



Term of Reference

# The People Living with HIV STIGMA INDEX INDONESIA



SPIRITIA FOUNDATION

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## **1. EXECUTIVE SUMMARY**

This note outlines the major activities, work plan, and deliverables of the implementation of the PLHIV Stigma Index in Indonesia

It is a collaborative work between Spiritia Foundation, PLHIV Catalyst and Support Group, the Indonesia Network of People Living with HIV/AIDS, and UNAIDS Indonesia. It builds upon work carried out by the Spiritia Foundation supported by The Global Fund.

### **1.1 What we hope to achieve**

Using the PLHIV Stigma Index will:

- Facilitate more effective communication, education and dissemination of knowledge about the laws that protect people living with HIV in Indonesia, so that people living with HIV know their rights.
- Serve as a source of information for developing policy and adopting practical measures related to human rights, confidentiality and testing among vulnerable population groups, including young people.
- Provide us with facts about the successes (or failures) of existing programs (the National AIDS Program, donor programs, etc.) and enable us to see gaps in our work that require further action
- Allow people living with HIV to contribute in a meaningful way to the HIV response by being researchers in the study as well as being interviewees, thereby building capacity and skills.

As a result, the Stigma Index will become an advocacy tool that will help achieve the shared goal of the Indonesian government, non-governmental organizations and activists: to reduce the level of stigma and discrimination associated with HIV, and to improve policies related to advocating the rights and interests of PLWHA in Indonesia with due regard for their actual needs. Overall we hope the results will have an impact on increasing ARV uptake and minimising lost to follow-up rates.

### **1.2 The idea of Implementing in Indonesia**

The idea to implement the PLHIV Stigma Index started in 2017 as part of the NFM Phase funded by The Global Fund. As the guideline revised on mid-2017, all partners agree to postpone the implementation to 2019 and become one of the key activities in Human Rights intervention.

## **2. BACKGROUND**

### **2.1 Why is this work necessary?**

Stigma and discrimination are the biggest obstacles to effective actions against the AIDS epidemic. They prevent governments from recognising the need to take timely steps to fight AIDS and from implementing these steps. They make people afraid to find out their HIV status. Due to stigma and discrimination, people who know that they are infected hesitate to reveal their diagnosis or to seek necessary treatment, care and support. According to many reports, people living with HIV do not seek help until 2-3 years after they diagnosed with HIV. From experience, we know that much of the reluctance to come forward and seek the necessary help and support is due to the stigma that people living with HIV/AIDS feel and experience.

## 2.2 The epidemiology of HIV/AIDS in Indonesia

In Indonesia, adult HIV prevalence remains high, with pronounced social and economic inequity in access to HIV prevention, testing and care services. Prevalence is even higher among key populations, specifically Female Sex Workers (FSW) and Men who have Sex with Men (MSM), due to their high risk of HIV infection and low uptake of HIV testing. Stigma among these groups acts as an additional barrier to accessing facility-based HIV-related services.

Recent HIV epidemic modelling (MoH, 2016)<sup>1</sup> indicates that although generally, the new infection trend is flat, the new infections among MSM people are still growing up until 2030. Figure 1 below depicts that by the year 2030, Indonesia is not heading to ending the epidemic.

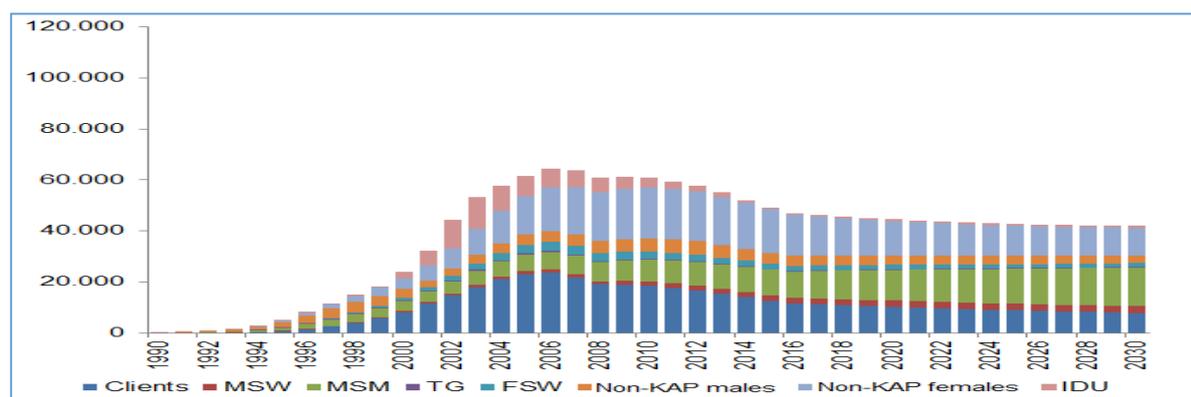


Figure 1: Estimated and Projected Annual Number of New HIV Infections, 1990-2030\*

One of the main obstacles to improving treatment coverage is an insufficient volume and decentralisation of HIV testing. Although the number of HIV tests performed and the number of HIV-positive persons identified continues to increase (see table 1), these numbers fall far short of that needed to reach more aggressive treatment aspirations. Beyond numbers being tested, the available data indicate that positivity rates of HIV testing have been declining (but not for all groups between 2015 and 2016) and tend to be lower than HIV prevalence for KAPs measured in the 2015 IBBS. This may indicate that the highest risk KAPs are not being tested.

Indonesia lags behind other countries in the region concerning ART coverage. While some success has been achieved in increasing the number of persons on ART reaching nearly 78,000 by the end of

<sup>1</sup> Estimates and Projection of HIV/AIDS 2015-2030, MoH, 2016

\*Source: Estimates & Projection of HIV/AIDS 2015-2030, MoH 2016

2016, the most recent “cascade” data available indicate that further progress is needed. According to UNAIDS data, an estimated 620,000 people were living with HIV in 2016, among whom 13% were accessing antiretroviral therapy.

### 3. RESEARCH OVERVIEW

#### 3.1 Study goal and objectives

**Study goal:** is to gather information about the stigma, discrimination and rights of people living with HIV and determine the level of the stigma of PLWH in Indonesia through a participative and PLHIV lead process using the PLHIV Stigma Index process and methodology.

**Research method:** questionnaire-based survey involving PLWH as both respondents and interviewers. The survey will make it possible to assess the current situation, identify problems associated with stigma, and ultimately facilitate efforts to protect the interests of PLWH. The Stigma Index study will help reveal the stigma and discrimination experienced by PLWH, while the data collected in the course of the study will help formulate the necessary arguments and identify measures to improve programs and policies in the field of combating the social consequences of the HIV epidemic.

#### **Study objectives.**

1. To obtain information about the situation and various events associated with HIV stigma and discrimination in the lives of PLWH in Indonesia;
2. To formulate recommendations on the necessary steps to fight the stigma and discrimination experienced by PLWH;
3. To provide an evidence base for improving policy and programs related to PLWH in Indonesia.

The results of the study will serve as a tool for protecting the interests of people living with HIV, which may be used by HIV-service organisations, activists and other interested parties in the field of preventing the stigma and discrimination experienced by PLWH in Indonesia.

#### 3.2 Methodology and tools

**Research method:** questionnaire-based survey involving PLWH as both respondents and interviewers.

#### **Ethical issues: informed consent and confidentiality**

In determining the level of stigmatisation experienced by people living with HIV, as with other studies that involve gathering data, it is essential to observe certain rules about ethics and data protection. The people responsible for conducting the study must ensure that it complies with ethical standards and the requirements of confidentiality.

Data collection and polling will be carried out on a confidential basis. The collected data is expected to include such information as sex, age, city of residence, etc. In this study, special attention devoted to observing the principles of informed consent and confidentiality.

### **Informed consent**

The principle of informed consent means that each respondent must give his or her consent to the collection and processing of his or her personal data, being fully informed about the nature of the study, its participants and the proposed methods of processing and storing information, as well as the intended use of that information. Interviewers will be supplied with informed consent forms.

### **Confidentiality**

The concept of confidentiality determines the number of people who have the right to view data provided by the respondents. When conducting the study, it is essential to take appropriate measures to ensure with absolute certainty that the identities of the survey participants, if known, will be kept secret. The utmost effort must be made to maintain the confidentiality of data collected in the process of determining the level of stigmatization of PLWH. This means that the person responsible for conducting the study (e.g., the study coordinator in a selected region) must take the appropriate steps to guarantee the confidentiality and protection of information. Any breaches of confidentiality may cause harm to the respondents in the form of stigmatization, dismissal from work, loss of access to services, physical violence, etc. The questionnaire that will be used in the survey must be anonymous and take into account the need to maintain confidentiality.

It will be necessary to sign an **Informed Consent form** with each respondent and a **Confidentiality Agreement** with each interviewer or person responsible for collecting data. The Informed Consent forms and Confidentiality Agreements will be supplied to organizations participating in the study before the study begins.

To keep track of the questionnaires and informed consent forms, depersonalized identification codes will be used in addition to the respondents' names to ensure confidentiality and anonymity. Each respondent's code will consist of the following:

1. A two-character code for the city in which the study is being conducted (or for the organization conducting the study);
2. A two-digit code for the interviewer;
3. A two-digit code for the respondent (sequential number);
4. The date of the survey in six-digit form (dd/mm/yy).

**The study will utilise the tools outlined in the *PLHIV Stigma Index User Guide*.**

### 3.3 The questionnaire

The main data-collection tool for determining the level of stigmatization of people living with HIV is the **questionnaire**. The questionnaire consists of three main sections:

**Section1.** General information about the respondent: age, education, family status, income level, profession and sexual orientation.

**Section 2** is aimed at identifying subjective reasons for stigmatization and discrimination and includes questions about how the respondent views the reasons for stigmatization and discrimination associated with his or her HIV status, as well as questions about internal stigma. This section of the questionnaire also includes questions about the respondents' awareness of their rights and existing laws and regulations governing the stigmatization and discrimination associated with HIV status.

**Section3.** Information about specific instances of stigma and discrimination associated with HIV status that occurred in the respondent's life within the past year, particularly in connection with HIV testing, receiving medical or social assistance, the respondent's access to work, healthcare services and education, or the disclosure of confidential information about the respondent's HIV-positive status.

### 3.4 Additional questions:

The questionnaire allows for specific additional questions to be used that are specific to the situation in Indonesia. Also as part of an initiative supported by PLHIV Network in Indonesia, an additional set of questions for examining the effects of stigma and discrimination on access to testing and treatment have been devised. These questions supplement in quantities method qualitative questions already asked as part of the survey.

On average, it is expected that the questionnaires will take no more than 40-60 minutes to complete. However, it is a participative process of side-by-side interviewing which may well require follow-up and referral as part of the interaction between the interviewer and interviewee.

### 3.5 Capturing the participant's journey – a qualitative process

It is recognized and acknowledged that the journey of the participants as interviewers is an integral part of the research process – for the PLHIV Stigma Index the process is as important as a result. As part of the implementation of the Index, a variety of ways of capturing the journey of the participants will be used. This will include focus groups and opportunities for reflection during the process of implementation as well as after the research phase.

The qualitative research component of the Indonesian rollout of the Index has two overall **goals**:

1. To capture the journey of the research team—this will include reflections of the team about the impact working with the Index has had for them, as well as their anecdotes about the interview process, the peer support and outreach to other people living with HIV during the research process.

2. To reflect on lessons learnt from implementing the Index—this will include reflections about what worked well in the process and what could be improved for the next implementation, and also their vision for the change they want to see as results from working with Index.

#### **4. TRAINING OF COORDINATORS, INTERVIEWERS AND THE INTERVIEW PROCESS**

**Before the study begins, a national workshop will be held for 11 districts coordinators from 11 districts of Indonesia. After the questionnaire finalized, a national training for the interviewers will be conduct.**

The training programs include such issues as understanding the concepts of "stigma" and "discrimination", interviewing methods, the arrangements for gathering and storing data, and the procedures for conducting the survey and filling out forms. The training course will be conducted by staffers from a research agency with the help of representatives from the Spiritia Foundation. The training course programs will be made available to everyone involved in the study once it has been approved.

The interviewers will be trained to carry out the interviews using the People Living with HIV Stigma Index questionnaire and the User Guide. They will also be trained in interviewing, facilitating participatory group discussions and recording case studies. Also, they will receive guidance on dealing with difficult emotional situations and referring people for counselling or further sources of advice and information.

The Stigma Index will also undertake qualitative interviews as case studies to strengthen the quantitative data derived from the questionnaires. Two possible approaches will be used depending upon the nature of the data collected:

- i. Focal discussions.
- ii. Life history approach.

This will be done in collaboration with the institutional research partner and the core team.

##### **4.1 Requirements for study participants**

The Stigma Index aims to unite efforts and involve all interested parties in its work, particularly:

1. NGOs that provide care and support to PLWH, which will act as regional study coordinators, collecting information and coordinating the process of surveying (interviewing) respondents;
2. PLWH, who will act as both interviewers and respondents, in keeping with the principle of broad engagement;
3. Research agencies, which will provide professional data, entry, checking and analysis, as well as preparing a report on the study.

##### **4.2 Districts coordinators:**

Districts coordinators for overseeing the study will be selected by the in-country partnership. They will be either NGOs or individuals. They will be selected on the following basis

The districts coordinators must:

1. Have access to the target group;
2. Have experience in coordinating studies;
3. Have experience in conducting studies (preferable but not mandatory);

4. Have established partnerships with organizations that provide services and support to PLWH in their regions;
5. Have premises where the survey may be conducted;

Additionally, they will be expected,

6. Upon completion of the study, to submit a financial report using the prescribed form.

#### **Functions of the districts study coordinator:**

1. Taking part in the interviewer training course;
2. Coordinating the survey process at the regional level;

#### **4.3 Referral System**

In certain instances, it will become necessary for the interviewer to provide the interviewee with information about referral services if they need them. The idea here is not actually to provide a referral service following the interview, as this would probably be beyond the capacities and resources of most study teams, but to try to provide the interviewee with information about referral services. Often interviewers do this on an informal basis anyway, following their instincts of solidarity and support for fellow human beings.

The proposed approach formalises the process. To provide this referral and follow-up support, the team will develop a local resource list of organisations they feel could, collectively, meet most of the needs of PLHIV. This will be done by compiling a list of appropriate contacts for each locality at district, provincial and national levels.

Where the interviewee asks for advice during an interview, the interviewer will be encouraged not to provide such advice unless they are professionally qualified to do so. Instead, the interviewee will be provided with the local resource list.

Again if during the interview, a need for medical, emotional or legal support is noticed of which the interviewee seems to be unaware, the interviewer will be encouraged to inform the interviewee if they believe that not to do so might endanger the interviewee's future well-being. In such cases, the interviewee will be provided with the appropriate contacts from the local resource list.

About referrals, it is important to keep a sensible balance with the onus on providing information and contacts for the interviewee to pursue rather than interviewers promising to make referrals themselves. However, not being prepared to provide information could put interviewers in an awkward position.

#### **4.4 Checking and storing the questionnaires and keeping track of information**

All of the questionnaires will be sent by the interviewers to the regional project coordinators in the selected districts. They will be checked by the coordinator and undergo quality control. Quality control will ensure that the questionnaires were filled out correctly and meet the mandatory requirements. After being checked, each questionnaire will be sealed with the signature of the regional project coordinator, and all of the collected questionnaires will be sent by express mail to the research agency or

researcher, who will enter the data from the questionnaires into a data processing programs for further analysis and reporting.

#### 4.5 Data Analysis

The first step will be to collate and summarize the data collected to enable some comparison. Subsequent analysis will be based on these initial observations and key findings but also by testing hypothesis put forward by those stakeholders that know the epidemic well. The research team will produce a report that will document the key findings and make recommendations based on the analysis. The responses recorded in open-ended (qualitative) questions, will be extracted, translated and categorized to see any pattern of the attitudes and behaviours of PLHIV.

It is also expected that at the end of the initial data cleaning and entry that the research institute will work closely with the PLHIV Network to analyze the data appropriately as well as providing the data to GNP+ in a format to be determined so that it can be used for further analysis and cross tabulation with other countries and regions to provide comparative analysis.

#### 4.6 Sampling method This study will use a probability sampling method (stratified sampling).

**Referred to the total number of HIV cases in Indonesia from 2005 – July 2018 by districts level then we divided into subgroup or strata by the highest number of cases in each district, and choose the sample numbers from each district proportionally. Sample size and sampling**

The sample size will take at least **706 people** living with HIV from 15 districts of Indonesia. Study participants will include representatives of PLWH from various socially vulnerable groups (IDUs, CSWs, TGs, MSMs, Others).

Determination of sample size considers the desired value of  $\alpha$ , the proportion of previous relevant research, the limit value of absolute error or precision, and the design value of the effect as in the Lemeshow formula below

$$n = \frac{Z^2_{1-\alpha/2} P(1-P)}{d^2}$$

n = Sample Size

Z = Z score based on the desired  $\alpha$  value (for 99%, Z = 2.56)

P = the expected population proportion (set = 0.5)

d = the level of precision desired (assumed to +/- 5 percentage points)

The calculation results from the formula above are 588; an additional 20% was added to the calculated minimum sample size to allow for dropouts. Therefore, the sample size needed for this study is **706**

#### Districts coverage

The districts that are expected to be included in the study selected from Indonesia's three time zones (west, east and central) based on the region's most and least affected by the HIV/AIDS epidemic. The analysis was done using the Spiritia Data Report; PLHIV Currently Receiving Psychosocial Support across

32 potential participating provinces, the following highlighted provinces in Table 1 were selected based on some criteria:

- PLHIV Currently Receiving Psychosocial Support from 24 Implementing Unit
- Presence of peer support
- The diversity of the population to ensure the inclusion of key populations

The district selections are based on Stratified Sampling Method, divided into six strata on the region. The number of samples is divided into each selected districts into each stratum based on proportions.

Table 1: Number of HIV Cases Reported by Provinces until June 2018

Nama IU	Provinsi	Ibukota Provinsi	Kasus HIV yang Dilaporkan	Total Case per strata	% per national data	Proposed Sample Size	Sampled Cities	Proposed Sample Size
<b>INDONESIA</b>			<b>301,959</b>			<b>706</b>	<b>11</b>	
<b>Strata 1 Sumatra</b>								
NAD SUPPORT GROUP	NAD	BANDA ACEH	498					
MEDAN PLUS	SUMUT	MEDAN	15,812				v	59
TARATAK JIWA HATI	SUMBAR	PADANG	2,632					
YAYASAN SEBAYA LANCANG KUNING	RIAU	PEKANBARU	4,696					
KANTI SEHATI	JAMBI	JAMBI	1,563					
SRIWIJAYA PLUS	SUMSEL	PALEMBANG	3,034					
MEDAN PLUS	BENGKULU	BENGKULU	675					
SABURAI SUPPORT GROUP	LAMPUNG	LAMPUNG	2,700					
MEDAN PLUS	BABEL	PANGKAL PINANG	1,177					
KOMPAK	KEPRI	TANJUNG PINANG	8,363				v	37
				41,150	0.14	96		
<b>Strata 2 Java</b>								
KOTEX	DKI JAKARTA	DKI JAKARTA	55,099				v	220
FEMALE PLUS	JABAR	BANDUNG	31,293					
PEDULI KASIH	JATENG	SEMARANG	24,757					
VICTORY PLUS	DIY	YOGYAKARTA	5,100					
MAHAMERU	JATIM	SURABAYA	43,399				v	171
KOTEX BANTEN	BANTEN	SERANG	7,502					
				167,150	0.55	391		
<b>Strata 3 Bali, Nusa Tenggara</b>								
SPIRIT PARAMACITTA	BALI	DENPASAR	18,046				v	55
INSET	NTB	MATARAM	1,544					
FLOBAMORA	NTT	KUPANG	3,875					
				23,465	0.08	55		
<b>Strata 4 Kalimantan</b>								
PONTIANAK PLUS	KALBAR	PONTIANAK	6,712				v	22
PONTIANAK PLUS	KALTENG	PALANGKARAYA	755					
PONTIANAK PLUS	KALSEL	BANJARMASIN	2,010					
MAHAKAM PLUS	KALTIM	SAMARINDA	5,803				v	15
MAHAKAM PLUS	KALTARA	TANJUNG SELOR	492					
				15,772	0.05	37		
<b>Strata 4 Sulawesi</b>								
BATAMANG PLUS	SULUT	MANADO	3,882				v	13
BATAMANG PLUS	SULTENG	PALU	1,040					
YPKDS	SULSEL	UJUNG PANDANG	8,714				v	22
YPKDS	SULTRA	KENDARI	827					
BATAMANG PLUS	GORONTALO	GORONTALO	166					
	SULBAR	MAMUJU	145					
				14,774	0.05	35		
<b>Strata 5 Maluku Papua</b>								
YAYASAN PELANGI MALUKU	MALUKU	AMBON	3,541					
	MALUT	TERNATE	667					
SORONG SEHATI	PAPBAR	MANOKWARI	4,741				v	10
YAYASAN CENDRAWASIH BERSATU	PAPUA	JAYAPURA	30,699				v	83
				39,648	0.13	93		
<b>TOTAL</b>			<b>301,959</b>	<b>301,959</b>	<b>1.00</b>	<b>706</b>	<b>11</b>	<b>706</b>

## **STUDY ACTION PLAN**

The study will be conducted in February 2019 to January 2020 or 12 months. The preparatory phase will be in February-April 2019, fieldwork will be conducted from May-October 2019 and reporting will be conducted in Nov 2019 - January 2020.