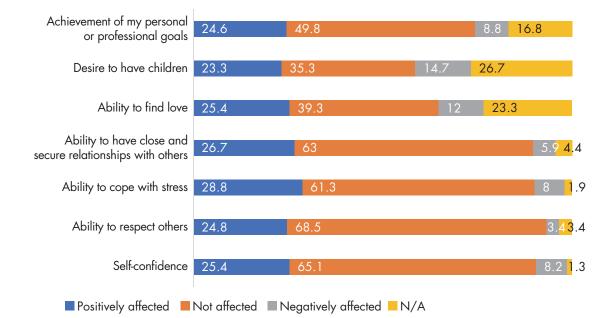
#### Figure 3. Internalized stigma (N=1222)

#### Resilience

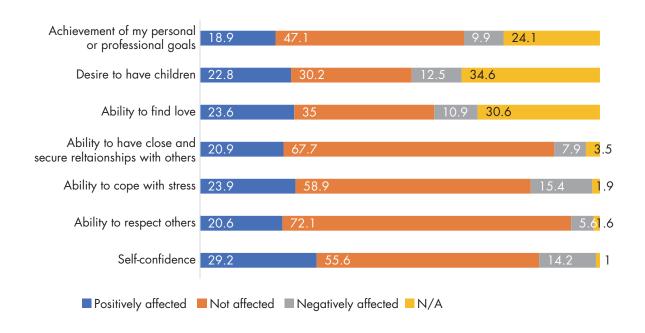
Respondents were asked how their HIV status has affected their desires and abilities. Responses in which desires and abilities were "positively affected" by knowing their HIV status represents resilience. Among men, the ability to cope with stress was the aspect with the greatest proportion of respondents (29 percent) who answered that this aspect was positively affected by their HIV status (Figure 4). Among women, self-confidence was the aspect with the greatest proportion of respondents (29 percent) who believed it was positively affected (Figure 5).



#### Figure 4. Resilience among men (n=476)



#### Figure 5. Resilience among women (n=746)



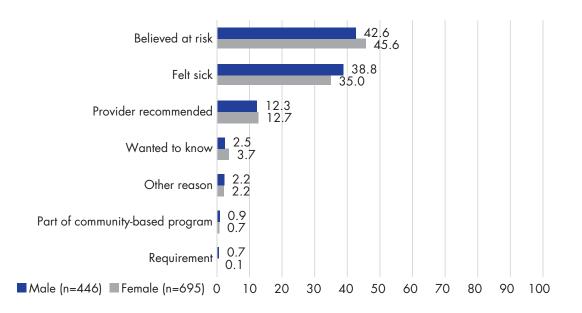


# 4.5 HIV Testing, Care, and Treatment, and Viral Suppression

#### **HIV testing**

Ninety three percent of respondents tested for HIV by their own choice (n=1141), with no differences by sex. Of the six provinces, Phnom Penh had the highest proportion of respondents who tested by their own choice (98 percent). Approximately half of respondents said that fears about how others would respond if they tested positive made them hesitate to get tested for HIV, with no differences between men and women.

Among those who had been tested by their own choice (n=1141), the most common reason for getting an HIV test was that respondents believed they were at risk (43 percent of men and 46 percent of women) (Figure 6). The second most common reason was that the respondent felt sick and the third most common reason was that a provider recommended an HIV test. Higher proportions of respondents from Battambang and Kandal reported self-perception of risk and feeling sick as the most common reasons for taking an HIV test.

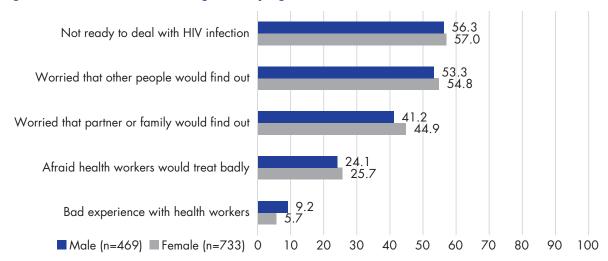


#### Figure 6. Reason for taking HIV test (n=1141)

#### **HIV care and treatment**

Not all respondents started taking HIV care and treatment right after being diagnosed with HIV. The top reasons for delaying treatment were not being ready to cope with their HIV infection and worried that other people would find out (Figure 7). A small proportion of respondents reported bad experiences with health workers, with higher proportions of men reporting so compared to women (9 percent vs. 6 percent, respectively) as a reason for delaying their HIV care and treatment.



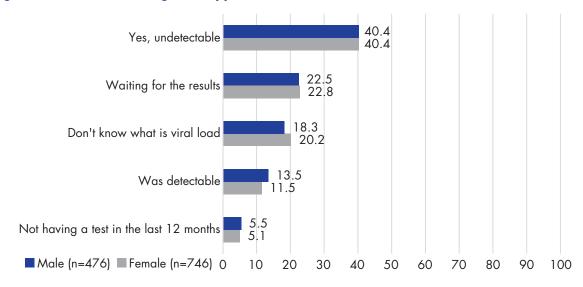


#### Figure 7. Reasons for hesitating or delaying HIV care and treatment (n=1202)<sup>2</sup>

#### **Viral suppression**

Of all respondents, 40 percent reported being virally suppressed within the last 12 months with an undetectable viral load (Figure 8). There were no differences between men and women. Nearly one quarter of respondents reported that they were waiting for their results. Approximately 20 percent of respondents did not know the meaning of viral load testing or suppression. Siem Reap had the highest proportion of respondents reporting undetectable viral load (72 percent), followed by Banteay Meanchey (47 percent) and Kampong Cham (46 percent). However, Battambang had the highest proportion of respondents reported waiting for the results of testing (56 percent). Kandal had the highest proportion of respondents not knowing what viral load or viral suppression are (36 percent).

#### Figure 8. Viral load testing and suppression within the last 12 months (N=1222)



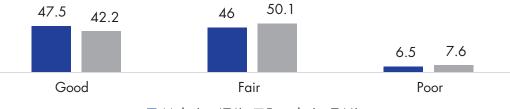
<sup>2</sup> Those who said they were born with HIV or acquired HIV in infancy/childhood and were not aware they had been tested were not asked these questions (n=20).



# 4.6 General Health Status and Other Health Conditions

Overall, most respondents reported their health to be good or fair (Figure 9). Only 7 percent of respondents reported poor health.

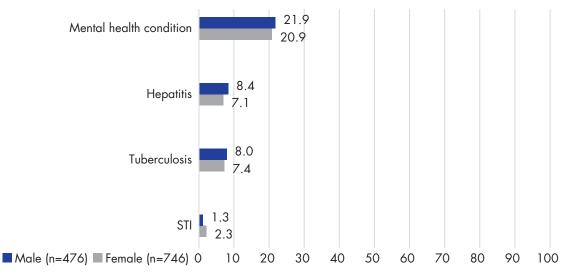




■ Male (n=476) ■ Female (n=746)

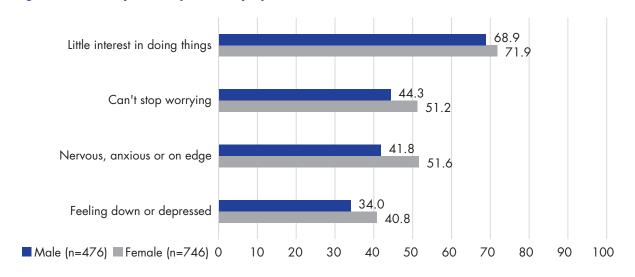
In the last 12 months, approximately 20 percent of respondents had been diagnosed with a mental health condition (e.g. anxiety, depression, insomnia) (Figure 10). Additionally, about 8 percent had been diagnosed with hepatitis or tuberculosis. Very few respondents were diagnosed with a sexually transmitted infection. Overall, less than half of respondents who had a diagnosis of at least one of these four diseases reported that they had treatment for these health problems.

#### Figure 10. Diagnosis of other health conditions in the last 12 months (N=1222)



A much greater proportion of respondents from Banteay Meanchey had been diagnosed with tuberculosis (35 percent) or hepatitis (28 percent) in the last year. A slightly lower proportion of respondents from Phnom Penh were diagnosed with a mental health condition in the last year (23 percent). Respondents self-assessed anxiety and depressive symptoms in the last two weeks. A high proportion of respondents reported little interest in doing things (69 percent of men and 72 percent of women) (Figure 11). Approximately half of respondents reported anxiety symptoms—can't stop worrying and nervous, anxious or on edge. Overall, a greater proportion of women reported anxiety and depressive symptoms than men. Larger proportions of respondents from Kandal and Battambang had symptoms of anxiety and depression.





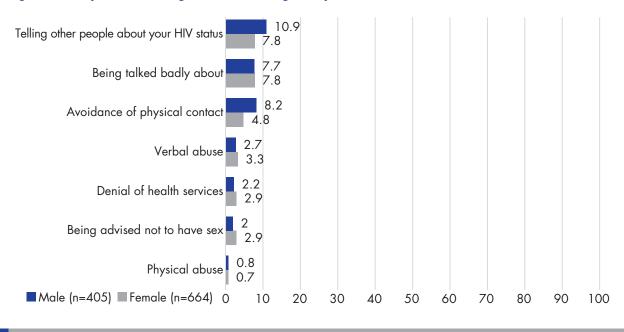
#### Figure 11. Anxiety and depressive symptoms in the last 2 weeks (N=1222)

Overall, 76 percent of those who had symptoms of anxiety and depression did not receive any type of support. An even greater proportion of respondents from Phnom Penh (89 percent) and Battambang (86 percent) reported not receiving support for their symptoms.

# 4.7 Healthcare Stigma

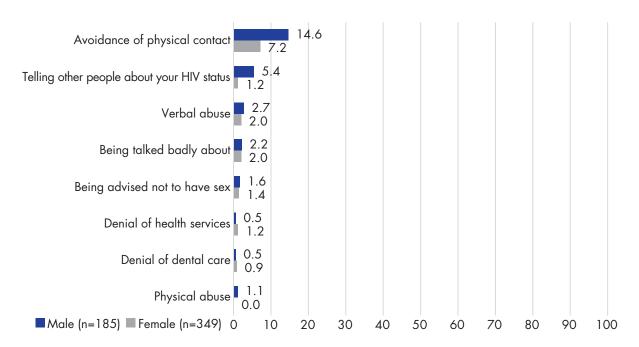
Among those who sought HIV-specific healthcare within the last 12 months (n=1069), there were low levels of experiences of healthcare stigma. However, 11 percent of men and 8 percent of women reported that health facility staff disclosed their HIV status to others without their consent (Figure 12). Almost 8 percent of respondents (same for both men and women) reported being spoken badly about or gossiped about because of their HIV status. More men reported avoidance of physical contact by facility staff compared to women (8 percent vs. 5 percent, respectively).

#### Figure 12. Experiences of stigma when seeking HIV-specific healthcare in the last 12 months (n=1069)





Among those who sought non-HIV related healthcare within the last 12 months (n=534), there were also low levels of experiences of healthcare stigma in general. However, instances of healthcare staff avoiding physical contact with PLHIV clients (9.7 percent), particularly for male clients compared to female clients, followed by healthcare staff disclosing clients' HIV status to others without consent (2.6 percent) were observed.



#### Figure 13. Experience when seeking non HIV-specific health care within the last 12 months (n=534)

Low levels of stigma and discrimination were reported when accessing sexual and reproductive healthcare across gender and provinces.

## 4.8 Human Rights and Effecting Change

Thirty-four percent (34 percent) of women and 30 percent of men did not know that there are laws for protecting PLHIV from discrimination, while 5 percent of women and 3 percent of men said there are no laws at all. Very few respondents reported being forced to get an HIV test in order to obtain a visa, apply for a job, attend an educational institution, get healthcare, or get medical insurance. The main reason for not trying to affect positive changes in their community was that respondents did not know where to go or how to take action. Most respondents did not challenge or participate in activities supporting PLHIV.

# 4.9 Stigma and Discrimination Experienced for Reasons other than HIV Status

Eight respondents from our total sample identified themselves as transgender, non-gender binary, or as people who were assigned a gender on their original birth certificate that does not match



their current gender identity. Among respondents who currently identified themselves as male (n=474), 15 respondents identified themselves as currently or previously a member of a key population group, which included MSM (9 respondents), gay/homosexual (3 respondents), and bisexual (3 respondents). Among respondents who currently identified themselves as female (n=745), six respondents identified themselves as currently or previously a member of a key population group, which included women who have sex with women (1 respondent), gay/ lesbian (4 respondent), and bisexual (1 respondent). Among this small sample of respondents, there was no report of stigma and discrimination for reasons other than HIV status during the last 12 months.

## **4.10 Social Protection Scheme**

Of 1,032 respondents,<sup>3</sup> nearly half are covered, or their family members are covered, by any social health protection scheme (47 percent). Of those, 69 percent are covered by the health equity fund; 54 percent have Equity Cards obtained through the ID poor program; and 48 percent are covered by both health equity fund and ID poor programs. Of those with Equity Cards, 93 percent said that their cards were issued in their communities/at home (pre-ID poor), and another 7 percent had their cards issued at health facilities (post-ID poor).

<sup>3</sup> Due to data entry errors, all respondents from Siem Reap had to be excluded from this analysis, hence the smaller total N.



# 5. Additional Analysis on Stigma

# 5.1 Comparison of Stigma Index 1.0 and 2.0

Results of the Stigma Index 1.0 and 2.0 on external and internalized stigma are not directly comparable due to design differences in the questionnaires between the surveys in terms of topics of the questions and how the questions were asked. The Stigma Index 1.0 and 2.0 did not have same sets of questions, and in Cambodia, were fielded utilizing different sampling techniques and sizes and in overlap only in three of the six provinces covered in the 2019 study. Thus, one-to-one comparisons were not possible.

Similar questions were fielded differently in each survey. The Stigma Index 1.0 first asked respondents if they had ever experienced certain forms of stigma and discrimination. Only if respondents answered "yes", a follow-up question was then asked if it was because of respondent's HIV status or due to other reasons. This design rendered the sample size of those who responded to questions on stigma and discrimination specifically due to HIV status to be much smaller than the total sample size. On the contrary, the Stigma Index 2.0 asked all respondents directly if they ever experienced certain forms of stigma and discrimination due to their HIV status, making the total number of respondents answering these questions the same as the total sample size of the survey – a figure much larger than in Stigma Index 1.0. The proportions expressed in the respective survey summaries, however, take into account the different sample sizes in each.

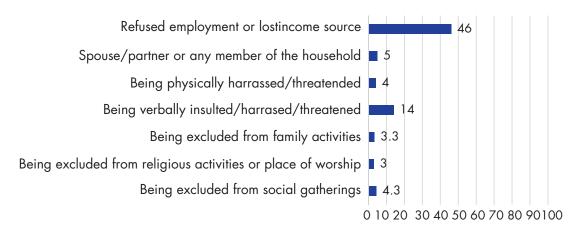
For external stigma and discrimination, results from seven questions that were asked in both the Stigma Index 1.0 and 2.0 are presented taking into account the differing sample sizes in Figure 14. Notably, in the 2019 survey, 2 percent of participants reported that they were refused employment or lost their income due to their HIV status and 3 percent reported being verbally insulted or harassed. In 2010, on the questions regarding discrimination related to employment or lost income and verbal harassment, the figures were 46 percent and 14 percent respectively. Only small proportions of participants in the Stigma Index 2.0 (2019) reported experiencing physical harassment, spouse/partner discrimination, exclusion from family activities, exclusion from religious activities, and exclusion from social gatherings due to their HIV status. On similar measures in the Stigma Index 1.0 study in 2010, these figures were similarly low.

For internalized stigma, results from 10 questions that were asked in both the Stigma Index 1.0 and 2.0 studies are presented in Figure 15 with the same considerations regarding sample size as noted above for external stigma (Figure 15). In 2019, respondents' reports of experience of internalized stigma, in particular on three measures: feelings of worthlessness, guilt and shame about being HIV positive were considerably high. On a similar set of measures in the 2010 survey, reports of experience of internalized stigma was observed to be significantly high on five measures including those related to feeling of worthless, guilt, shame about being HIV positive, and desire to have children or low self-confidence.

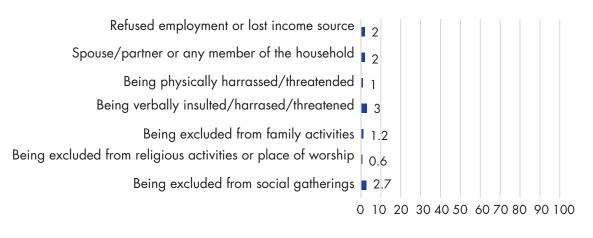


#### Figure 14. Experiences of external stigma reported in Stigma Index 1.0 and 2.0

#### External Stigma in Stigma Index 1.0 2010 (%) (N=397)



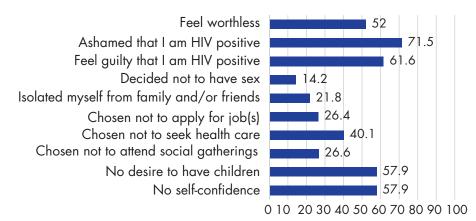
#### External Stigma in Stigma Index 2.0 2019 (%) (N=1222)



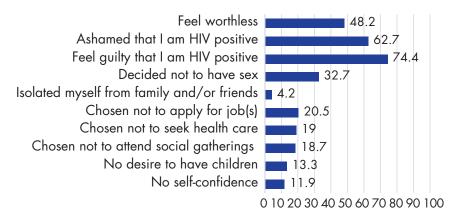


#### Figure 15. Experiences of internalized stigma reported in Stigma Index 1.0 and 2.0

#### Internalized Stigma in Stigma Index 1.0 2010 (%) (N=394)



#### Internalized Stigma in Stigma Index 2.0 2019 (%) (N=1222)





## 5.2 Stigma Indices by Different Socio-Demographic Groups

In an additional set of analyses, three additive indices/scales were used to measure different types of stigma: experiences of external stigma and discrimination (11 items; Alpha=0.82) and resilience (10 items; Alpha=0.81), and internalized stigma (6 items; Alpha=0.80). Results from Cronbach's Alpha test for internal consistency suggests good reliability for each of the four scales. Kruskal-Wallis H tests were used to compare the scales by socio-demographic characteristics and sampling method, and scale means are highlighted below.

### External stigma and discrimination index

The external stigma and discrimination index adds up all "yes" responses to questions on experience of external stigma and discrimination. Thus, a lower value on this index represents a lower experience of external stigma and discrimination. Results of Kruskal-Wallis H tests showed that there were significant differences in mean value of the external stigma and discrimination index by sampling method (p=0.017) and education level (p=0.003).

- Among the three sampling methods, mean value of the external stigma and discrimination index was highest among clinic-based sample (0.28), then those recruited by snowball sampling (0.24), then those recruited through list-based sampling (0.15).
- Mean value of the external stigma and discrimination index was higher among those with primary or less education compared to those with secondary or more (0.28 vs. 0.14, respectively).

### **Resilience index**

The Resilience Index similarly adds up all "positively affected by HIV status" responses to all questions on resilience. Thus, a higher value of the index represents higher resilience or ability of the respondent to cope with their HIV status and fulfill their own needs. Results of Kruskal-Wallis H tests showed that there were significant differences in mean value of the resilience index by education level (p=0.002) and duration of known positive HIV status (p=0.022).

- Those with primary or less education had higher mean value of the resilience index than those with secondary or more education (0.94 vs. 0.75).
- Those who knew their positive HIV status more than 10 years had the greatest mean value of the resilience index (1.02). The next highest mean value of resilience index was among those who knew their positive HIV status 1–4 years (0.95) and 5–9 years (0.69). The lowest mean value of resilience index was among those who knew their HIV status less than one year (0.33).



#### Internalized stigma index

The internalized stigma index added up all "yes" responses to internalized stigma. Thus, a lower value on the index represents a lower level of experience of internalized stigma among respondents. Results of Kruskal-Wallis H tests show that there were significant differences in mean value of internalized stigma index by age group (p=0.008), duration of known status (p<0.001), education level (p=0.042), intimate relationship status (p<0.001), perceived ease of disclosing HIV status (p<0.001), knowledge of laws for PLHIV (p<0.001), and health coverage under a social health protection scheme (p<0.001).

- Those aged 28–32 had the highest mean value of the internalized stigma index (4.70) followed by those aged 33–37 (4.29). Those with the lowest mean value of the internalized stigma index were ages 48–52 (3.6).
- Those who knew their HIV status less than one year had the highest mean value on internalized stigma index (4.67) and those who knew their HIV status more than 10 years had the lowest mean value (3.48).
- Those with primary education or less had higher mean value of internalized stigma index scores than those with secondary or more (3.93 vs. 3.68, respectively).
- Those who were currently in an intimate relationship had a higher mean on internalized stigma index than those who were not in a relationship (4.05 vs. 3.62, respectively).
- Those who agreed or somewhat agreed that they had ease in disclosing their HIV status had lower mean internalized stigma index score compared to those who disagreed (3.57 vs. 3.96 vs. 4.53, respectively).
- Those who knew that there were laws protecting PLHIV had lower mean value on internalized stigma index than those who thought there were no laws and those who did not know (3.67 vs. 4.0 vs. 4.16, respectively).
- Finally, those who were covered under a social health protection scheme had a lower mean value on internalized stigma index compared to those who were not (3.46 vs. 4.12, respectively).



# 6. Discussion

This section discusses three specific quantitative results of the current survey in further detail: (1) external stigma and discrimination; (2) internalized stigma; and (3) viral load detection and suppression. The results are discussed in light of inputs from stakeholders participating in the six provincial interpretation workshops and the third National Advisory Committee meeting.

## 6.1 External Stigma and Discrimination

The level of external stigma and discrimination observed in the current survey shows that external discrimination experienced by PLHIV communities in the six provinces is very low. This observation might not be unusual, as evidence emerging from other countries (e.g., PLHIV Stigma Index 2.0 in the Dominican Republic) has observed similar results showing high levels of internal stigma among PLHIV while external discrimination was low. However, in Cambodia, together with the finding of low external discrimination, the current survey also reported relatively low rates of disclosure of HIV status, especially to non-family members. These findings have led to a concern that the low prevalence of reported external discrimination could be associated with the low disclosure rate of HIV status, rather than evidence of changing public stigma towards PLHIV.

The various discussions in the six provincial interpretation workshops and the NAC meeting suggest that this concern warrants further investigation. The low disclosure rate might be a reflection of the changing support environment for PLHIV. In the past, PLHIV communities possibly saw a stronger need to disclose their HIV status in order to be eligible for various schemes of social support. However, PLHIV now receive less social support but more clinical support at ART clinics, reducing their need to disclose their HIV status to people in other spheres of life. Although the finding on reduced external discrimination in the survey provinces was highly supported at the provincial interpretation workshops, there was also a strongly expressed belief in the existence of external stigma, or the fear that external stigma is still present for some PLHIV. Community-based HIV education for both PLHIV and non-PLHIV was similarly recommended across the provincial workshops as a mean to reduce external stigma. Therefore, taking into account the prevalent fear of external stigma and that non-disclosure reduces the risk of exposure to external discrimination, whether the low reported rate of external discrimination is evidence of changing external stigma towards PLHIV or due to low disclosure rate remains unclear.

## 6.2 Internalized Stigma

The level of internalized stigma was observed at very high levels in the current survey. PLHIV representatives in the six provincial interpretation workshops supported the finding of a high prevalence of internalized stigma, especially internalized stigma, in their communities. The reduction in community-based HIV sensitization activities, self-help/peer support groups, and home-based care was noted as one of the causes, since it disconnected PLHIV from the broader community and the needed social and emotional support that can help keep them motivated in life.



Moreover, the survey results and the resulting discussions at the interpretation workshops revealed that it was common among PLHIV to not be aware that an undetectable viral load also meant that they could not transmit the HIV virus. This lack of understanding appears to contribute to the high levels of self-stigma, as survey results indicated high proportions of PLHIV noting that they "feel that they are dirty" or reports of high levels of guilt.

The results of bivariate analyses between internalized stigma and socio-demographic factors show that the ability to meet various needs in life was associated with duration of known HIV status, as well as levels of education. Similarly, the level of self-stigma was different among PLHIV with different backgrounds in terms of age, duration of known HIV status, education level, having an intimate relationship, perceived ease of disclosing HIV status, knowledge of AIDS law, and experience receiving the social health protection schemes. As expected, those who have known their status for the longest, were older and had higher levels of education, knew about laws protecting PLHIV, and felt ease in disclosing their HIV status had lower levels of self-stigma. On the other hand, PLHIV who were in intimate relationships, were younger and those recently diagnosed had higher levels. These results suggest that the continued prevalence of self-stigma among PLHIV is a complex issue that depends on many socio-demographic factors. In order to develop programs and policies that can effectively reduce self-stigma among PLHIV, these issues warrant further rigorous investigation utilizing multivariate analyses, which allow for examining specific associations while controlling for confounding effects.

## 6.3 Viral Load Detection and Suppression

Survey results indicated that there continues to be a lack of clear understanding of viral load testing and viral load suppression. First of all, a sizeable proportion of the sample, close to one-fifth of respondents, reported that they did not know the meaning of viral load suppression. During the provincial interpretation workshops, discussions indicated among PLHIV who are aware of viral load testing and viral load suppression that there may be some misunderstanding among some PLHIV that an undetectable viral load indicates they are cured of HIV. Participants noted that this misunderstanding may lead to PLHIV dropping out of treatment and disconnecting from HIV support networks, raising risks of elevated viral loads after having left treatment as well as lack of social supports. Moreover, this misunderstanding was noted to possibly lead to rising incidence of sexually transmitted infections and unwanted pregnancy and potentially new HIV infections as a result of risky sexual behaviors. Additionally, as noted above, most PLHIV who participated in the interpretation workshops also were not aware that undetectable viral load levels meant that they could not transmit HIV, which conversely may have implications of perceptions of self-stigma and guilt.



# 7. Recommendations

Based on the results of the PLHIV Stigma Index 2.0 survey, discussions among the NAC and at the six provincial interpretation workshops, several actions were identified as potential strategies to address persistent issues related to stigma and discrimination against PLHIV in Cambodia. These recommendations are discussed below:

## 7.1 Promoting HIV/AIDS Education

- HIV/AIDS education should expand its scope beyond basic information about HIV transmission and prevention. Content should also cover broader and contemporary issues related to HIV including the changing nature of the epidemic, global progress and success in curbing HIV worldwide, law on the control and prevention of HIV/AIDS in Cambodia, viral load detection and suppression, the consequences of dropping ART care and treatment, various forms of stigma and discrimination, and the importance to eliminate stigma and discrimination for PLHIV and society as a whole. These topics should become a part of mainstream education curricula as well as medical training curricula in Cambodia.
- Target audiences of HIV/AIDS education should include both PLHIV and the general public in order to reduce stigma and discrimination that might have become normative due to declining exposure of PLHIV in the community. Improved understanding among the general public in Cambodia that PLHIV can live full, productive lives if they adhere to ART and that the HIV is not transmissible if the viral load is undetectable, may facilitate the reduction of external stigma around HIV/AIDS, which subsequently could lead to reduction in internalized stigma as well.
- Educational activities need to be held in various settings, including communities, health
  facilities, social and mass media platforms, medical training systems, and formal education
  systems. Social and mass media platforms are particularly important to reach not only a
  much wider audience but also those who hide their status. Influencers in social media who
  promote educational activities related to HIV/AIDS and demonstrate solidarity with the PLHIV
  community may help reduce broader external stigma related to HIV/AIDS.

## 7.2 Improving Client-Provider Interaction and Health Service Coverage

• The lack of clear understanding of viral load detection and suppression among PLHIV suggests the need to further improve the quality of client-provider interactions and information exchange at ART sites. HIV healthcare providers may need to use more innovative approaches to explain these concepts, as well as the importance of receiving and adhering to regular ART care and treatment clearly.



- Since there were some reported incidences of involuntary disclosure of HIV status by healthcare staff in healthcare settings, more training might be needed for service providers to provide improved levels of confidentiality as well as ethical and non-judgmental care at facilities.
- Improved client-provider interaction can help address clients' challenges in staying in ART care
  and treatment. For example, providers should continue to communicate with clients at risk of
  migration, particularly in provinces bordering Thailand or Vietnam, during appointments about
  how they can plan their ART treatment if they plan to migrate for work or other reasons. Although
  multi-month prescription of ART drugs remains a topic that is debated, some ART sites have
  already begun implementing the approach as a strategy to keep clients in the health system.
- Combining opportunistic infection, mental health, and ART services together could potentially
  encourage visits to ART sites and reduce internalized stigma and other health issues beyond
  HIV. Low levels of access to needed health supports outside ART sites was reported in the
  current survey, which may have been related to financial and time related costs associated
  with those services.

## 7.3 Providing Community-Based Social Support

- Although some PLHIV continue to choose to hide their status and not use any social support or connection with HIV support networks, providing community support in various forms was repeatedly recommended by stakeholders as a potentially important strategy to reduce internalized stigma.
- The practice of home-based care or peer support groups (e.g., "Friends Helping Friends") was highly appreciated as an effective way to provide needed social and emotional support to PLHIV. These support networks do not exist anymore in Cambodia and a desire for their return was expressed by the PLHIV community and other stakeholders.

## 7.4 Expanding Social Health Protection Support

- Granting Equity Cards through the ID poor program to all PLHIV could potentially help improve their lives in various aspects and could have the potential effect of reducing internalized stigma enabling PLHIV to lead more normal lives. The majority of PLHIV in Cambodia belong to the lowest socio-economic groups and are unemployed. They are also not able to migrate for work easily away from their ART clinics for long periods of time, and they are not able to take on heavy lifting jobs due to their health condition. Thus, access to social protection programs could provide the support that PLHIV need in these spheres in life.
- However, some indications of inconvenience were noted of the use of ID poor cards and Health Equity Funds to seek health services. For example, PLHIV noted long waiting times when seeking services under Health Equity Funds. Furthermore, risks of accidental disclosure was heightened due to the need of various paperwork requirements and the requirement of utilizing Wing Agents for reimbursement of travel costs.



# 8. Lessons Learned: The Implementation of the PLHIV Stigma Index 2.0 Survey

A number of key lessons were learned during the implementation of the PLHIV Stigma Index 2.0 Survey in Cambodia, which may be helpful to consider in implementation of the updated tool in other settings.

- One of the key challenges encountered in implementing the survey was in reaching the desired sample size through list-based sampling through phone calls to potential participants. CAA workers responsible for facilitating participant interviews found it challenging to reach potential participants on the phone and exhausted several randomized lists of clients due to unavailability or non-consent to participate in the survey. When participants were reached, the survey team found it challenging to garner consent from potential participants on the phone because participants were generally hesitant to agree to an interview to someone that they were not familiar with. The survey team noted that in provinces where the calls were made by CAA workers who were familiar to the potential participants and had served in the clinics that they visited, the success rate was higher. In Phnom Penh, where one CAA worker made calls to participants across the province, including those seeking services at ART clinics that they did not serve, this was more difficult. A key lesson learned was that if list-based sampling is to be conducted via phone call, success will depend on the familiarity and prior history between the caller (typically a service provider) and the potential participant. Success is unlikely if the participant is not familiar with the caller.
- Due to the challenges in reaching the desired sample size from the list-based sampling strategy, the survey team had to readjust the sampling strategy to reach the overall desired sampling size. Through consultative processes, the survey team reached a decision to switch to site/clinic-based sampling in-person in order to reach the final sample sizes in survey provinces (in particular Phnom Penh) where list-based sampling had been the most challenging. The change in strategy led to unanticipated delays in the data collection timeline. The key lesson learned is that the survey team must remain flexible in their sampling strategy in order to reach desired sample sizes within a constrained timeline. Decisions to switch to alternative sampling strategies, however, must be reached only through consultation and agreement from survey stakeholders through detailed discussions and weighing of options available.
- Data collection utilizing tablets and the ODK platform proved to have positive results in terms
  of efficiency of implementing data collection and management of data. A dedicated data
  manager well versed in ODK and tablet-based data collection proved to be critical in making
  the process efficient. The survey team in Phnom Penh received accurate daily updates on
  completed interviews against desired sample sizes, allowing for effective planning of the
  survey through the end of the survey. Data quality checks were easily made within the ODK
  platform and corrective measures taken in a timely manner when needed.



• The provincial interpretation workshops where participation was sought from a range of local stakeholders within provinces, including members of the PLHIV community, was among the most critical aspects of this survey that helped nuanced interpretation of results. A skilled facilitator and a participatory agenda that featured not only presentation of results but also one that sought feedback from participants through group discussions proved to be vital in interpreting results and determining recommendation based on survey results. The lesson learned is that these interpretation workshops should become a routine part of the survey design of future Stigma Index 2.0 efforts.



# 9. Conclusion

The Cambodia PLHIV Stigma Index 2.0 was successfully concluded under the leadership of the PLHIV community and through the guidance of a range of stakeholders in the HIV/AIDS community in Cambodia through a participatory and inclusive process. As one of the first Stigma Index 2.0 studies to be implemented in the world, and the first in Asia, the survey has provided an impetus globally for countries that are preparing to conduct the second iteration of their Stigma Index studies and the learning from the implementation of the survey, the successes and the challenges will provide invaluable learning as the survey begins to be implemented around the world.

The Cambodia PLHIV Stigma Index 2.0 survey has provided a much needed update to the knowledge and understanding of the state of stigma and discrimination faced by the PLHIV community in Cambodia. The survey not only greatly improved upon the coverage and sample size of the previous Stigma Index Survey 1.0 in Cambodia, conducted in 2010, but through the implementation of a more nuanced and updated questionnaire, it has generated evidence that is more useful in light of the state of HIV and AIDS in contemporary times in Cambodia and globally, recognizing the evolution of HIV and the populations, particularly the vulnerable groups, it affects.

Among the many insightful findings of the survey described in this report, the findings that internalized stigma among PLHIV still remains high despite the reports of external stigma are nearly non-existent in the survey provinces in Cambodia, and that PLHIV in Cambodia still continue to face gaps in critical knowledge on HIV, such as on viral load suppression, have been particularly illuminating for the HIV and AIDS community. As discussed above, the results have led to valuable evidence for improving programs and policies related to HIV with recommendations spanning various sectors including improving education and client-provider interactions during service delivery, extending community-based social support and providing social health and other protections to PLHIV in the country. Due to the participatory nature of the survey, which has included the voices of the PLHIV community themselves, following the GIPA principle, and with close engagement of the government, non-governmental organizations and service provision sectors, the evidence that has been generated from the survey has been readily actionable, both from a programmatic and advocacy standpoint. The recommendations set forth in this report are a result of discussions and interpretations of survey results by all key stakeholders including the PLHIV communities themselves at the provincial level.

With the successful conclusion of the survey, it is the survey team's hope that the results of this survey will be utilized in developing programs and policies as recommended, and beyond, which meet the needs of the PLHIV population as highlighted in the report in order to support the community in living healthy and productive lives. It is also our hope that the survey sets an example of a best practice for the GIPA principle as well as for a collaborative multi-stakeholder and multi-sector effort to achieve a common goal: to eliminate stigma and discrimination related to HIV and AIDS and to ensure that PLHIV can lead full and productive lives.



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# Appendix: Terms of Reference and Membership of the National Advisory Committee (NAC)

### NATIONAL ADVISORY COMMITTEE THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0

#### I. Background

The People Living with HIV Stigma Index (the PLHIV Stigma Index) is a survey that was developed by the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), International Planned Parenthood Federation, and UNAIDS to generate evidence on and to measure and detect changes in stigma and discrimination experienced by PLHIV that can be used to develop evidence informed advocacy and action against stigma experienced by this vulnerable population. The PLHIV Stigma Index was launched in 2008 and by the end of 2017 had been implemented in nearly 90 countries with over 100,000 PLHIV around the world.

The PLHIV Stigma Index survey was first implemented in Cambodia in 2010 by the Cambodian People Living with HIV Network (CPN+) in collaboration with Khmer HIV/AIDS NGO Alliance (KHANA) with support from UNAIDS.

Shifts in the HIV epidemic, increased evidence on the epidemic and the population groups it affects, and changes in global responses to HIV required that the Stigma Index be updated and strengthened to be a better measurement and advocacy tool. Between 2015 and 2017, the Population Council's Project Supporting Operational AIDS Research (Project SOAR) project and a consortium of partners comprised of representatives from GNP+, ICW, UNAIDS, USAID, and experts in the field assessed and updated the original Stigma Index to develop a strengthened PLHIV Stigma Index 2.0. The PLHIV Stigma Index 2.0 was pilot tested in 2017 in Uganda, Cameroon and Senegal, and based on the results of these pilots, was finalized in December 2017.

Under the leadership and guidance of the National AIDS Authority (NAA), the PLHIV Stigma Index Survey 2.0 will be implemented in Cambodia in 2018-19 by the Population Council, with support from FHI360 LINKAGES/USAID and UNAIDS, in close partnership with Cambodian People Living with HIV Network (CPN+), ARV User's Association (AUA) and the PLHIV and Key Populations communities.



### **II. Goal and Objectives**

The overarching goal of this survey is to document stigma and discrimination experienced by PLHIV, and the causes, the amount, and the effects of stigma and discrimination on them. This survey will enhance the contemporary knowledge on the situation of stigma and discrimination experienced by PLHIV in Cambodia and enhance evidence-based programs and policies to better address PLHIV's needs in priority provinces in Cambodia.

Specific objectives:

- Provide an updated situational analysis of HIV related stigma and discrimination in Cambodia utilizing the Stigma Index 2.0 tool to provide an evidence base for improving policies, programs to better meet the needs of PLHIV in priority provinces.
- Improve evidence-based advocacy on HIV related stigma and discrimination and to ensure that research utilization and evidence based programming and policymaking practices are systematically improved and documented.
- Continue to improve and model the best practice of the greater involvement of PLHIV (GIPA) within the survey to empower and develop capacities of PLHIV.

The Stigma Index 2.0 will be implemented with approximately 1200 PLHIV in six provinces in Cambodia including Phnom Penh, Battambang, Siem Reap, Banteay Meachey, Kampong Cham and Kandal.

### III. Roles of National Advisory Committee (NAC)

The primary role of the NAC is to oversee the Stigma Index 2.0 process and provide guidance on the implementation of the Stigma Index 2.0, including technical, advocacy from inception and preparatory phase to research implementation, dissemination and research utilization phase.

NAC's specific roles:

- To actively participate in stakeholder workshops and National Advisory Committee meetings as convened by the Advisory Committee chair/co-chair;
- To provide technical inputs and guidance during the development, refinement and finalization of survey procedures including research protocol and tools;
- To provide support in the facilitation of approvals and processes with government partners;
- To facilitate and ensure full participation of PLHIV and Key Populations throughout all stages of the implementation process;
- To ensure the ethical treatment of survey participants, confidentiality, informed consent and respect for PLHIV rights;
- To closely monitor and provide guidance during the implementation, including data collection, analysis etc.;



- To provide constructive feedback and advice on interpretation of survey results and to ensure proper contextualization of findings;
- To support and guide on the development of knowledge products and monitoring tools;
- To provide guidance on dissemination and research utilization plans as well as policies and programming advocacy.

### IV. Chairmanship, Secretariat and Membership

The NAC is co-chaired by the Vice Chair of National AIDS Authority (NAA) the National Coordinator of CPN+ and assisted by a secretariat coordinated jointly by FHI360-LINKAGES, UNAIDS and Population Council.

Members of the NAC will comprise representatives from the Cambodian Government, civil societies, bilateral and multilateral agencies and PLHIV and key population networks. Government: NAA and NCHADS, MoLVT, MOSVY, Municipal/Provincial Health Department (MHD/PHD)

#### Development Partners: USAID, UNAIDS, US-CDC

Civil Society:

- Cambodian People Living with HIV/AIDS Network (CPN+)
- ARV Users' Association (AUA)
- Linkages Across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES) Project, FHI360
- Population Council
- Health Action Coordinating Committee (HACC)
- Khmer HIV/AIDS NGO Alliance (KHANA)
- Bandanh Chaktomuk (BC)
- SMARTgirl
- Men's Health Social Service (MHSS)
- Cambodia Network for People Used Drug (CNPUD)
- Reproductive Health Association of Cambodia (RHAC)
- Cambodian Women for Peace and Development (CWPD)
- Catholic Relief Services (CRS)
- Chhouk Sar
- Cambodia Center for Human Rights (CCHR)/Sexual Orientation and Gender Identity (SOGI)



### V. Operating Procedure

- The Chair of NAC convenes meetings on a bi-monthly basis.
- The Chair of NAC can convene ad hoc meetings on specific issues with relevant partners/ stakeholders.
- Ad hoc members or special guests can be invited according to topic to be discussed.
- Small groups can be temporary assigned as necessary to help NAC on detailed technical work.
- The secretariat provides support and facilitates all preparation of NAC meetings and documents key discussion points of each meeting.















