

Baseline Assessment - Indonesia

# Scaling up Programs to Reduce Human Rights- Related Barriers to HIV and TB Services

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## Disclaimer

Towards the operationalization of Strategic Objective 3(a) of the Global Fund Strategy, Investing to End Epidemics, 2017-2022, this paper was commissioned by the Global Fund to Fight AIDS, TB and Malaria and presents, as a working document for reflection and discussion with country stakeholders and technical partners, findings of research relevant to reducing human rights-related barriers to HIV and TB services and implementing a comprehensive programmatic response to such barriers. The views expressed in the paper do not necessarily reflect the views of the Global Fund.

## Acknowledgements

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## List of Acronyms

AIDS - Acquired Immunodeficiency Syndrome  
AHM – Nightlife Association  
ART - Antiretroviral therapy  
ARVs – Antiretroviral drugs  
BAPPEDA – Badan Perencana Pembangunan Daerah, Indonesia regional body for planning and development  
CCM – Country Coordinating Mechanism  
CSO – Civil society organization  
DFAT –Department of Foreign Affairs and Trade  
FGD – Focus group discussion  
HCW – Healthcare worker  
HIV - Human Immunodeficiency Virus  
IAC – Indonesia AIDS Coalition  
IBBS - Integrated Biological and Behavioral Surveys  
ID – Identification  
IDR – Indonesian rupiah  
ILO – International Labor Organization  
IPPI – Indonesian Positive Women Network  
JKN – Jaminan Kesehatan Nasional, Indonesia’s Universal Healthcare Plan  
JSI - John Snow, Inc.  
KI(I) – Key informant (interview)  
KIPEM - Temporary resident permit card  
KOMNAS HAM - Indonesia National Human Rights Commission  
KOMPOLNAS – National Police Commission  
KP - Key Population  
KPA – Komisi Penanggulangan AIDS; National AIDS Commission  
KPAK – National AIDS Commission, district level  
KPAN – National AIDS Prevention Commission  
KPAP – National AIDS Commission, provincial level  
KTP – Kartu tanda penduduk; national identification card  
LBH(M) - Lembaga Bantuan Hukum (Masyarakat), Community Legal Aid Institute  
LGBT(IQ) - Lesbian, gay, bisexual, and/or transgender (and/or intersex and/or queer)  
LIPONSOS – Lingkungan Pondok Sosial, social housing  
LKB – Continuum of Care  
MAHA STAR – Masyarakat Anti HIV/AIDS & Stop ARV  
MDR-TB – Multidrug-resistant TB  
MMT – Methadone maintenance therapy  
MoH – Ministry of Health  
MSM - Men who have sex with men  
NGO – Nongovernmental organization  
NSP - National HIV & AIDS Strategic Plan  
OPSI – Indonesian Sex Workers Network  
PABM – Community-based addiction recovery program  
PELINDO – Pelabuhan Indonesia; Indonesia Port Corporation  
PEPFAR – The United States President’s Emergency Plan for AIDS Relief  
PITC – Provider-initiated HIV testing and counseling  
PITCH – Partnership to Inspire, Transform and Connect the HIV response

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PKBI - Planned Parenthood Association of Indonesia  
PKNI – Indonesian Network of People Who Use Drugs  
PLHIV - People Living with HIV  
PMTCT – Prevention of mother to child transmission  
POP TB - Perhimpunan Organisasi Pasien TB; Association of TB Patient Organizations  
PROPAM – Police Professional and Security Division  
RiH – Results in Health  
RSHS – Dr. Hasan Sidikin Hospital  
SITT – National register for notified TB cases  
SIHA – Sistem Informasi HIV/AIDS; HIV reporting  
SKPD – Local Government Work Unit  
SPM - Minimum Standard Service Procedure  
STI – Sexually transmitted infection  
SWs - Sex workers  
TB - Tuberculosis  
UNAIDS - The Joint United Nations Programme on HIV/AIDS  
UNDP – United Nations Development Program  
UNFPA – United Nations Population Fund  
UNODC – United Nations Office on Drugs and Crime  
UNTF – United Nations Trust Fund to End Violence Against Women  
USAID - United States Agency for International Development  
USC - University of Southern California  
VAW – Violence against women  
VCT – Voluntary counseling and testing  
WHO - World Health Organization  
WPA - Warga Peduli AIDS; Citizens Concerned with AIDS  
XDR TB – Extensively drug-resistant TB

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# I. Executive Summary

## Introduction

Since the adoption of its strategy, *Investing to End Epidemics, 2017-2022*, the Global Fund has joined with country stakeholders, technical partners and other donors in a major effort to expand investment in programs to remove human-rights related barriers in national responses to HIV, TB and malaria (Global Fund, 2016a). It has done so because it recognizes that these programs are an essential means by which to increase the effectiveness of Global Fund grants as they help to ensure that health services reach those most affected by the three diseases. This report comprises the baseline assessment conducted in Indonesia as part of operationalizing Strategic Objective 3, which commits the Global Fund to Fight AIDS, TB and Malaria to: “*introduce and scale up programs that remove human rights barriers to accessing HIV, TB and malaria services*”.<sup>1</sup>

Though the Global Fund will support all countries to scale up programs to remove human rights-related barriers to health services, it will provide intensive support to 20 countries to enable them to put in place comprehensive programs aimed at reducing such barriers.<sup>2</sup> Programs are considered “comprehensive” when the right programs are implemented for the right people in the right combination at the right level of investment to remove human rights-related barriers and increase access to HIV and TB services.<sup>3</sup> Based on criteria involving needs, opportunities, capacities and partnerships in country, Indonesia and nineteen other countries were selected for intensive support. This baseline assessment is the first component of the package of support Indonesia will receive and is intended to provide the country with the data and analysis necessary to identify and implement comprehensive programs to remove barriers to HIV and TB services.

Towards this end, this assessment: (a) establishes a baseline concerning the present situation in Indonesia with regard to human rights-related barriers to HIV and TB services and existing programs to remove them, (b) describes comprehensive programs aimed at reducing these barriers and their costs, and (c) suggests opportunities regarding possible next steps in putting comprehensive programs in place. As a draft, this report will be shared extensively with a broad range of partners for input, including at a multi-stakeholder meeting in country where country stakeholders, the Global Fund and other donors, and technical partners can consider its findings, as well as the possibility of the development of a mutually-agreed upon and cost-shared plan by which to fund and implement a comprehensive response to human rights-related barriers to services.

The key program areas involving interventions and activities to remove human rights-related barriers to services are those recognized by technical partners and other experts as effective in doing so. For HIV and TB, these program areas comprise: (a) stigma and discrimination reduction; (b) training for health care providers on human rights and medical ethics; (c) sensitization of law-makers and law enforcement agents; (d) reducing discrimination against women in the context of HIV and TB; (e) legal literacy (“know your

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<sup>1</sup> *The Global Fund Strategy 2017-2022: Investing to End Epidemics*. GF/B35/02

<sup>2</sup> *Ibid*, Key Performance Indicator 9.

<sup>3</sup> This definition of “comprehensiveness » for the purpose of GF Key Performance Indicator 9 was developed with the Global Fund Human Rights Monitoring and Evaluation Technical Working Group.

rights”); (f) legal services; and (g) monitoring and reforming laws, regulations and policies relating to HIV and TB. In addition for TB, there is the need to: ensure confidentiality and privacy related to TB diagnosis, mobilize and empower TB patient and community groups, address overly-broad policies regarding involuntary isolation or detention for failure to adhere to TB treatment, and make efforts to remove barriers to TB services in prisons.<sup>4</sup>

## **Methodology and limitations**

This baseline assessment examined human rights-related barriers in Indonesia that inhibit access, uptake, and retention of HIV- and TB-related services. Data collection included a desk review, followed by in-country work. In-country work involved a total of 37 in-person and 3 telephone interviews, carried out with approximately 410 participants. Participants included key populations of female sex workers, men who have sex with men, transgender individuals, people living with HIV, people who use drugs, and people living with TB. The interviews and focus group discussions were carried out in Jakarta, Surabaya, Bandung, and Makassar. While the focus of interviews was in these four cities, information was also captured about surrounding areas and the country as a whole, to the extent possible.

Limitations to the assessment comprised the following. It was not possible to speak to certain key stakeholders, including but not limited to male sex workers, traditional and religious leaders, people who work in prisons and prisoners. It was also not possible to visit any prisons or government managed drug detention and rehabilitation centers. Moreover, relatively few inputs were received from people outside the four cities where primary data collection took place. The report provides data from the many FGDs. This data is very important in understanding the views of representatives of key affected populations and concerned stakeholders, but in many cases, data collected might have been the participants’ opinions and did not undergo validation through data triangulation or other analytical methods.

## **Summary of baseline assessment findings**

### ***Key and vulnerable populations***

This review examined the human rights-related barriers to health services of key and vulnerable populations in the HIV and TB epidemics in Indonesia. The key and vulnerable populations selected for review were based on three considerations:

- (a) the Global Fund definitions of key and vulnerable populations;<sup>5</sup>

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<sup>4</sup> See *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses*, Guidance Note, UNAIDS/JC2339E (English original, May 2012); ISBN: 978-92-9173-962-2. See also *HIV, Human Rights and Gender Equality Technical Brief*. Available via [www.theglobalfund.org/en/human-rights](http://www.theglobalfund.org/en/human-rights)

<sup>5</sup> See, for the GF definitions of key and vulnerable populations: [www.theglobalfund.org/en/key-populations](http://www.theglobalfund.org/en/key-populations)

- (b) the 2017 Review of the National Health Sector Response to HIV in the Republic of Indonesia in which “key affected populations” include sex workers, people who inject drugs, men who have sex with men, and transgender persons; and
- (c) the data collected during this research from the desk review and the in-country research.

Based on these considerations, the key and vulnerable populations that were seen to be most affected by human rights-related barriers to HIV and TB services in Indonesia and were therefore included in this report were: female sex workers, men who have sex with men, transgender individuals, people living with HIV, people living with TB, people who use drugs, prisoners, women and children.

In general, this assessment finds that: (a) strong programs by which to reduce human rights-related barriers to HIV and TB services exist in Indonesia; (b) these provide an important foundation to which additional activities can be added; (c) there is national commitment to expanding the range and scale of interventions to bolster the national response to human rights barriers to HIV and TB services; (d) this is an opportune moment for advancing these efforts; and (e) there has been increasing coordination and interaction between HIV and TB programs and services, although many challenges remain.

However, broad challenges exist and include: (a) complications and restrictions related to utilization of the National Health Card; (b) insufficient coordination and integration among government entities and NGOs working on HIV and TB-related human rights concerns; (c) an increasingly punitive environment for key populations, with important variations in different parts of the country; (d) limited availability and accessibility of HIV and TB services due to long lines, inefficient referral systems, inadequate availability of health care workers, restrictive opening hours; (e) poverty and economic and social inequality that makes it difficult for people to deal with the costs of testing, transport and lost working hours; and (f) difficulties regarding required documentation, as health coverage is intended to be location-specific.

### ***Human rights-related barriers to HIV services***

The major human rights-related barriers to HIV services that were observed are summarized as follows:

**Stigma and discrimination relevant to HIV:** Despite some recent improvements, stigma and discrimination from health care workers, community members, employers and family, as well as self-stigma, continue to be significant barriers to HIV testing, diagnosis, care, treatment and adherence to treatment. Stigma in the context of HIV is often the result of lack of community knowledge and awareness regarding HIV, particularly in remote areas. Stigma is especially severe against people perceived as coming from key populations. For key populations generally, judgmental attitudes and poor treatment by



health care workers can be a significant deterrent to use of HIV services. There are also prevalent concerns about confidentiality when seeking services.

**Punitive laws, policies, and practices relevant to HIV:** There are some laws and policies intended to be protective of key populations and favorable to accessing services. However, implementation and enforcement of the legal framework appears to be weak or inconsistent, and there is little access to justice. Furthermore, punitive laws, policies and practices also exist and act as major barriers to HIV services. In many places, police engage in illegal police practices against key populations. These practices include: harassment, extortion, arbitrary arrest, violence (including sexual violence) and the failure to protect members of these populations when in danger. There is also significant discordance between and among national and local laws, policies, and practices – as well as their implementation. Most people, including populations affected by HIV, are not aware of their rights and are unclear as to where to turn if their rights have been violated. Some health policies may also directly or indirectly prevent key populations from accessing services.

Additionally, there are reports of mandatory HIV testing being conducted in various contexts, as well as disclosure of HIV status in the contexts of employment, education, and marriage certificates.

In terms of access to justice, major barriers for many Indonesians are lack of awareness of rights amongst the population; the unavailability of legal information and advice particularly for low-income populations; and low levels of awareness of and existence of legal aid services available to address HIV-related violations.

**Gender inequality and gender-based violence relevant to HIV:** Indonesia remains a largely patriarchal culture, with women often financially dependent on their male partners. If they test positive for HIV, they may fear disclosing their status to their partners for fear of stigma, rejection and/or violence. Men and transgender populations also experience gender-related barriers to access services. Gender-based violence is prevalent. Female sex workers, transgender women, women who use drugs, and women who are living with HIV are all particularly vulnerable to gender-based violence with implications for access and use of relevant health services. Additionally, there is a dearth of adequate services and support for women who suffer violence.

### ***Existing programs to address human rights-related barriers to HIV services***

In Indonesia, there are many programs that address human rights barriers to HIV services, as well as many gaps and areas for improvement. Recent or current interventions to address human rights-related barriers to HIV services are summarized as follows.

In terms of reducing stigma and discrimination relating to HIV and membership in a key population, there has been a significant amount of peer-based programming, which helps

to reduce self-stigma and facilitate access to services by building knowledge, self-esteem, and support networks. There is also community education to reduce stigma and discrimination among community members. In some places, this has included the offering of legal assistance, and has often engaged strategic partners such as religious leaders and employers. There have also been efforts to influence broader societal perceptions about HIV and the lives of key populations through engaging media. However, the overall reach of these efforts remains limited.

There have been various initiatives to sensitize health care workers on non-discrimination, HIV, and human rights, as well as media, albeit to varying degrees and in different parts of the country. There have been a very limited number of training efforts to sensitize lawmakers and law enforcement agents.

There are a number of community-run programs with a legal-empowerment approach that include legal literacy and human rights education programs. In some prisons, nongovernmental organizations have been implementing activities to build awareness among inmates regarding their health and rights.

Although Indonesia broadly lacks specific legal services for people living with HIV, there are notable efforts by NGOs working to provide key populations with paralegal support and access to other forms of legal services. Additionally, some local government structures are trying to support access to HIV-related legal services. However, many populations appear to be unaware of their rights or of the complaint procedures and legal assistance options available to them, as limited as they are.

NGOs have advocated increasing the rights of and protections for key populations and have contributed to the research base for such advocacy. There have also been various activities toward creating more supportive environments for women living with HIV, including addressing intersections with violence, but again with limited geographic scope.

However, there are significant gaps in programs to reduce human rights-related barriers to HIV services including:

- Insufficient large-scale public education about HIV and human rights to reduce stigma and discrimination, particularly in remote/rural areas
- Insufficient coverage and follow-up for trainings of health care workers on human rights and medical ethics related to HIV
- Insufficient sensitization of police and police management on the rights of key populations and the need to avoid illegal practices and support access to health services
- Limited efforts to ensure an enabling environment for the protection of rights of key populations
- Limited collaboration/coordination across programs, including referral networks
- Limited monitoring and evaluation of human rights-related program impacts on addressing barriers to services, and

- Uncertainty about program sustainability, impacting capacity and the ability of organizations concerned with the human rights dimensions of HIV to operate to the best of their ability.

### ***Comprehensive programs to reduce human rights-related barriers to HIV services***

This section summarizes recommendations for program areas that would help Indonesia address the gaps outlined above, and achieve a more comprehensive response to human rights-related barriers to HIV services. These recommendations should be viewed as opportunities for stakeholders engaged in addressing barriers to access to HIV services in Indonesia to scale up and/or complement existing programming, and are set forth in more detail in the body of the report.

Additional interventions to ensure a more comprehensive effort to remove human rights related barriers to HIV services could include:

- Public education campaigns to increase knowledge about HIV and human rights, and reduce discrimination against key and vulnerable populations;
- Pre-service and in-service sensitizations and trainings of health care workers, community workers, and law enforcement agencies;
- Expanded paralegal and human rights peer education programs;
- Capacity-building of legal aid services to work on HIV-related issues, and to work with key populations;
- Expanded HIV-related rights reporting and accountability mechanisms; and
- Increased capacity and support for NGOs to carry out policy monitoring and advocacy, including to reduce logistical and financial barriers to HIV services.

### ***Human rights-related barriers to TB services***

The major human rights-related barriers to TB services can be summarized as follows:

**Stigma and discrimination relevant to TB:** Stigma and discrimination from health workers, community members, employers, family, as well as self-stigma, continue to be significant barriers to testing, diagnosis, care and adherence with respect to TB services. For key populations generally, judgmental attitudes and poor treatment by health care workers can be significant deterrents to use of TB services. Concerns about lack of confidentiality when seeking services also act as a barrier to TB services.

Misconceptions about TB and how it is spread also increase stigma and discrimination towards people diagnosed with TB. People diagnosed with TB are often negatively stereotyped to be from lower economic backgrounds and education levels and are poorly treated. Those who have MDR-TB may be more highly stigmatized.

There are multiple reported cases of people diagnosed with TB being rejected or fired from their jobs. In some cases, people diagnosed with TB report being asked to leave their job

with no pay until treatment has been completed. Children with TB have also been asked to take leave from school, or relocate to another school, during treatment.

**Punitive laws, policies, and practices relevant to TB:** While there are many laws in place that are intended to be support access to services and/or be protective of key populations, there is significant discordance among national and local laws, policies, and practices – as well as their implementation – which negatively impact TB prevention and control. Most people, including key populations, are not aware of their rights in relation to TB and are unclear of where to turn even if they recognize their rights have been violated.

**Gender issues relevant to TB:** Men have a higher disease burden in terms of TB, and may present to services late. Women most often carry the caregiving burden, even if they themselves are ill, when someone else in the family is diagnosed with TB. Women may not have sufficient agency to determine and respond to the health needs of themselves or family members.

### ***Existing programs to address human rights-related barriers to TB services***

In Indonesia, there are few programs that directly address human rights barriers to TB services, leaving many gaps and areas for improvement. However, there has recently been a major positive shift in terms of how TB programs are implemented. This has gone from an almost exclusive reliance on medical services-centered approaches to more NGO-centered approaches that work in and address community contexts. Recent or current interventions to address human rights barriers to accessing TB services are highlighted as follows.

A new, national network of TB patient groups is intended to help ensure more visibility and agency for those affected by TB, including in the formation of national policies. However, with regard to health care workers and lawmakers and law enforcement agents, there appears to be a general lack of training incorporating human rights perspectives. Similarly, there appears to be limited legal services and limited efforts to ensure awareness and access to existing services that might be of assistance in cases where individuals with TB suffer violations of their rights. Oftentimes when rights violations occur in the context of TB, people do not know their rights and are therefore unaware that violations have occurred.

The National Stop TB Partnership Forum, launched in 2013, acts as an advocacy and lobbying group for social and political action. It seeks to ensure the development and proper implementation of policies to support TB control efforts and increase national and local government budgetary allocations for TB programs.

Human rights- related gaps in existing TB related programming include:

- Limited large-scale public education about TB and human rights to reduce stigma and discrimination, particularly in remote/rural areas
- Insufficient coverage and follow-up for trainings of health care workers on human rights and medical ethics related to TB, as well as TB/HIV
- Limited efforts to ensure an enabling environment for the protection of rights of key populations
- Limited collaboration/coordination across programs, including referral networks and those that would address TB and HIV related concerns together
- Limited monitoring and evaluation of human rights-related program impacts on addressing barriers to services
- Uncertainty about program sustainability, impacting capacity and the ability of organizations concerned with the human rights dimensions of TB; and
- Limited economic empowerment and/or financial assistance for people living with TB and their communities.

### ***Comprehensive program to address human rights related barriers to TB services***

This section summarizes recommendations for program areas that would help Indonesia address the gaps outlined above, and achieve a more comprehensive response to human rights-related barriers to TB services. These recommendations should be viewed as opportunities for all stakeholders engaged in or interested in addressing barriers to access to TB services in Indonesia to scale up and/or complement existing programming, and are set forth in more detail in the body of the report.

Additional interventions to ensure a more comprehensive effort to remove human rights related barriers to TB services could include:

- Public education campaigns to increase knowledge about TB and human rights, and reduce discrimination against key and vulnerable populations
- Pre-service and in-service sensitizations and trainings of health care workers, community workers, and law-makers and law enforcement agencies (can be integrated with such training on HIV)
- Expanded peer paralegal and human rights peer educator programs
- Capacity-building of legal aid services to work on TB-related issues, and to work with key populations
- Expansion of TB and rights-related reporting and accountability mechanisms, and
- Increased capacity and support for NGOs to carry out policy monitoring and advocacy, including with regard to logistical and financial barriers to TB services.

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## **Next Steps**

Following from this baseline exercise, the Global Fund would like to engage with a range of country stakeholders working on these and other dimensions of health and human rights, ideally through a joint, multi-stakeholder meeting in Indonesia. Country stakeholders, the Global Fund and other donors could then clearly map what is already being supported, what gaps exist, and where there are opportunities to fund and implement these or other recommendations in order to make the existing responses more comprehensive.

## II. Introduction

This report comprises the baseline assessment carried out in Indonesia to support its efforts to scale-up programmes to reduce human rights and gender-related barriers to HIV and TB services. Since the adoption of the *Strategy 2017-2022: Investing to End Epidemics*, the Global Fund has joined with country stakeholders, technical partners and other donors in a major effort to expand investment in programmes to remove such barriers in national responses to HIV, TB and malaria (Global Fund, 2016a). This effort is grounded in Strategic Objective 3 which commits the Global Fund to: “*introduce and scale up programs that remove human rights barriers to accessing HIV, TB and malaria services*”; and, to “*scale-up programs to support women and girls, including programs to advance sexual and reproductive health and rights and investing to reduce health inequities, including gender-related disparities.*” The Global Fund has recognized that programmes to remove human rights and gender-related barriers are an essential means by which to increase the effectiveness of Global Fund grants as they help to ensure that health services reach those most affected by the three diseases. The Global Fund is working closely with countries, UNAIDS, WHO, UNDP, Stop TB, PEPFAR and other bilateral agencies and donors to operationalize this Strategic Objective.

Though the Global Fund will support all countries to scale up programs to remove barriers to health services, it is providing intensive support in 20 countries in the context of its corporate Key Performance Indicator (KPI) 9: “*Reduce human rights barriers to services: # countries with comprehensive programs aimed at reducing human rights barriers to services in operation (Global Fund, 2016b).*” This KPI measures, “*the extent to which comprehensive programs are established to reduce human rights barriers to access with a focus on 15-20 priority countries.*” These programs are considered “comprehensive” when the right programs are implemented for the right people in the right combination at the right level of investment to remove human rights-related barriers and increase access to HIV and TB services.<sup>6</sup> Based on criteria that included needs, opportunities, capacities and partnerships in the country, the Global Fund selected Indonesia, with 19 other countries, for intensive support to scale up programs to reduce barriers to services. This baseline assessment for Indonesia, focusing on HIV and TB, is a component of the package of intensive support the country will receive.

### **Purpose, objectives, and expected outcomes of the Baseline Assessment**

The objectives of the baseline assessment are to:

- Identify the key human rights and gender-related barriers to HIV and TB services in Indonesia
- Describe existing programs put in place to reduce such barriers

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<sup>6</sup> This definition of “comprehensiveness » for the purpose of GF Key Performance Indicator 9 was developed with the Global Fund Human Rights Monitoring and Evaluation Technical Working Group.

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- Indicate what a comprehensive response to existing barriers would comprise in terms of the types of programs, their coverage and costs; and,
- Identify the opportunities to bring these to scale over the period of the Global Fund's 2017-2022 strategy.

The assessments will provide a baseline of the situation as of 2017 and will be followed up by smaller scale assessments at mid- and end-points of the Global Fund Strategy to assess the impact of the scale-up of programs to reduce human rights-related barriers.



### III. Methodology

#### Conceptual framework and program areas to remove human rights-related barriers to HIV and TB

The conceptual framework that guided the assessment was as follows:

- In Indonesia, as in other countries regionally and globally, there exist human rights and gender-related barriers to full access to, uptake of and retention in HIV and TB services.
- These barriers are experienced by certain key and vulnerable populations who are more vulnerable to and affected by HIV and TB than other groups in the general population.
- There are human rights-related program areas comprising interventions and activities that are effective in removing these barriers.
- If these interventions and activities are funded, implemented and taken to sufficient scale in the country, they will remove or significantly reduce these barriers.
- The removal of these barriers will increase access to, uptake of and retention in HIV and TB services and thereby accelerate country progress towards national, regional and global targets to significantly reduce or bring to an end to the HIV and TB epidemics.
- These efforts to remove barriers will also protect and enhance Global Fund investments, and strengthen health and community systems.

The general categories of human rights-related barriers, as specified by the Global Fund, include those related to (a) stigma and discrimination; (b) punitive laws, policies, and practices; (c) gender inequality and gender-based violence; and (d) poverty and economic and social inequality.

There are seven key program areas comprising activities recognized as effective to remove human rights related barriers to health services. For HIV and TB these seven comprise:

- Stigma and discrimination reduction
- Training for health workers on human rights and medical ethics related to HIV
- Sensitization of lawmakers and law enforcement agents
- Legal literacy (“know your rights”)
- HIV-related legal services
- Monitoring and reforming laws, regulations, and policies related to HIV; and
- Reducing discrimination against women in the context of HIV.<sup>7</sup>

Additional program areas relevant to the removal of barriers in the context of TB include:

- Ensuring confidentiality and privacy
- Mobilizing and empowering patient and community groups; and
- Programs in prisons and other closed settings.<sup>8</sup>

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<sup>7</sup> HIV and TB Technical Briefs : available via [www.theglobalfund.org/en/human-rights](http://www.theglobalfund.org/en/human-rights)

<sup>8</sup> Ibid, TB Technical Brief.

## ***Steps in the baseline assessment process***

### **Desk review**

The desk review entailed literature searches, legal and policy environment data extraction, and key informant interviews related to human rights barriers to accessing HIV and TB services in Indonesia and programs to address these barriers. To identify relevant peer-reviewed literature, a comprehensive search was conducted using PubMed, Popline, and Embase. Articles were initially selected for keywords in their abstracts and then further searched for relevance. Thirty-nine peer reviewed articles and 11 pieces of ‘grey literature’ were ultimately selected for inclusion in the desk review. Grey literature was also reviewed: data were extracted from a range of documents identified through a combination of Google searches as well as documents and reports recommended by Global Fund and key informants.

Overall, 93 documents from the desk review as well as received in country were reviewed in depth, including reports, newsletters and presentations (Annex 1). Assessment of the legal and policy environment was largely based on an assessment carried out in 2015 entitled ‘*National Consultation on Legal and Policy Barriers to HIV in Indonesia,*’ and included also analysis of relevant laws, policies and strategies specifically brought to our attention. Finally, a series of telephone interviews were carried out with key informants representing a range of perspectives including Spiritia, the Indonesia AIDS Coalition (IAC), and UNAIDS.

### **Preparation for in-country research**

Based on the desk review and discussions with the Global Fund, an initial list of key informants was identified prior to in-country work. This list was expanded over the course of data collection through consultations with stakeholders and key informants, with particular focus on the lived experience of impacted populations. Instruments were adapted to the circumstances of Indonesia. Researchers (nationals of Indonesia) were given these tools for input and familiarization.

### **In-country research**

In July 2017, a team of researchers conducted interviews with key informants and focus groups, with a focus on key populations. In Jakarta interviews were used primarily to gather national-level data and in Bandung, Makassar, and Surabaya to gather city-level data. The purpose of the in-country data collection was to deepen understanding of the most urgent and important barriers to both HIV and TB services in Indonesia, to learn about the most effective programs to date, and to think about what it would take to propose a scaled-up approach to reducing these barriers. Costing data were not collected as part of

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the Indonesia assessment as per agreement with UNAIDS and the Global Fund prior to the start of the mission.

At the onset of the in-country data collection, there was an inception meeting with approximately 30 national stakeholders and community members. In addition to discussing the baseline assessment and data collection procedures, and presenting the findings of the Indonesia desk review, the meeting provided an opportunity to collect reactions, clarifications, and additional suggestions for further exploration during in-country work, including additional potential key informants and relevant programs.

### **In-country interviews**

In total, the research team carried out 37 in-country interviews with approximately 410 participants, and 3 telephone interviews. Interviews represented a range of groups and entities including NGOs, affected communities, government agencies, hospitals, and research universities (Annex 2). In-country interviews gave priority to focus group discussions with female sex workers, men who have sex with men, transgender individuals, people living with HIV, people who use drugs, and people living with TB. The focus of these interviews resulted in the collection of extensive and new information about barriers, and to some degree information on existing programs. Data were collected on:

- Human rights-related barriers to HIV services
- Key and vulnerable populations most affected by barriers to HIV and TB services respectively
- Current or recent programs that have been found, through either evaluation or consensus among key informants, to be effective in reducing these barriers; and
- Gaps and recommendations regarding what is needed to comprehensively address the most significant barriers for groups most affected by these barriers.

### **Data analysis**

The detailed notes from the in-country data collection were synthesized and analyzed together with the desk review findings. This synthesis established a baseline understanding of the barriers that populations face in accessing and using HIV and TB services in Indonesia reflect the strengths and gaps of existing programming to address these barriers to the extent possible. Building on this analysis, a description of a comprehensive response was developed. This description includes programs that should be scaled-up and programs that should be added.

### **Finalization and next steps**

At the conclusion of the in-country work, a follow-up meeting was held to present and discuss a preliminary synthesis of the data collected and to garner reactions and inputs from stakeholders and community members. The meeting generated support for the initial findings and interest in what recommendations could follow from this exercise.

As a draft, this report will be shared extensively with a broad range of partners and community members for input. Following from this baseline exercise, the Global Fund would like to engage with a range of country stakeholders working on these and other dimensions of health and human rights, ideally through a joint, multi-stakeholder meeting in Indonesia in which human rights barriers to HIV and TB services could be a theme in a broader discussion. Country stakeholders, the Global Fund and other donors could then clearly map what is already being supported, what gaps exist, and where there are opportunities to fund and implement these or other recommendations in order to make the existing responses more comprehensive.

### **Overarching policy issue for HIV and TB: National Health Card**

HIV and TB services are, for the most part, free for those with JKN (Jaminan Kesehatan Nasional, the major social health insurance scheme intended to be accessible to all Indonesian nationals and documented migrants). The Ministry of Health has very limited influence on the issuance of IDs and thus access to JKN, as these responsibilities fall under the Ministry of Internal Affairs (FGD5). Acquiring a national health card is reportedly complicated (FGD31). According to the national health insurance scheme, everyone in Indonesia is intended to have access to medical services within their home area. Typically, every family pays a premium for the insurance and every individual listed on the card is entitled to services. Special provisions are made for people who are categorized as poor (FGD13). With this family-based plan, the card's premium is paid for the whole family rather than for individuals. If one family member does not pay the premium, the card will be blocked, barring all other family members from using it (FGD17). For those who do not live with or are excluded from their families, they cannot pay their own premiums and therefore do not have a health card. Interview participants noted that fines are given to those who have not paid their premiums, contributing additional barriers to accessing health services. Such barriers particularly impact those who are poor or have unsteady income. Furthermore, the family-based card system means that services accessed on family cards are visible to all members listed on the card. This may make it difficult to keep sensitive diagnoses or treatments hidden from one's family (FGD21).

In-country interviews revealed a lack of clarity surrounding many different aspects of the national health cards, including that different health facilities cover different services under JKN. In addition, there remains much confusion amongst providers as to how the national health card covers services. The two primary interpretations are: a) One can access covered services up to a certain monetary amount, or b) Once a person has accessed one particular service, he or she cannot access it again, even if they still have money left and need the service they can only access services they have not yet used (FGD21). These differences in interpretation have significant implications for accessing both HIV and TB-related services.

Other aspects of the national health card make it particularly difficult for key populations to access services. Acquisition of health cards requires an identification (ID) card as well.

Transgender individuals or street children, for example, cannot easily access services even if they are on offer as they may not have an ID card (FGD31, FGD5). One potential solution tried in some places are temporary cards issued by the Social Affairs Office. These cards are issued by local (sub-national) authorities for the sole purpose of accessing health and social services. However, even where they do exist, getting such cards is reported to be a long and cumbersome process (FGD22).

The difficulties in accommodating mobile populations were frequently discussed as key limitations of the national health card scheme (FGD17, FGD16). Migrants are required to get KIPEMs (temporary resident permit cards) to access public services. However, many migrants may be reluctant to get a KIPEM because the application process requires not only a family card but also a relocation referral letter from the administrative head of their original neighborhood (FGD19). According to FGD participants in Surabaya, without a Surabaya ID, patients will be sent back to their home communities to access services (FGD19).

For those living in poverty, not having health insurance creates barriers to accessing services even when there are measures in place to assist. Focus group discussion participants in both Bandung and Surabaya mentioned that those who cannot afford health insurance *can* get letters certifying their poverty and confirming they do not have to pay. However, not everyone who can wants to use this option, and further, not everyone knows this is an available option (FGD17, FGD20).

In addition, it is possible to access free antiretroviral therapy (ART) regardless of CD4 if one declares one's key population status. People who are not from among key populations are only eligible for HIV treatment in most areas with a CD4 below 350, although test and treat for all is being rolled out. However, there have been cases where people are denied care upon declaring they are sex workers because the female sex worker population is not mentioned as a "key target group" in the recent SPM (Minimum Service Standard Procedure) decree (FGD13). People who use drugs are recognized as key populations and are meant to be offered ART if living with HIV. However, people who use non-injected drugs do not fall in this category and are not entitled to such care. As a result of these barriers, if they do feel the need to access services, some people use the ID cards of friends or counterfeit ID cards (FGD32).

## IV. Baseline Findings - HIV

### **HIV epidemiology**

Indonesia is known to be facing one of the most rapidly growing HIV epidemics in Asia (UNAIDS 2013). Most new infections are reported to be sexually transmitted (Puras, 2017). As of 2016, there were 48,000 new HIV infections in Indonesia, with an estimated 620,000 people living with HIV across the country. Among those living with HIV, 11-15% were reported to be accessing antiretroviral therapy (UNAIDS, 2016). Since 2010, new HIV infections have increased by 68% while AIDS-related deaths are said to have decreased by 22%, indicating a treatment gap (UNAIDS, 2016). Prevalence remained the same for males between 2014 and 2016. For females, the estimate increased by 10,000 women from 2014 to 2015, and was steady between 2015 and 2016. Most recent data show that, amongst pregnant women living with HIV, 14% (12% - 16%) were accessing treatment or prophylaxis to prevent transmission of HIV to their children. An estimated 3200 (2500 - 4000) children were reported to be newly infected with HIV due to mother-to-child transmission in 2016 (UNAIDS, 2016). 2016 UNAIDS data also reflects HIV prevalences of 5.3% among sex workers, 25.8% among gay men and other men who have sex with men, 28.76% among people who inject drugs, 24.8% among transgender populations, and 2.6% among prisoners (UNAIDS, 2016). Among prisoners, the highest reported prevalence is in specialized narcotic prisons (Directorate of Corrections, 2010a, 2012; Nelwan et al., 2009; National AIDS Commission, 2010; Culbert et al., 2015).

### **Protective laws and policies relevant to access to HIV services, with issues of enforcement**

There are many laws and regulations in place in Indonesia that promote non-discrimination towards people living with HIV, equality, protection of confidentiality, and informed consent in access to services. In-country interviews and focus group discussions highlighted that some local laws (“Perda,” enacted on the Provincial or District level, often in consultation with local AIDS Advisory Committees) are most often intended to be protective of key populations, alongside the general population, even as problems may exist in implementation (FGD16).

A list of potentially protective laws for HIV was identified by the Legal and Policy Barriers Consultation conducted in 2015. As listed below, applicable protective laws include not only general legal provisions, such as nondiscrimination provisions in the 1945 Constitution and space for legal recognition, but the right of every citizen to civil registration as per Law No. 23/2006 on Civil Registration, and equal employment opportunities without discrimination as guaranteed by Law No. 13/2003 on Manpower (National AIDS Commission, 2015a). Other particularly relevant laws include:

- Law No. 40/2004 on National Social Security System [ostensibly if amended to include people living with HIV]
- Health Ministerial Decree No. 1190/2004 on the Provision of Free Anti Retroviral (ART) Medication for HIV/AIDS

- Guarantees the provision of free ART, but in practice there are questions about accessibility.
  - Health Ministerial Decree No. 189/Menkes/SK/III/2006, on National Drugs Policy for HIV/AIDS
    - “Governs the uninterrupted supply of drugs, including their equal distribution and accessibility...also stipulates that the availability of essential drugs is to be the obligation of the government and health providers, both public and private.” (National AIDS Commission, 2015a)
  - Presidential Regulation No. 76/2012 on the Implementation of Patents by the Government of Antiviral and Antiretroviral Drugs
    - Positive regulation, but supply issues persist, particularly in relation to Trade-Related Aspects of Intellectual Property Rights and free trade agreement with European Union and Indian patent holders
  - Law No. 13/2003 on Manpower
    - To limit employment discrimination
- (National AIDS Commission, 2015a)

It is important to note that Indonesia’s National HIV Strategy and Action Plan 2015-19 includes initiatives to increase public awareness of gender-based violence and implement campaigns against homophobia and transphobia to reduce HIV vulnerability. However, it has also been recommended that the Indonesia National Human Rights Commission (KOMNAS HAM) be more assertive regarding sexual orientation and gender identity (SOGI) and HIV related issues to be more effective (UNDP, UNAIDS, ESCAP, 2016; National Human Rights Commission of Indonesia, 2013).

However, focus group discussions participants noted that, broadly, the challenges are less with the laws and policies than with how these are, or are not, enforced, or how they are understood and (mis)applied by law enforcement agencies and the judicial system. Focus group discussion participants who work within government noted that, while contradictory laws may exist, at an administrative level people whose job it is to enforce them know how to live and work with them (FGD16). From the perspective of the key populations interviewed, this nonetheless generally results in punitive or hostile environments. One interesting initiative in this regard is that the City of Bandung is in the process of drafting a major regulation to address conflicting local laws and regulations that are unfavorable to HIV prevention, care and treatment (FGD16).

Furthermore, people are generally unaware of the existence of or how to use legal complaint mechanisms if their rights are violated (KII2). Representatives of the Ministry of Justice and Human Rights and of the National Commission on Women acknowledged the rarity of cases relating to HIV or TB brought to their attention. The National Human Rights Commission (not met during this research) had also reported in an earlier evaluation a similar lack of referral of HIV or TB-related cases (WHO & Kementerian Kesehatan Republik Indonesia, 2017).

## **Political and social environment relevant to access to HIV services**

The political and social environment is complicated, with particular repercussions for key populations, including people who identify as LGBT, sex workers and people who use drugs. For the LGBT community, interviewees noted that in recent years LGBT issues have become increasingly politicized and used by politicians for their own interests and political gains. Homophobia is used to achieve political power (FGD12). Given this recent trend, attacks on sexual acts between men and LGBT populations more broadly have worsened (“Key Findings” PPT Aceh). For example, there was a recent crackdown on the LGBT community in Jakarta, resulting in police raids and arrests. Further illustrating the increasingly punitive environment for the LGBT community across Indonesia, a law was proposed to Parliament in September 2017 that seeks to ban all gay characters and LGBT “behaviours” on television (Dideriksen, 2017).

It is clear that outreach and awareness campaigns for men who have sex with men are slowing down out of fear of those conducting the campaigns facing reprisals (Equal Eyes, 2017). Several social media outlets that used to relay information—including health-related messages—to men who have sex with men have been shut down. Others temporarily continue to operate. Given that some of the current discriminatory beliefs about key and vulnerable populations are fueled by political agendas and populist movements invoking socio-cultural norms and beliefs, it is essential to continue, and to intensify, efforts to engage traditional and religious leaders (as some organizations have already been doing).

With respect to people engaged in sex work, barriers exist throughout the country as a result of the Ministry of Social Affairs’ 2015 announcement that they will close all brothels by 2019 (FGD13, FGD5). Additionally, the Ministry of Social Affairs has announced that sex work will be eradicated from Indonesia by 2019 and injecting drug use by 2020. These statements are likely to have a chilling effect on opening up access to HIV services for sex workers and people who use drugs.

With respect to people who use drugs, as the assessment mission was proceeding, the National Chief of Police Tito Karnavian announced the launching of a war on drug traffickers. This announcement was inspired by the punitive policies of the Philippines and subsequently backed by an Indonesian Presidential declaration. It suggested it would allow for mass arrests and summary execution if the suspect “resists arrest.”

## **Human rights-related barriers to HIV services**

This section of the report focuses on specific barriers experienced by relevant key populations in accessing HIV services. Broadly these barriers include: stigma and discrimination; punitive laws, policies and practices; gender inequality and gender-based violence; poverty and economic and social inequality, as well as barriers concerning insufficient availability and accessibility of services and government and health service coordination.



Each subsection below includes a descriptive analysis of the nature and direct and indirect impacts of barriers in the context of HIV as well as HIV and TB together, as relevant. Many punitive laws and policies that affect access to services for key populations in the context of HIV also affect such access for these populations in the context of TB.

### ***Punitive laws, policies and practices relevant to HIV***

In-country interviewees noted that, even as government ministries agree that HIV is a priority, there are conflicts in law that need to be addressed. In particular, ministries do not agree on how to define, talk about or address the needs and demands of key populations, and do not agree on what services are appropriate or how they should be financed (FGD16). As a result of this, as noted by one focus group in Bandung, policies, laws and regulations issued at the central and peripheral level are too numerous and at times conflicting, as they are issued by different ministries with different intents. The group noted that, while HIV prevention, care and treatment are cited as top national priorities, there is also no general agreement as to who constitutes key populations as stated in legal or policy provisions (FGD16).

The Legal Environment Assessment conducted in 2015 under the auspices of UNAIDS revealed many contradictions between central (national) level laws and local laws and regulations. (FGD5). Interviews revealed that there were over 270 Perdas related to HIV or related behaviors in the country and this number was increasing. No evaluation of the impact of these disparate laws and regulations has been conducted. A worrisome feature of these Perdas is their replication across districts without scrutiny of their intent, what they say, the extent to which they can be made enforceable, and what positive or negative impacts might be. Additionally, there is a plethora of local laws and regulations criminalizing key populations' behaviors (KII2).

### ***Punitive laws, policies and practices relevant to people living with HIV***

The desk review noted that the Ministry of Health regulation No. 21/2013 on HIV and AIDS Control states that care and treatment costs for people living with HIV who are poor are to be borne by the state, and health services must not refuse treatment to people living with HIV (WHO & Kementerian Kesehatan Republik Indonesia, 2017). However, it was reported that there was a case where people living with HIV were not covered by JKN after revealing their HIV status (FGD24). In focus groups in Jakarta and Bandung, people living with HIV reported that they often had to pay for HIV services (e.g.; consultations, injections) out-of-pocket.

It is thought that current criteria applied to determining who will (or will not) have free access to HIV treatment will soon become irrelevant in the advent of the "Treat All" strategy. This strategy is currently being piloted in a handful of districts. It is slated to be rolled out in 2018, and is reportedly regarded as a key strategy to achieving the "90-90-90" goal by 2020 (WHO & Kementerian Kesehatan Republik Indonesia, 2017). If this goal

is to be achieved, it will necessitate a realignment of national and local policies, laws and regulations.

The desk review also highlighted the fact that HIV transmission, exposure, and non-disclosure are criminalized (WHO & Kementerian Kesehatan Republik Indonesia, 2017). This is in conflict not only with international guidelines, but also with Law No. 23/2014. This law mandates local governments to implement the National HIV & AIDS Strategic Plan (NSP), which includes an effective HIV response (WHO & Kementerian Kesehatan Republik Indonesia, 2017). In-country interviews revealed that HIV-related punishments still exist. These include prison time for: (a) people living with HIV who are thought to break the rules and regulations around food-selling hygiene; (b) donations of blood, organs and human tissues by people living with HIV aware of their seropositivity; and (c) 'reckless' transmission by people living with HIV to an uninfected partner or spouse (FGD16). An issue noted was that many arms of the government both at national and local level still see HIV largely as a moral issue rather than as a public health issue (FGD12).

Other legal issues, such as mandatory HIV testing and involuntary disclosure "with regard to employment, education and pre-marriage" (National AIDS Commission, 2015a) still exist. Although the MoH Regulation 21/2013 "clearly states that HIV testing must be performed with the patient's consent," this does not always happen (WHO & Kementerian Kesehatan Republik Indonesia, 2017). HIV testing is mandated by the MoH Regulation 74/2014 in the medical check-up requirements for incoming migrants, prospective employees applying for jobs overseas, as well as army and police recruits (WHO & Kementerian Kesehatan Republik Indonesia, 2017). This is not in line with the Minister of Manpower and Transmigration Decree No. 68/Men/IV/2004. This decree builds on norms, guidelines and best practices recommended by the International Labor Organization (ILO) regarding HIV Prevention and Control in the workplace and prohibits HIV testing as a pre-condition for employment (WHO & Kementerian Kesehatan Republik Indonesia, 2017). Reportedly, large-scale enterprises in Indonesia are commonly adhering to the ILO recommendations concerning HIV at the workplace (FGD11). However, this is not the case for medium and small enterprises that claim they do not have the means to finance and implement these recommendations (FGD11). Private companies and hotels in Surabaya were also noted to require HIV testing before employment (FGD8). It was also noted people had been fired when their HIV status became known (FGD8).

In-country interviewees widely reported that mandatory testing still occurs in a variety of ways. Provider-initiated testing and counselling is recommended by national policies, but its interpretation and modes of implementation are poorly understood among the health staff. Furthermore, it often amounts to HIV tests being performed on the initiative of the care provider without prior information or explicit informed consent. HIV testing occurs in other ways as well. For example, an interviewee in Surabaya stated that periodically, the police raid the LIPONSOS (a form of social housing) and require everyone there to undergo an HIV test. The HIV status of whoever is found HIV-positive will then be revealed to their families (FGD7). Another interviewee noted that there is a Standard

Operating Procedure in Surabaya stating that when police arrest people they suspect of being HIV-positive, the Dinkes (District Health Office) and Puskesmas are called upon to forcibly test these individuals (KII3). Other reports indicate that people who are under arrest, for example for using drugs, are tested for HIV at the police station. These individuals are kept under custody for the short time before the test result becomes available. If the result is negative, judicial action will be triggered for the offense having caused the arrest. If the result is positive, the alleged offender may be sent home or directed to a compulsory drug detention or rehabilitation center.

There are attempts in Surabaya to establish a shelter for people living with HIV and key populations, as well as TB patients who do not have Surabaya IDs. It was noted that current laws, however, do not allow local governments to fund shelters for HIV-positive individuals. While the central government funds three shelters in Indonesia (in Medan, Sukabumi and Ternate), there are strict criteria for admission. Focus group discussion participants noted that a potential solution would be to reform this law to provide local government a mandate to allocate funds to build such shelters (FGD19).

In-country interviews often touched on marriage requirements and the implications for people living with HIV. Couples are often required to get tested for HIV and are only given a permit for marriage when determined to be negative (FGD20, FGD26). Sometimes marriage licenses require proof of HIV testing (“West Kalimantan”). Focus group discussion participants from Surabaya noted that HIV-positive couples are referred to the neighboring Puskesmas for access to care and treatment, including ART if eligible. (FGD8).

### **Punitive laws, policies and practices relevant to female sex workers**

Local laws that regulate brothels occupy a legal grey area. Some provinces or districts prohibit sex work. Regarding policy, the national-level goal to eliminate brothels in Indonesia by 2019 and related crackdowns are a major concern (WHO & Kementerian Kesehatan Republik Indonesia, 2017). Furthermore, the evidence gathered by the review found in most cases that sex work continues with far less safety for the person engaged in sex work, including vulnerability to abuses and violence. This policy environment also makes this population more difficult to reach with HIV and other related health services (OPSI, 2016; Praptorahardjo et al., 2016; WHO & Kementerian Kesehatan Republik Indonesia, 2017).

In-country interviews strongly complement findings from the desk review with regards to the impacts of brothel closures. This policy, instated by the Ministry of Social Affairs in 2015, has already resulted in some places in the inability of sex workers to access services, health guidance, and goods (FGD13, FGD16). Focus group discussion participants stated that the closure of brothels has been inconsistently implemented across provinces and districts, and closures rely greatly on local regulations (FGD13). However, those that have occurred have resulted in the dispersion of sex workers who are now much harder to reach

for health and support civil society organizations (CSOs) (FGD5). Multiple studies around the impact of brothel closures are being conducted by a range of organizations, including the Indonesian Sex Workers Network (OPSI) in collaboration with the National AIDS Commission and PPH Atma Jaya. The goal is to understand the types of health-related services that are utilized by sex workers and how these are impacted by the closures. (FGD16).

Sex workers can be involuntarily detained in rehabilitation centers for up to six months (WHO & Kementerian Kesehatan Republik Indonesia, 2017). Overall, interviewees highlighted the fact that local (sub-national) regulations on the prohibition of sex work have flourished in recent years (FGD8, FGD11). Some focus group discussion participants noted that raids and testing might be done with the agreement of the Provincial Health Office and the Provincial AIDS Commission, although this remains unconfirmed (FGD11). Another interviewee noted that when sex workers are in police custody and test positive for HIV, they are encouraged to undergo treatment. HIV-negative sex workers are more likely to be kept under police custody, pending a court case. The decision as to how to address sex work is left to the local law enforcement authority (FGD16), resulting in very different approaches in different cities (FGD11).

The Indonesia desk review highlighted that while sex work is not directly proscribed at the national level, the Criminal Code prohibits women (and their families) living on earnings as a sex worker. The possession of condoms may be used by law enforcement personnel as evidence of sex work in several provinces. Oftentimes police confiscation of condoms occurs (Wolfe et al., 2012; Bhattacharjya et al., 2015). Outreach health workers have reportedly been arrested for carrying condoms as suspected sex workers, driving sex workers further away from health services (Godwin, 2012). In-country interviewees additionally noted that laws such as the 'tourism law' are cited as making the holding of condoms illegal (this remains to be checked in the language of the law). Other laws, such as those focused on peace and security and anti-pornography, are also used to target sex workers, which can all greatly constrain their access and use of services (FGD13).

The desk review also noted that many local regulations directly criminalize sex work despite evidence of the harms that these laws can cause (WHO & Kementerian Kesehatan Republik Indonesia, 2017). In Bandung, for example, the city government enacted a Perda (sub-national law or regulation) in 2005 that prohibited transactional sex. Recommendations to repeal such regulations were included in the HIV/AIDS National Strategy, but the desk review suggested that there had been no advocacy work since then (WHO & Kementerian Kesehatan Republik Indonesia, 2017). Fieldwork in Bandung clarified there has been little advocacy work in relation to this law since 2005. The SPM can be a basis for local districts to provide funding for HIV prevention and care (in particular for those who are not covered by health insurance) and to reach particularly vulnerable populations. Therefore, the invisibility of sex workers is of great concern (FGD13). To make things worse, CSOs noted that in the past services extended to sex workers were ignored by domestic and external funding sources.

### **Punitive laws, policies and practices relevant to men who have sex with men**

The desk review noted that there are national laws and policies in Indonesia that characterize same-sex sex as “deviant” or “immoral” (e.g. No. 44/2008 on Pornography and provincial regulation No. 13/2003 on Eradicating Immoral Acts in the Province of South Sumatra) (National AIDS Commission, 2015a). The Ministry of Law and Human Rights has reportedly indicated that laws criminalizing men who have sex with men are inappropriate and the Constitutional Court rejected a petition in December, 2017, seeking criminalization of same-sex sexual conduct and sex out of wedlock (WHO & Kementerian Kesehatan Republik Indonesia, 2017). In-country interviewees support the information gathered in the desk review in that existing policies are not in any way favorable to key populations, particularly men who have sex with men (FGD5).

### **Punitive laws, policies and practices relevant to transgender people**

The 2015 National Consultation included in the desk review listed several concerns for transgender people in relation to the legal environment. Interviews in country noted that broadly speaking, current public policies are not favorable to transgender populations (FGD5). In particular, Chapter XIV: Crimes against Morality in the Penal Code criminalizes the identity of transgender people. There are also regulations that exist at the local level around immoral and indecent acts that are used to target transgender populations.

### **Punitive laws, policies and practices relevant to people who use drugs**

In Indonesia, drug use and possession are criminalized. This creates serious barriers to access to HIV and TB services for people who use drugs. Even as methadone and/or needle and syringe exchange programs may exist, they are undermined by the criminalization of drug use (WHO & Kementerian Kesehatan Republik Indonesia, 2017). In this vein, the criminalization of drug use has been noted to result in “...marginalization; arbitrary detention, torture, inhumane prison conditions, excessive punishments including death penalty; antiquated methods of forced treatment and detoxification; as well as exposure to increased risk of infection with HIV/AIDS” (Forum Korban NAPZA et al., 2012). People who use drugs may be subjected to lengthy pretrial detention and extortion at the hands of police and prison guards (OSF, 2013). According to OSF, the “war on drugs” in Indonesia has truly become a war on people who use drugs (OSF, 2013). In 2017, the UN Special Rapporteur on the Right to Health noted that the approach to drug policy in Indonesia “remains excessively punitive, undermining the right to health of people who use drugs and public health efforts” (Puras, 2017).

It was reported in 2013 that police officers regularly pressure those arrested for drug use to pay bribes to avoid more serious offenses (OSF, 2013). Detainees often found themselves paying these bribes because they held the promise of sparing them weeks of intimidation and torture while they awaited trial. Not surprisingly, these bribes usually have little bearing on the actual duration of their pre-trial detention. The police also

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reportedly extort money from any relatives or friends who come to visit the accused (OSF, 2013).

Focus group discussion participants in Makassar noted that the police sometimes visit methadone maintenance therapy (MMT) locations to seek information and details about users. In these cases, workers may end up forced to reveal names of their clients. The police then use this information to conduct surveillance on the users with the intent to catch them when they are doing drugs (FGD31) or to track their suppliers. Government Regulation No. 25/2011 on Implementation of Mandatory Self Reporting notes that this practice is meant to facilitate access to treatment and rehabilitation for drug users. However, the National Consultation discussed it as a legal protection “not proven to positively impact” people who use drugs.

Most people who use drugs interviewed by the research team reported that they received needles from needle and syringe programs. However, focus group discussion participants noted that such programs have many problems. These include the limit of five syringes that can be received per visit, distances required to be traveled, an overall absence of health care workers and inconvenient opening hours. Furthermore, a new regulation requires people who use drugs to provide a copy of their ID card if they want to access needle and syringe programs (FGD22). This is another deterrent to harm reduction services.

Focus group discussion participants noted that there is a Presidential Decree that states any treatments related to drug use will not be covered under the national health insurance plan such as methadone and treatment for hepatitis C (FGD10).

### **Punitive laws, policies and practices relevant to women in the context of HIV**

The desk review noted that there are multiple reports suggesting that pregnant women are required to take an HIV test and are not informed of their right to refuse. While such practices are not in line with ministerial regulations, they are still occurring.

Notably, some potentially protective laws include the Law No. 23/2004 on Elimination of Domestic Violence. This contains broad protections against domestic violence and sexual violence (National AIDS Commission, 2015a). However, focus group discussion participants noted that there is no clear mechanism for women to lodge complaints or seek redress if the law is violated (FGD11). One focus group also noted that forced or “strongly recommended” sterilization of HIV-positive women by care providers still occurs in some provinces. According to this focus group, these situations have re-emerged since 2014: there was a case of forced sterilization of a woman with HIV reported in Banten which revealed the “lack of legal and human rights awareness of the victim and limited legal aid assistance available for this type of issue” (FGD11). Although the case was reported to the Commission of Women Protection and later taken to court, the case against the medical practitioner was dismissed. The court concluded that this was not a case of individual professional misconduct, but instead was a “systemic” case. The Women HIV Network is

monitoring the situation closely to determine if ultimately this will result in better or worse rights protections for women. It should also be noted that there is no law to prevent or condemn “bodily harm” in the health care setting, even if a patient’s consent to a procedure has not been secured (FGD11)

### **Punitive laws, policies and practices relevant to children**

The desk review highlighted a number of concerns related to children, particularly provisions regarding the age at which a child is considered ‘of age’ for a variety of legal activities (National AIDS Commission, 2015a). A key barrier identified was the age of consent for independent access to services (WHO & Kementerian Kesehatan Republik Indonesia, 2017). Parental (or guardian) consent remains required, including for HIV testing, treatment, and services (WHO & Kementerian Kesehatan Republik Indonesia, 2017). This potentially limits access to vital services for young people who are unable to obtain parental consent. In-country interviews gave examples of how parental consent as a mandatory requirement for testing and treatment for people less than 17 years of age acted as a barrier to services (FGD11, Spiritia PPT). Some Puskesmas staff indicated, however, that unaccompanied children who could present an ID card would be served. It was noted that children under 14 can be supplied with injection equipment if they can show parental consent. However, this disqualifies children who are living on the street (FGD22).

Furthermore, there is no legal protection to ensure children living with HIV are able to continue their education. In some instances, in violation of their right to education, children have been expelled from school on the basis of their HIV status only.

### ***Stigma and discrimination relevant to HIV***

Stigma and discrimination are frequently cited as barriers to accessing and using services for both TB and HIV. However, it is important to note that multiple in-country focus group discussion participants noted that in the past five years, stigma and discrimination for both HIV and TB have lessened to some extent (FGD31, FGD24, FGD19). Despite such improvements, stigma and discrimination from health workers, community members, employers, family, and self-exclusion, serve as barriers to both HIV and TB services. High levels of discrimination and violence towards key populations also lead to difficulties protecting and defending their rights. This increases vulnerability and creates hidden populations (PITCH, n.d. b; Praptoraharjo et al., 2017). Overall, communities’ perceptions of TB and HIV play off one another negatively, resulting in culture clashes between HIV and TB patients as well as amongst implementers (FGD27).

According to in-country interviews, stigma in the context of HIV oftentimes is the result of lack of public knowledge or understanding about HIV, particularly in remote areas (FGD24). Social media affects communities’ perceptions of HIV. For example, the organization Masyarakat Anti HIV/AIDS dan Stop ARV (MAHA STAR) has a Facebook group that says ARVs are poison and recommends herbal treatments (FGD31). According to a study in Bandung, low HIV testing coverage was related to high HIV-related stigma

and discrimination amongst the general population (FGD16). HIV stigma is especially severe against people perceived as coming from key populations. (FGD24). In-country interviews also noted that stigma may be also internal, resulting in self-exclusion from communities as well as health services. People living with HIV will sometimes refuse to accept visits from health staff at home, fearing their neighbors and their community will “become suspicious.” In these cases, if a patient does not initially want to get tested for HIV, then at the next visit at the Puskesmas, the health staff will advise the patient to accept the test and will continue to offer the test until the patient feels ready to do so. Overall, HIV continues to be seen as a frightening disease by many people throughout Indonesia (FGD20).

### **Stigma and discrimination relevant to people living with HIV**

Non-discrimination against people living with HIV is explicitly promoted in national policy. However, stigma against people living with HIV is pervasive, particularly in rural areas where there is still ignorance around the disease (FGD31, FGD19). In-country interviewees noted that if people living with HIV seek services at their local Puskesmas, information about their status could spread quickly. This may lead them to leave their community (FGD25, FGD7). Other interviewees noted that people living with HIV in urban areas may self-exclude when they test positive for HIV. This in turn is particularly a problem for university students, leading to high dropout rates (FGD7, FGD32). In addition to the many cases of overt discrimination against people living with HIV found through the desk review process, many more cases of such discrimination were reported throughout the in-country interviews. Examples include students being barred from enrolling in school, houses of people living with HIV being burned down, local religious leaders stating it is *halal* (i.e. allowed) to kill people living with HIV or evict them from the community, and military personnel’s ranking being “put on hold” when they are found to be HIV-positive (FGD19, FGD25).

While focus group participants in Bandung reported that there are protocols for support upon positive HIV diagnoses, it was noted that 50% of people living with HIV do not end up joining support groups. This may be the result of distance, but also fear of stigma, lack of confidentiality, self-exclusion, and overall lack of acceptance of their status (FGD22).

Multiple focus group discussion participants also noted that people living with HIV do not feel comfortable being open about their status in their workplace. This is supported by reports of people living with HIV being fired from their jobs (FGD32, FGD7, FGD19, FGD22). People have become aware of someone’s HIV status because of breaches in confidentiality from health care workers to a place of employment, or from companies demanding test results from health facilities (FGD7, FGD25).

### **Stigma and discrimination in health care facilities**

Some focus group discussion participants reported that health care workers at Puskesmas are generally welcoming. However, others noted that stigma and discrimination among



health care workers towards key populations living with HIV are extremely prevalent (FGD32, FGD19). Focus group discussion participants in Makassar reported that patients feel unwanted and disregarded, and often experience hurt feelings because of the way health care workers have treated them. In Surabaya health care workers were reported to keep patients living with HIV waiting for a long time. It was also reported that before testing, patients have been asked to seek forgiveness by health workers because of perceived sins before they will be seen. One interviewee noted that patients were sometimes abandoned entirely, and health workers refused to “handle” individuals who were HIV-positive (KII2, KII3, FGD7). It was noted that people living with HIV cannot always assume confidentiality when seeking services (KII3).

Interviewed program implementers noted that some health care workers who administer ART in Bandung are afraid of people diagnosed with TB who come to them for HIV treatment (FGD7, FGD21). This is important to note in the context of barriers to accessing such services

Overall, such experiences reduce people’s willingness to continue to seek services (FGD25). For example, transgender individuals in Makassar reported being made fun of by health care workers (FGD32). Although stigma appears to be rampant in health facilities, there is limited data or documentation available to assess the magnitude of the problem across the country (FGD11).

### **Stigma and discrimination relevant to female sex workers**

Sex work is highly stigmatized in Indonesia. Sex workers report being afraid to seek care, fearing their occupation will be revealed (FGD8). While sex workers are not often rejected by services when they are diagnosed with HIV, the personal and familial shame of being a sex worker persists. This has impacts on longer-term use of services (FGD22, FGD31). One instance was mentioned where a female sex worker was denied care by Puskesmas staff on the premise that the ban on sex work made sex workers ineligible for free care (FGD 5).

Condoms, while key to HIV prevention, are particularly an issue for sex workers as they may be used as evidence of sex work. Possession of condoms was reported in the past to lead to harassment and extortion by the police (Godwin, 2012). In Bandung, although condoms are sometimes provided by health services for free, most sex workers buy condoms themselves. The reasons for doing so included not liking the condoms on offer or feeling uncomfortable in being identified as a sex worker because of the type of condom they have. Sex workers reportedly rarely seek out free condoms when visiting NGOs, clinics for sexually transmitted infections (STIs), or Puskesmas (FGD22).

### **Stigma and discrimination relevant to men who have sex with men**

Focus group participants noted that key populations feel that society’s image of LGBT populations and men who have sex with men in particular is stigmatized much in the same ways as people living with HIV. Thus, some HIV-positive men who have sex with men

report feeling a “double stigma” for being both gay and HIV-positive, and fear rejection from their families and society (FGD32, FGD31, FGD8, KII3). Men who have sex with men in both Makassar and Surabaya report fear of their HIV status being discovered, leading to a hesitancy in accessing testing services (FGD31, FGD8). When men who have sex with men do access HIV services, they report many forms of discrimination in health care facilities (Norella & Ignacio, 2015).

The recent rise of the anti-LGBT movement in Indonesia has also been a strong deterrent to men who have sex with men accessing needed HIV services (FGD12). In Jakarta, men who have sex with men were recently rounded up by a mob and sent to the police where they were accused of pornography. Afterwards their photos were taken and released to the media by a police officer (FGD5). A focus group of HIV program implementers and people living with HIV in Jakarta reported that clubs of men who have sex with men are increasingly attacked by anti-LGBT activists and law enforcement officers (regular police or “administrative” police—the “brown shirts” tasked to “protect morality”). Mandatory urine tests to detect substance use are reportedly often performed after they are rounded up.

### **Stigma and discrimination relevant to transgender people**

While stigma and discrimination towards key populations broadly may have slightly lessened in some areas in the recent past, there seems to have been little improvement for transgender individuals (FGD32). An important issue affecting transgender people in Indonesia is their inability to obtain an ID conforming to the gender with which they identify (FGD31). Heavy discrimination in health care settings as well as social discrimination reveals a strong bullying culture against transgender individuals (KII3). This discrimination has made job options very limited for transgender individuals, many of who live in extreme poverty.

Transgender people also report experiencing violence at the hands of local law enforcement, motorcycle gangs and the Islamic Defenders Front (FGD31, FGD32). Violence against “waria”<sup>9</sup> is common, as these populations are considered to be “obvious in public” (“FGD Report: Community & Youth,” 2017). Transgender individuals report being afraid to fight back when verbally attacked. They also report being beaten, hurt, and sexually harassed by local thugs as well as the police. One interviewee noted that the police do not respond when transgender individuals report cases of violence (FGD8).

Furthermore, direct stigma and discrimination is fostered by governmental programs, such as the Makassar mayor’s “Guard Our Children” program. This program discredits

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<sup>9</sup> “The term *wadam* (*wanita Adam*, “Adam woman”) was coined to substitute for the pejorative *banci* or *bencong*. In 1978 the term was replaced by *waria* (*wanita pria*, “man woman”) because the Council of Muslim Clerics deemed it inappropriate to use a prophet’s name (Adam) in the term referring to men who express their gender more like women (“Being LGBT in Asia: Indonesia Country Report,” 2014).

transgender people as dangerous. The Islamic Defenders Front promotes images of transgender people as sinners (FGD32). Such examples of stigma and discrimination may result in transgender people moving to other cities. This is problematic in that for the few of them who have health insurance cards or IDs, their new location will not match their city of residence. This creates a further barrier to accessing services (KII3, FGD8).

In Surabaya, some Puskesmas offer transgender-friendly services on specific days. On those specific days, transgender individuals reportedly do not have to wait as long (FGD8).

### **Stigma and discrimination relevant to prisoners**

Among HIV-positive inmates, there is much self-stigma, resulting in choices to exclude oneself from services, particularly when prisoners are uncomfortable or unfamiliar with health staff (FGD19). According to another source, prisoners can be denied access to medication and segregated from other inmates, because people lack knowledge of how HIV is transmitted (FGD31; OSF, 2013). Additionally, it was noted in Surabaya that not all hospitals would accept positive prisoners for care (FGD19). Upon their release from prison, inmates are referred to the Puskesmas in their place of residence for treatment follow-up. No information was available on the loss to follow-up of this population. Released inmates residing in a different province clearly do not benefit from any systematized referral for follow-up.

In Makassar, focus group participants noted that there is forced HIV testing in prisons and inmates who test positive may be left without counseling. In Surabaya, prisoners with HIV are finding it difficult to continue their treatment due to a lack of ARV supplies in prisons. Interviewees also reported that upon release there is often loss to follow-up (FGD8).

### **Stigma and discrimination relevant to women**

There is no systematic attention to capturing instances of stigma and discrimination against women living with HIV in Indonesia (WHO & Kementerian Kesehatan Republik Indonesia, 2017). Interviews revealed a considerable amount of self-stigma amongst HIV-positive women, even in cases where their families accept them. Such stigma leads to some women living with HIV avoiding treatment or taking ARVs in hiding (FGD31). In both Makassar and Surabaya, married and unmarried women reported they do not want to know their HIV status, out of fear that no one will marry them or that their partner will leave them (FGD31, FGD20). In Makassar, an HIV-positive diagnosis for women was noted to have resulted in difficulties for women in marrying and taking care of children (FGD31). In-country interviews found that it is much more common for men to leave their wives when they become HIV-positive (or have an STI) than it is for women to leave their husbands (FGD19, FGD 14). HIV-positive pregnant women are often afraid to disclose or have their status discovered by their husbands for fear of stigma, rejection, risk and violence. As a result, some women take ARVs secretly not at all (FGD19).

Focus group discussion participants noted that gender inequalities in Indonesia might lead to such actions as a husband's prohibiting his wife from taking ARVs because he does not want anyone to suspect that he may be positive (FGD31). While focus group discussion participants noted that women do not legally need a letter of permission from a husband to receive testing for HIV or access treatment, women's actions and decision-making may be controlled or undermined by their husbands in many ways, including as noted above (FGD31). These unaddressed issues, and potentially other factors relating to service availability and provider and patient awareness, result in very low HIV testing up-take in antenatal clinics across the country, rarely exceeding 10-15% (WHO & Kementerian Kesehatan Republik Indonesia, 2017).

Focus group discussion participants in Surabaya noted that women are particularly vulnerable to stigma because if they are HIV-positive they are perceived to be sex workers (FGD20). In Bandung, a case was brought to court by a husband accusing his wife to have knowingly transmitted HIV to him. A local legal aid group has engaged in this case, which was still pending at the time of the assessment.

### **Gender-based violence**

Overall, sexual violence, fear of violence, and difficulties negotiating safe sex are all factors known to contribute to Indonesian women's HIV risk. Gender-based violence increases the potential for other violations of women's rights (Veenstra, n.d.). A 2016 study by Indonesia's Women's Empowerment and Child Protection Ministry, the Central Statistics Agency, and UNFPA determined that 41% of women in Indonesia experience at least one of four types of violence at least once in their lifetime (physical, sexual, emotional, and economic). Among them, 33% of women aged 15-64 had reported experiencing such abuse (Hulupi, M. E., 2017).

In a 2015 report of a project conducted by the Indonesian Positive Women's Network (Ikatan Perempuan Positif Indonesia; IPPI) and ResultsinHealth (RiH), it was noted "almost all of the WLHIV interviewed experienced various forms of violence throughout their lives." Violence experienced is most commonly physical violence, particularly sexual violence in the home (and other forms of psychological abuse, including stigma and discrimination and related threats), for which the women attributed their HIV status as a cause (Veenstra, n.d.). Regarding violence against women living with HIV (by intimate partners), focus group discussion participants noted that verbal and psychological violence are extremely prevalent. The male spouses of HIV-positive women often perpetrate this violence, and complaints are rarely lodged (FGD22).

There is a dearth of services available to follow up gender-based violence reports in provinces across Indonesia. While most services are aware of the medical dimensions of HIV (and TB), they are not well versed at handling the social aspects, including those needed to address gender-based violence. In West Java, for example, widespread reports of violence and sexual violence, with no recourse, and victim blaming by health

professionals have been reported (Praptoraharjo et al., 2017). In Bandung it was noted that most health services are siloed and therefore practitioners do not know about relevant organizations and where to refer patients within in the same city for services if violence has occurred. Focus group discussion participants noted that there also appears to be a lack of donor support for addressing gender-based violence (FGD21).

In a recent study conducted in Jakarta with around 700 women who inject drugs, sexual harassment or violence presented itself as a major issue for such women (FGD10). Overall, the support services available for women who use drugs are still very limited. Considering the high levels of sexual harassment and violence experienced by this population, this constitutes a major barrier to their accessing and using health services (FGD10).

### **Stigma and discrimination relevant to people who use drugs**

The desk review highlighted that people who use drugs experience stigma and discrimination at many levels, limiting their ability to access methadone as well HIV treatment as needed. In-country interviews highlight this as well, noting that, in general, health care workers tend to be suspicious of people who use drugs even when they are coming to access services (FGD8). In Makassar, people who use drugs are also not allowed to wait inside some Puskesmas to receive their methadone due to negative stereotypes of what people who use drugs will do, and in Bandung, despite hiring security, a local Puskesmas deliberately excluded people who use drugs from night-time services, for the reason that they were suspected to have stolen materials within the facility (FGD32, FGD17). Furthermore, it was noted that police in Surabaya are known to target rehab centers to arrest people who use drugs, further discouraging access to treatment (FGD19).

According to focus group discussion participants, one of the most pertinent concerns amongst drug users accessing methadone is that it must be accessed daily. Given the limited number of dispensaries, this can make it difficult for people who use drugs to do anything with their day besides access their methadone. These and other human rights issues around accessibility of services makes it difficult for drug users to have the time to seek employment or integrate back into society more generally (FGD10). The effects of this are worsened if the nearest methadone dispensary is far away, even as some drug users have stated they *prefer* accessing services far away to avoid “being detected” (FGD10, FGD8).

Women in Java have reported experiencing double stigma from family, friends, and health services due to their injecting drug use and being a woman. To avoid this stigma, most study participants hid their drug use, socially isolated themselves, and were reluctant to access HIV prevention services, even when outreach workers came to their home (Spooner, C. et al., 2015). This may be replicated also in other parts of the country.

## **Stigma and discrimination relevant to children**

Starting at very young ages, children are subject to serious stigma and discrimination if they are diagnosed with HIV. Being diagnosed with HIV was reported to result in instances where children were rejected by their families, were forced to stay in orphanages, or were forced to enroll in schools in different cities (“FGD Report: Community & Youth,” 2017; FGD24). Focus group discussion participants in Bandung and Surabaya reported cases of students being excluded from school due to positive HIV status, although it is unclear at what level of schooling and what happened as a result (FGD22, FGD8).

Furthermore, it was noted that rural locations and expensive services are barriers to availability and accessibility of HIV-related services, particularly for those below 18 years of age. Oftentimes people below the age of 18 do not have IDs and are often afraid to disclose diagnoses to their parents (FGD32).

## ***Additional barriers to HIV services***

### **Availability and accessibility of HIV services**

Overall, access to HIV testing is increasingly improving (FGD24). As discussed in a Makassar focus group, most people get tested for HIV because of awareness and outreach within their sub-population (FGD32). However, once tested, poor referral systems within Puskesmas, JKN, and lab networks foster long lines, confusion about where to refer people, and disproportionate patient loads (FGD31, FGD7, FGD32). While voluntary counseling and testing (VCT) services are offered at all Puskesmas, the requirement of signed consent forms is seen as a barrier to high uptake. Key populations will only access services if they feel the staff are friendly (FGD19; JEMM, 2017b).

Processes at health care facilities are barriers to availability and accessibility of services for people living with HIV, including “never-ending loops of referral,” (FGD31, FGD32). In addition, relevant HIV services are often geographically distant from one another (FGD31, FGD8). An upcoming government rule “centralizes the procurement of HIV commodities...[which] makes the provinces and cities wholly dependent on central procurement, with no flexibility for them to procure [supplies] themselves, even in cases of emergency.” This rule will further exacerbate the many reports of stock-outs of HIV-related supplies in health care facilities. It will also potentially limit access to many needed services across the country (FGD19, FGD32, FGD7, FGD31). In this context it is important to note that the National AIDS Commission (or Komisi Penanggulangan AIDS/KPA) is currently being restructured to be under the Ministry of Health. It is likely that prevention commodities will be purchased and managed by MOH in the future although as of March 2018 the processes and responsibilities for this have still not been determined.

Spiritia and other NGOs such as Gaya Nusantara are helping to address these barriers by including directories of where to access services on their websites (FGD12, FGD10). In Surabaya, an initiative by Gaya Nusantara was carried out to provide a directory of what services are covered by JKN in different health facilities. These pages and other websites

and apps are useful in helping people access services, although not everyone has smartphones or internet (FGD8, FGD14).

It is important to note that in Surabaya there are currently 10 KP-friendly Puskesmas that offer longer hours a few days a week and there are key population representatives who participate in the trainings for health care workers (FGD19).

Focus group discussion participants noted that oftentimes HIV and TB services are on the same floor within a health facility with only a wall between them. This would seem to be great but they tend to operate independently with implications from a service delivery perspective, and result in an undue and unnecessary burden on the patient. When HIV NGOs want to offer HIV testing to TB patients, there are reported instances of TB practitioners not wishing this to happen because they do not want to “frighten their patients.” In this vein, health worker training could be an avenue to begin to address such barriers to service delivery.

Availability and accessibility of services is very difficult for a variety of other vulnerable populations such as migrants and rural dwellers. In rural areas, information and services are generally more limited (FGD32, FGD25). Focus group discussion participants in Makassar discussed administrative barriers as a deterrent to accessing services for migrants. Although migrants can access most services for free without documentation, they are often hesitant to “be open” about their HIV status (FGD24, FGD32, FGD8). Several focus group discussion participants noted that mobile populations cannot access health services at more than two Puskesmas without re-registering their city of residence or obtaining waivers from the government (FGD5).

### **Poverty and economic and social inequality relevant to HIV**

In-country interviews identified poverty and economic inequalities as barriers to accessing HIV services, in particular for key populations (FGD7, FGD21, FGD22). Although HIV testing is meant to be free, it is not usually paid for by health insurance. One key informant noted that the cost of baseline HIV testing could reach up to IDR 600,000 (approximately US\$40-44) (FGD22). Some people living with HIV from lower economic backgrounds do not even seek care out of fear of it being too expensive (FGD7). Others worry that ARVs will run out once treatment has commenced and they will then be asked to pay for them (FGD31).

In some cases, the cost of the test may be paid by the hospital (not the patient) – such as in the Hasan Sidikin Hospital in Bandung (FGD18). Furthermore, if patients are not a part of JKN, they are required to pay an administrative fee to the health facilities for each visit (FGD31). Few facilities have created work-arounds for low-income patients who do not have an ID card or the ability to access services during regular service hours. For example, some hospitals in Makassar will allow NGOs to carry the ARVs to patients who live in rural areas (FGD32). Some health facilities will provide two months of ARV for those living far away to reduce transportation costs (FGD31). These work-arounds for low-income patients could be explored further under potential programs to address economic barriers.

### **Insufficient coordination between HIV and TB policies and services**

In-country interviews revealed structural and systemic lack of sufficient coordination between HIV and TB structures and systems that significantly influence people's lived experience. Though such issues should be subject to informed human rights advocacy and legal empowerment, they cannot be addressed with the funding made available to human rights programs. However, as they impact an effective, comprehensive human rights response to HIV and TB in Indonesia, this section briefly discusses the issues involved.

Although governmental bodies have recently made efforts to better link HIV and TB services, these efforts are still generally very new and services continue to be largely siloed and disconnected. The limited integration of HIV and TB services, including the lack of adequate referrals systems, significantly reduces access to adequate treatment and care. Multiple focus group discussion participants, including representatives from key populations, NGOs, program implementers and government actors, noted the need to improve coordination and understanding between TB and HIV programs, particularly at the district/municipal levels.

More generally, there is a lack of coordination between services in the private and public health sectors, and insufficient regulation of the private sector. The proportion of people living with HIV receiving long-term care and follow-up from private facilities is unknown. People living with HIV reported that they might move back and forth between public and private sector facilities depending on the severity of their complaints and the resources available to them. This on occasion implies changes to their treatment regimen depending on the availability of specific medicines. The Ministry of Health is considering establishing an accreditation scheme for HIV care facilities that may impact positively on adherence by private prescribers to national treatment norms and improve the quality of cooperation between public and private providers (WHO & Kementerian Kesehatan Republik Indonesia, 2017).

Several focus group discussion participants in Bandung noted that the RSHS Hospital TB and HIV clinics constitute a collaborative model for health facilities between TB and HIV that might usefully be replicated. It was observed that there is little, if any, loss of patients during the initial two-ways referral process, and that services seem to meet quality standards and implement best practices (FGD30). Other focus group discussion participants noted that in Surabaya, there are collaboration efforts that are taking place between local Puskesmas to treat TB and HIV patients (FGD19). These efforts provide opportunities for replication, and need to be sustained, monitored, evaluated and scaled-up.



## **Existing programs to address human rights-related barriers to HIV**

### ***Introduction***

In Indonesia, HIV-related programs have had a specific, sometimes exclusive, focus on key and vulnerable populations. Given these populations' heightened vulnerability, this prioritization has generally been both appropriate and necessary. It is important to consider how the focus on key and vulnerable populations is implemented and communicated within the Indonesian context. It is also important to consider the implications for effectiveness, particularly when programs require a certain degree of self-identification and/or disclosure on the part of individuals. On the one hand, a particular identification may not necessarily reflect how individuals perceive themselves or choose to identify themselves. This has particular implications when people are perceived to belong to more than one key or vulnerable population (FGD5). Choosing non-identification may also often be a matter of protecting oneself from stigma and discrimination. This was repeatedly noted in relation to access to the insurance or the ID card. Furthermore, given the increasingly hostile environment, individuals from particular populations may be increasingly hesitant to disclose certain identities or statuses. They may be hesitant to access any services or programs which might inadvertently expose them to public disclosure. How programs or interventions are being designed and implemented poses serious challenges. On the other hand, some key populations must balance this with the fact that to name themselves as someone from a key population may entitle them to free access to certain services. For example, until 2018, members of key populations were eligible for ART care regardless on CD4 count, whereas others were only eligible at the CD4 350 cut-off. Test and treat for all is being rolled out but is still not in place in all districts.

As described below, there are many notable model programs in Indonesia that address human rights barriers to HIV services. However, overall, when considering the seven key program areas that are the focus of this effort, there are still significant opportunities for growth. To a certain degree, existing gaps have been the result of the funding landscape. For example, a recent UNAIDS survey found that HIV and human rights organizations seem to be caught in the middle of different funding priorities, with one respondent reflecting: "in Indonesia, it is very difficult to find traditional HIV donors to provide support for HIV-related human/legal rights issues. [At the same time], traditional human rights/justice donors have not seen HIV-related human rights work as a priority for them," (UNAIDS, 2015).

The Global Fund supports much of the current HIV-related human rights programming in Indonesia. There is much notable work starting to happen, but due to the relatively recent start of much of the work, there is limited data on implementation and effectiveness. In addition, there is the issue of how expected targets and indicators

influenced programming priorities and activities. One program implementer in Bandung reflected: “even as NGOs think that the (human rights) barriers are critical to addressing HIV and TB, the issue is that the targets and indicators NGOs are responsible for reporting to the government are not on these issues. Until this disconnect is addressed, and the government asks NGOs to report on these barrier issues, it will be very hard to have these issues prioritized by the organizations responsible for implementation” (FGD21).

The programs identified during the assessment have been organized below according to the seven key program areas. Each section begins with the overall status of existing programming in that area, including, where available, highlights of nationally oriented efforts. This is followed by brief discussions of programming relevant to the alleviation of barriers to access and use of services in the three focus cities (to the extent this information exists and was identified during the assessment.) Each program area concludes with a reflection on opportunities moving forward.

The box below briefly notes some of the most relevant implementing organizations for human rights-related HIV programs in Indonesia.

**BOX: Key implementing organizations for human rights-related HIV programs**

GAYa Nusantara, established in 1987 in Surabaya, is a non-profit organization that advocates for the equality and well-being of LGBTIQ and people with diverse sexual orientations, identities, and gender expression.

Ikatan Perempuan Positif Indonesia (IPPI) is a national network of women living with and affected by HIV, established in 2007 in Surabaya. Their mission is to strengthen women living with and affected by HIV and their ability to empower themselves and other women in health, social, educational, and economic aspects through advocacy, funding and skill improvement.

Indonesia AIDS Coalition, established in 2011, is a community based organization that works with and for key populations affected by HIV in Indonesia to provide them an enabling environment, to ensure their rights are respected, and to promote participatory and transparent governance of AIDS-related programs, and government accountability. The Indonesia AIDS Coalition (IAC) is one of the upcoming principal recipients for the next round of funding from the Global Fund.

Indonesia National AIDS Commission (KPA), established in 1994, was part of the Office of the Coordinating Minister for People's Welfare and is the lead agency responsible for the development and implementation of the National HIV/AIDS strategy in Indonesia. In 2016 the responsibility for the NAC Secretariat was placed under the Ministry of Health (MoH).

MAJU is a USAID-funded governance program with a broad human rights and governance mandate, being implemented by The Asia Foundation. MAJU provides technical support,

tools, and training to Indonesian government agencies and various civil society organizations, in their work to protect the rights of citizens, including religious and ethnic minorities, forest-dependent indigenous people in Eastern Indonesia, marginalized individuals, and female victims of violence and discrimination.

Ministry of Health organizes public health affairs within the Indonesian government. The MoH has the mission to improve public health status through community empowerment; protect the public by assuring the availability of complete health efforts; ensure the availability and distribution of health resources; and create good governance.

Lembaga Bantuan Hukum Masyarakat (LBH Masyarakat), established in 2007, is a non-profit organization that provides free legal services for the poor and victims of human rights abuses, including HIV-affected key populations, undertakes community legal empowerment, and advocates for law reform and human rights protections through campaigns, strategic litigation, policy advocacy, research and analysis.

Spiritia Foundation is a national non-profit organization established in 1995 focused improving the quality of live for people living with HIV and assisting in creating a supportive and non-discriminatory environment for people living with HIV. Spiritia is a Principal Recipient of the Global Fund, responsible for delivering prevention and support services to key populations.

### ***HIV-related stigma and discrimination reduction***

In addition to national policies, laws and regulations banning discrimination towards people living with HIV, there have been many efforts to address stigma and discrimination at various levels. These include peer-based programming to help reduce self-exclusion and facilitate access to services by building knowledge, self-esteem, and support networks. Community education programming also seeks to reduce stigma and discrimination among community members, often engaging particularly influential or strategic members such as religious leaders and employers. Although social media and programming with other media have not been heavily utilized outside of communities of men who have sex with men, there have been some efforts to influence broader societal perceptions about HIV and key populations. The role of social media and other media programming represents a large opportunity to reduce stigma and discrimination and improve access to services. Each of these efforts is briefly discussed below.

#### **Peer support/education programs**

There is a significant amount of peer-based programming for people living with HIV. In 2012, for example, it was reported that there were 274 peer support groups of people living with HIV (Wolfe et al., 2012). Of particular note is the work of Spiritia, a national NGO focused on issues for people living with HIV that reports to be currently operating in 181 districts (FGD5). Spiritia is currently one of the Global Fund's principal recipients. In addition to providing funding for people living with HIV, peer and psychosocial support

groups, Spiritia carries out education on positive prevention, treatment, and adherence. They work specifically with key populations including men who have sex with men, transgender people and people who use drugs (Spiritia PPT). Outreach and education efforts with these key populations include information, education, and communication materials and messages, distribution of condoms, and referrals for HIV counseling and testing. This work is meant to facilitate and strengthen the links to services.

In Bandung, program implementers noted that there are also some notable and ongoing peer-support models for women living with HIV such as Female Plus, as well as some integrated HIV and TB peer support activities (FGD21).

### **Community education**

In relation to the rights of gays and lesbians, GAYa Nusantara, a national gay rights group, actively carries out community outreach and campaigns to raise awareness among the general population (KII3). GAYa is now working with Nahdlatul Ulama (NU – Indonesia’s largest Muslim organization) and Persekutuan Gereja-Gereja di Indonesia (PGI – Indonesia’s largest organization of Christian churches) to try to engage religious leaders and communities (KII3).

Lembaga Bantuan Hukum Masyarakat (LBH Masyarakat) is primarily a legal aid organization, but it is well known for conducting activities that reach across all the program areas. One activity is carrying out community education workshops to help “humanize” people who use drugs. This also helps people who use drugs overcome stigma they have come to internalize (OSF Good Practices Guide). As will be discussed below, these community education workshops are part of a broader set of activities intended to create more supportive environments for people who use drugs, including facilitating their access to legal assistance.

As in other contexts, the media in Indonesia can play an important role in affirming or helping to challenge societal norms. As highlighted in the desk review, KPAN has developed guidance for the media on how to reduce stigma and discrimination in the media and conducted provincial-level programs with journalists (UNAIDS, 2012; WHO & Kementerian Kesehatan Republik Indonesia, January 2017). Additionally, NGOs, including LBH Masyarakat, have also implemented trainings for media professionals on HIV (FGD31; FGD5).

In Bandung, program implementers identified what they consider to be an exemplary program called “Community AIDS Care” which aims to reduce stigma and discrimination at a societal level. The program places cadres in each sub-district to provide communities with HIV information and promote utilization of HIV services (FGD21).

In Makassar, the provincial-level National AIDS Commission (KPAP) has specifically engaged religious leaders and communities. Between 2010 and 2011, for example, KPAP worked with other local government-working units (SKPD) to engage religious and

community leaders, among others, in trainings with human rights activists (FGD24). Government stakeholders<sup>10</sup> noted that since the training there had been no subsequent reports of sermons discrediting key populations by these actors. Interviewees emphasized that while most leaders are willing to support the issues personally, they may not be willing to do so on behalf of the institutions they work within (FGD24). There have also been efforts to include HIV messages in sermons. For example, women's Majelis Taklim (regular gatherings for religious learning and performance that have become widespread among Muslims) has been engaged (FGD24). KPAP is also currently creating a Dai Peduli AIDS network (Network of Religious Leaders who care about AIDS) at the Kecamatan (sub-district) level to disseminate accurate information about HIV and AIDS among the community. Some of the information includes correcting negative misperceptions about the use of condoms (FGD24).

There have also been other examples of collaborations in Makassar to deliver targeted sensitization and education to strategic segments of the general population. One example is KPAP's collaboration with PELINDO, the Indonesia Port Corporation, to implement edutainment activities with sailors and dockworkers, considered an important population given their mobility (FGD24; FGD31). There have also been sensitization and trainings done with AHM (Nightlife Association) (FGD32).

In addition to the above efforts with families and communities, program implementers noted efforts related to HIV education programming in workplaces, particularly in large infrastructure (e.g., construction) projects and industrial plants such as garment manufacturers. For example, infrastructure projects sponsored by the Japan International Cooperation Agency (JICA) require local infrastructure partners to have an HIV prevention program. As part of this program, NGOs educate workers and management alike. Program implementers in Makassar reported that no firing due to HIV+ status had been recorded (FGD31). Cultivating stigma-free workplaces where individuals do not have to fear losing their job if they are HIV-positive is an important step toward use of HIV services.

Various organizations have been involved in carrying out HIV education at the community level (FGD19). The Provincial Social Affairs Bureau provides HIV education for the general population in 38 cities/districts, including Surabaya. They are funded by APBN (national budget) and APBD (local government budget) (FGD19). Furthermore, KPAP has supported the establishment of Kecamatan (sub-district) AIDS Commissions and AIDS community-based support groups (Warga Pedulis AIDS or WPA) to educate the general population about HIV and TB. The activities are cost-shared by DinKes (local government health agencies) and village funds (Dana Desa) (FGD19). The WPAs work at the level of the villages and have provided stigma-related education on how to properly handle the

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<sup>10</sup> Government stakeholders included representatives from KPAP, KPAK, the Provincial Health Office, the City Health Office, the Local Government Office, and the Law & Human Rights Office.

body of a person who had HIV (to thus prevent community refusals or rejections for burials) (KII3).

### **Opportunities to strengthen reduction of stigma and discrimination**

Overall the reach of existing efforts is still limited (WHO & Kementerian Kesehatan Republik Indonesia, 2017). In addition to being of limited scale and coverage, the programs that have been implemented have been implemented inconsistently and have often lacked necessary follow-up (FGD21; FGD12). Another limitation is that such programs have not been well integrated into other activities. For example, peer education and community outreach have not necessarily been linked to services. Similarly, there has not been sufficient integration across issues, including for example, HIV and TB (see below) and HIV and violence against women.

In relation to the media, government stakeholders interviewed in Makassar<sup>11</sup> noted that there is a need to intensify media efforts, including trainings for current journalists (they cited earlier KPAP training but noted that turnover among journalist is high) (FGD24). A legal aid activist in Surabaya reflected that although the news is more balanced than it used to be, there are still serious concerns (KII2). Others noted that social media has not been sufficiently mobilized for dissemination of accurate information about HIV (FGD24).

Many NGOs are well adept with social media, as they have received trainings, including from IAC among others, on how to produce effective messages. However, there is still little consistent use of social media as a strategic communication vehicle. This is particularly noticeable in the context of combatting the prevalence of anti-ARV messages and campaigns on social media. According to one interview participant, the limited use of social media as a strategic communication vehicle is primarily due to the lack of employees with a background on social media in these organizations (KII2). There has also been increasing government pressure to shut down some LGBT-targeted social media accused of breaching moral values or disseminating pornography. Additionally, “Our Voices/Suara Kita,” a project conducted by the Women Youth and Development Institute of Indonesia, which aims to empower women to shape policy and programs through mobile technology, was filtered out by the government on several occasions in 2016-2017.

### ***Training for health workers on human rights and medical ethics related to HIV***

There have been various initiatives to reduce stigma and discrimination in health facilities by sensitizing and training health care workers on non-discrimination and HIV (FGD5; FGD21; FGD24; FGD32; FGD19). Some trainings have been carried out at the local level – others have been more centrally implemented, in Jakarta. However, there is a limit to how many professionals from each district are able to participate in such “central”

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<sup>11</sup> Government stakeholders included representatives from KPAP, KPAK, the Provincial Health Office, the City Health Office, the Local Government Office, and the Law & Human Rights Office.

trainings. Even as these trainings are needed and useful, they are not in and of themselves adequate unless there is follow-up (as is also the case with local trainings) (FGD21). Additionally, performance indicators for health workers focus on the number of clients served and do not include coverage or outcomes linked to an understanding of stigma, discrimination, or human rights issues more generally.

Currently, IAC is conducting human rights trainings for health workers from HIV and TB clinics (FGD19). Additionally, as part of a program to develop facilities friendly to men who have sex with men, some stigma reduction training for healthcare workers and communities has commenced. However, this program still needs to be monitored (UNAIDS, 2012; WHO & Kementerian Kesehatan Republik Indonesia, January 2017).

Key informants (KIs) described trainings for health care workers that incorporated Human Rights, albeit to varying degrees (FGD21; FGD31; FGD19). In Bandung, program implementers believe that health workers have generally been well trained on human rights and HIV (although not TB). The issue has been the sustainability of these efforts, particularly as workers move on (FGD21). In Makassar, both government stakeholders<sup>12</sup> and program implementers described multiple trainings addressing stigma and discrimination (FGD24; FGD31). Interviewees believe such trainings have increased the intake of transgender persons at facilities but monitoring the impacts from the perspective of transgender communities has not yet occurred (FGD24). They also explained that there had not been specific trainings on human rights. However, they believe some concepts had been integrated into trainings about effective communication and motivating patients (FGD24). In Surabaya, government stakeholders<sup>13</sup> noted that there is typically some inclusion of human rights and medical ethics in the regular training for health care workers (FGD19).

The UN Trust Fund to End Violence against Women (UNTF) called “One Stop Service” sponsors another beneficial training. This project works toward the integration of services for violence against women (VAW) and HIV. In terms of training, there have been capacity-building activities with counselors working on both issues, as well as peer educators, to increase skills and knowledge on how to provide integrated services for women affected by HIV and violence. This is done in an effort to reduce the stigma and discrimination these women may face when accessing services (FGD19).

### **Opportunities to strengthen training of health care workers on human rights and medical ethics**

As part of the assessment, several substantive issues were identified as critical to incorporate in future trainings for health workers. For example, there is a need to increase

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<sup>12</sup> Government stakeholders included representatives from KPAP, KPAK, the Provincial Health Office, the City Health Office, the Local Government Office, and the Law & Human Rights Office.

<sup>13</sup> Government stakeholders included representatives from KPAP, KPAK, the Provincial Health Office, the City Health Office, the Local Government Office, and the Law & Human Rights Office.

awareness of laws and regulations and how they impact patients, particularly those from key populations (WHO & Kementerian Kesehatan Republik Indonesia, 2017). Informed consent, particularly in the context of HIV, is another area, which requires additional training (WHO & Kementerian Kesehatan Republik Indonesia, 2017). There is also a need for trainings to address provider-patient power dynamics and issues of coercion (FGD11). Finally, one KI from a local health department raised the issue that most trainings currently address only the rights of patients but that there is a need to also incorporate content about the rights and responsibilities of health care workers (FGD19).

In addition to rounding out the content of trainings, key informants also emphasized the importance of ensuring adequate follow-up. Follow up could include trainings for new staff, refresher in-service trainings, continued monitoring and supports (FGD21) and expanding the reach of trainings to include other health services staff (e.g. guards and receptionists) (FGD19). It was also noted that ethics and human rights should be included as a standard part of medical and nursing curricula to ensure people coming out of school already have these sensitivities.

### ***Sensitization of lawmakers and law enforcement agents***

According to LBHM and other key informants, there appear to have been a very limited number of training efforts with lawmakers, police and judges.

In Bandung, program implementers recalled a local training with law enforcement on human rights but could not provide any details or any indications of who might have information about such trainings (FGD21). In Surabaya, government stakeholders<sup>14</sup> reported that Dinkes have some informational sessions for the police (FGD19) and that the Global Fund also supports some programs with the police (KII3). They also referenced a past initiative by the Indonesia HIV/AIDS Prevention and Care Project (IHPCP) to sensitize the court system to HIV and human rights issues in Batu city (FGD19).

There have been a substantial number of educational programs in the context of prisons. A legal aid activist in Surabaya, for example, affirmed that there had been many trainings for prison officers (KII2). These programs have been supported by UNODC and DFAT, with DFAT's HIV Cooperation Program for Indonesia (HCPI) having worked closely with the KPA and the Department of Corrections (DOC) in 11 model prisons to train staff on HIV and STI service provision and planning. DOC produced a DVD and mentoring guide on comprehensive HIV services and best practices that was distributed to all prison clinics. This program ended in 2016.

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<sup>14</sup> Government stakeholders included representatives from KPAP, KPAK, the Provincial Health Office, the City Health Office, the Local Government Office, and the Law & Human Rights Office.



### **Opportunities to strengthen sensitization of law-makers and law enforcement agents**

Key informants identified a series of challenges in working with the police. One challenge is that turnover among police is very high, so even if police may receive training it does not necessarily ensure a consistent level of awareness on human rights sensitivity within the force (KII2). One key informant also observed that police are becoming a “protector of morality,” exploiting the current antagonistic climate against key populations in order to commit coercion and extortion (“easy money”) (KII3).

As for the prison education efforts, it has been recommended that officers be provided with complete and up-to-date HIV/AIDS-related information and trained, as these efforts are limited. This will assist them in evaluating their limited personal risk in contracting HIV from inmates within the penal system (desk review). Materials developed under HCPI in 2015/16 could still be relevant, for example.

### ***Legal literacy (“know your HIV-related rights”)***

There are several community-run programs in Indonesia with a legal-empowerment approach that include legal literacy and human rights education (UNAIDS, 2012; WHO & Kementerian Kesehatan Republik Indonesia, January 2017). Of particular note is LBH Masyarakat’s (LBHM) paralegal training program for people who use drugs. Paralegals trained in this way can provide certain forms of immediate legal assistance, including trying to reduce the length of pre-trial detention, and visit individual drug users after their arrest, taking their testimony. Where procedural violations have occurred, they try to secure their release (OSF, 2013). The paralegals also consult regularly with lawyers who can represent detainees in court (OSF Good Practice Guide). To ensure that the paralegals are regularly updated in terms of laws and legislative developments, LBH Masyarakat seeks to provide ongoing trainings and updates (OSF Good Practice Guide).

LBHM aims to promote legal literacy and empowerment. This is done via a model that “aims to build trusting, long term, sustainable relationships with communities, by enhancing community knowledge, skills, confidence, and leadership capacity to take action for themselves wherever possible.” The key elements of [their] community legal empowerment model include training and supporting community paralegals to provide ‘legal first aid’ to resolve issues. LBHM also determines whether or not legal action is possible, and provides community legal education on specific issues identified by communities (FGD 6; IDLO, 2010; Godwin, J. 2012). As part of the program relating to people who use drugs, LBHM trains former and current users to be paralegals and conduct outreach and legal education (OSF, 2013). These paralegals also help document human rights violations and provide some immediate legal assistance to those facing arrest or detention (OSF, 2013).

In the context of prisons, NGOs have been implementing activities to build awareness among inmates regarding their health (and risks to their health), as well as their rights as

prisoners (FGD5). In Bandung, key informants described a legal literacy program for youth in public and private junior and senior high schools. The program started this last year with funding from the Ministry of Justice and Human Rights. It entails a one-day seminar with simulations that touch on HIV and TB human rights-related issues and there is interest in expansion (FGD17). There has not yet been any evaluation of the impact of these trainings.

In Makassar, government stakeholders<sup>15</sup> described how issues of basic rights have been more deliberately inserted into discussions in health service contexts. This includes access to health and welfare services and the right to reject counseling. They affirmed that patients generally know their rights when they seek HIV-related treatment and that there is no forced counseling and testing (FGD24).

### **Opportunities to strengthen legal literacy (“know your rights”)**

Overall there is still very limited legal literacy amongst key populations or the general public (FGD8; KII3; FGD13). Taking into account low perceived levels of reporting of violations, there is an urgent need for increased efforts in this programmatic area. There is also a need to ensure that the delivery and content of trainings are substantively accurate and tailored to audiences (KII2). As noted in the 2015 *National Consultation*, additional trainings are needed for people living with HIV to have a better understanding and awareness of their health-related rights. There is also a need to increase legal empowerment programming for other key populations. For example, a focus group with sex workers described very low legal literacy levels among sex workers. They noted that although there has been some work with this population (with Global Fund support), it was limited to only a few locations (FGD13).

### ***HIV-related legal services***

Although Indonesia generally lacks specific legal services for people living with HIV (FGD25), there are certain legal aid services that can be beneficial to people living with HIV. For example, NGOs such as OPSI (Indonesian Sex Workers Network) and LBH Masyarakat are working to provide key populations with paralegals to help represent them (UNDP (b), n.d.; UNDP, UNAIDS, & ESCAP, 2016). LBH Masyarakat and Indonesia Legal Aid Association also directly handle some HIV-related legal cases (FGD31).

However, key informants report that many key populations do not know about their existing options for legal assistance (FGD19; KII2). Individuals from stigmatized populations may encounter barriers when they seek out legal assistance or representation. For example, some lawyers may refuse, or be hesitant, to take on cases involving men who have sex with men and/or gay men (KII3). Where there are active KPAP or KPAD at provincial or district level, they may be able to act as a resource or referral entity for key

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<sup>15</sup> See above footnote.

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and vulnerable populations, but KPA itself does not provide direct legal assistance or services (FGD24).

Moreover, there are few existing complaint mechanisms in Indonesia for individuals who suffer human rights violations. KOMNAS HAM is in Jakarta and is apparently not easily accessible to those living outside the capital. For women who suffer domestic violence, including women living with HIV, there is no clear mechanism to lodge complaints or seek redress (FGD11). For people who use drugs, specifically those who experience abuses or violations at the hands of police, key informants identified two entities which are sometimes utilized to file complaint, but this generally entails having to leverage contacts and personal relationships through NGOs and KPA (FGD19). The first is PROPAM (the Police Professional and Security Division, which carries out internal investigation of police who violate internal policies) (KII2; KII3). The second is KOMPOLNAS (the National Police Commission, which also receives complaints about police performance) (KII3).

In terms of linking prisoners to legal services, key informants report incipient efforts (FGD21). Current paralegal efforts also seek to ensure that prisoners with HIV have access to their ART drugs (there is no evidence of paralegals doing similar work for TB patients) (FGD10). Key informants urged that there should be an effort to update the referral list that individuals receive upon release from prison. This would help to ensure that they are adequately informed regarding available supports, including those that offer legal services. Key informants noted that the current list that is provided is extremely outdated (FGD21).

In Bandung, key informants reported that the District Aids Commission had, with the support of the Global Fund, recently established a legal and advocacy unit with a part-time lawyer. The lawyer's job is to connect with legal services to ensure law and rights issues are being properly handled. However, the unit is not yet fully operational and there is still not complete clarity on what it intends to achieve (FGD21; FGD16). Key informants also described efforts to reach out to general legal aid services to sensitize them to HIV issues. These legal service providers were generally described as well trained and well connected to local NGOs. However, one key informant expressed concerns that legal services may be forging ahead with legal strategies or approaches in HIV cases without sufficient consultation with NGOs working on HIV or people living with HIV (FGD21).

In Makassar, NGOs have taken the initiative to coordinate with the local Puskesmas and KPAP to mediate in cases of discrimination, including in rural areas (FGD31). Program implementers noted that there is a paralegal service that works with PKBI (Planned Parenthood Association of Indonesia) and the city or district-level National AIDS Commission (KPAK) (FGD31). These may be important models to document, assess and follow.

### **Opportunities to strengthen HIV-related legal services**

As mentioned above, many individuals do not know about existing legal services and support that they may access. There are also few available complaints mechanisms. It is also not clear to what extent the mechanisms that do exist are accessible and responsive in Jakarta or more broadly across the country. There should be efforts to recruit, train and support cadres of peer paralegals for key and vulnerable populations. These efforts should follow and/or be integrated into community-based delivery of prevention and treatment to these populations. Also there should greater integration and expansion of HIV-related legal knowledge and support in existing legal services/aid programs.

### ***Monitoring and reforming laws, regulations, and policies relating to HIV***

Overall, efforts to establish a legal and policy foundation for an effective HIV response have ramped up considerably since 2011 (WHO & Kementerian Kesehatan Republik Indonesia, 2017). One such national-level effort is the Partnership to Inspire, Transform and Connect the HIV response (PITCH). PITCH is a 5-year advocacy and policy-oriented initiative (2016-2020) supported by the Dutch Ministry of Foreign Affairs (and also present in 8 other countries). The goal of PITCH is to build local institutional capacities to lobby and advocate for equal access to HIV and sexual and reproductive health-related services and to promote decriminalization, particularly for key populations. For example, in collaboration with the Institute for Criminal and Justice Reform, PITCH organized a training for members of an LGBT coalition. The training focused on human rights and the process of judicial law. After the training concluded, the coalition prepared an *amicus brief* to present during the Constitutional Court's judicial review on proposed revisions to the country's criminal code that would punish consensual same-sex behavior (PITCH Annual Report, 2016<sup>16</sup>).

NGOs have also contributed to building a research base for advocacy efforts. For example, through their ongoing work with people who use drugs who are caught up in the criminal justice system, LBH Masyarakat has collected data on human rights violations that have been leveraged for policy advocacy (UNAIDS, 2015).

In Makassar, key informants described a successful advocacy effort by NGOs – convincing the Satpol PP (municipal police) to once again allow transgender persons and men who have sex with men to gather in public places (FGD31).

### **Opportunities to strengthen monitoring and reforming laws, regulations, and policies relating to HIV**

As key informants described, NGOs have demonstrated substantial capacity to provide health, legal and support services, research, and training but much less so successful

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<sup>16</sup> <https://aidsfonds.nl/files/uploads/pitch-annual-report-2016-def.pdf>

advocacy or influence with regard to policies and laws. Given the deteriorating social and political environment, specifically for LGBT populations and people who use drugs, NGOs will be especially pressed in their capacity to mitigate the impact of adverse policies, laws, and regulations (FGD5).

While there has been some important research conducted on violations of rights among key populations, there is still a substantial need for additional evidence and advocacy on the effect of the legal and policy environment on the nature and impacts of abuses perpetrated against key populations (FGD11).

### ***Reducing discrimination against women in the context of HIV***

Leading the way to reduce discrimination against women in the context of HIV is IPPI, a national network of Indonesian women living with HIV. IPPI has had a crucial role in research, programming and advocacy activities to create a more supportive environment for women living with HIV. For example, IPPI has organized sexual and reproductive health and rights trainings for women living with HIV (Rivona & Mukuan, 2013). They have also collaborated with other groups, including the National AIDS Commission, to provide trainings for various key groups of women, including sex workers, housewives, migrant women, women who inject drugs, women who are partners of high-risk men, disabled women, women of reproductive age who are sexually active, traditional women, rural women and adolescent girls.

IPPI also carries out work at the intersection of HIV and violence against women. In collaboration with ResultsinHealth (RiH) and with support from UNTF, IPPI carried out activities to create awareness about HIV and violence against women and to ensure a more integrated response from services. These activities included efforts towards increasing the quality of care and reducing discrimination against women and girls who are living with HIV or experience violence. The project called “One Stop Services” (also described above) sought to increase availability of services and put into place more effective referral systems to link services for HIV and services for violence against women. As part of the project, guidelines and documents on VAW and HIV were created “to identify the presence of diagnostic items that indicate if a woman needs to receive additional assistance in the area of HIV or VAW, or other areas and information on the necessary referral.” The project has been able to “establish networks among organizations working on different issues, sharing and discussing the links between them and the opportunities to complement each other.” This involvement is reported to have generated “the opportunity to collaborate effectively towards the integration of their services and to better assist their clients” (Veenstra, n.d.).

In terms of the government response, the Ministry of Female Empowerment and Child Protection has also coordinated some HIV-related activities, which may be of interest, but additional documentation would be needed (FGD24).

**Opportunities to strengthen reducing discrimination against women in the context of HIV**

As with many other programs described, a main limitation in this area has been the limited scale of activities and the need for resources for any scale-up. (FGD22). Many of the activities under the 7 key program areas can be rolled out for women living with and affected by HIV. These include (a) deploying peer human rights educators and peer paralegals and sensitization of traditional and religions leaders to help women know their rights, address stigma, discrimination and violence and resolve disputes; (b) development and dissemination of patients' rights materials for women in MCH and PMCT settings; and (c) integration of HIV and scaling up of programs to address harmful gender norms and gender-based violence.

## V. Findings for tuberculosis

### **TB epidemiology**

As of 2017, the total TB incidence rate in Indonesia was an estimated 1,020,000 new and relapse cases per year. Additionally, there were approximately 32,000 cases of Rifampicin-Resistant or Multidrug-Resistant TB (RR/MDR-TB) reported in 2015. The TB case notification rate is reported to be only about 35%. The treatment success rate for new and relapse cases is 85% , and for MDR-TB 51% (WHO, 2017).

Overall, males reportedly experience significantly higher incidence of TB than women, with a reported 597,000 cases among males and 420,000 cases among females in 2015 (WHO, 2015). TB incidence is also thought to be particularly high in elderly populations; TB in the elderly is often more difficult to diagnose. (Byng-Maddick & Noursadeghi, 2016). Smoking may lead to poorer outcomes, and it is important to note that the smoking rate for males in Indonesia is estimated to be the highest in the world (JEMM, 2017b). Similar to the limitations relevant to the finding on the HIV epidemic in Indonesia, only limited city-specific information was found on TB. Very little information on the TB epidemic among individual key populations was found.

### **Legal, policy and social context for TB**

While no TB specific laws or policies were identified to be potentially protective, existing practices and strategies may be so. The collaboration that exists at national and local level via the Stop TB Partnership Forum is extremely important. The Forum to date consists of 65 member organizations/institutions from the national government, community-based organizations, academia, professional associations, private sector, health care institutions, international partners and individuals.

Additionally, TB is prioritized within the Strategic Plan of the Ministry of Health as well as the strategies listed below, which are generally supportive in human rights terms:

- The Directly Observed Treatment Strategy (DOTS) Strategy (1995)
- The revised National TB Control Strategy, 2016-2020
- Includes a roadmap of TB Elimination 2015-2035
- The previous National TB Control Strategy 2010 – 2014 included a focus on hospital DOTS linkages, MDR-TB management, improvement of laboratory network, and strengthening of quality assurance systems, and HIV collaborative activities.
- Ministry of Health Decree 67/2016 on Tuberculosis Control

The 2017 Joint External Monitoring Mission of Indonesia flagged some of the achievements of the country program which signify progress in addressing TB, including:

- Incorporation of TB as one of the care targets of the Midterm National Development Plan 2015-2019;
- Addition of TB as one of the minimum services standards and included in a government decree;
- Integration of TB services into the National Health Insurance program JKN; and

- Completion of regulations for the mandatory notification of TB.

The current National Strategic Plan of the TB Program includes a number of goals to strengthen leadership of TB programs at district level, increase access to quality TB services through: “TOSS-TB” (TOSS: find, treat and cure), implement risk factor control, increase partnership in TB through Expert Committee Forums, increase community empowerment in TB control, and strengthen program leadership and management through the strengthening of integrated Health Systems. Implementing such goals includes involving several ministries, each with delegated tasks (“National Strategic Plan of TB Control 2016-2020”).<sup>17</sup>

Effective implementation at local level is dependent on adhering to human rights protections in relation to each aspect of the plan although the National Human Rights Commission does not have local counterparts assigned at the provincial level or below. Provider initiated HIV testing and counseling (PITC) has been adopted as a national strategy for TB patients since 2013 (Minister Decree no.21/2013) (JEMM, 2017a), but at the local level TB facilities may not offer an HIV test. This reflects the discord between national and local laws and implementation. Importantly, HIV remains highly stigmatized, particularly when associated with TB, and that stigma appears to be linked to limited HIV testing services in local TB facilities (WHO & Kementerian Kesehatan Republik Indonesia, 2017).

There are few details of how local districts are adhering to national human rights protections in relation to TB. On the positive side, cadres in Surabaya and Bandung had not heard of TB patients being subjected to forced admission and isolation for not complying with treatment (FGD14, FGD29). The time-limited admission of MDR-TB patients into an isolation ward at RSHS in Bandung appears to be a requirement that is usually well accepted by patients. They are released and seen as outpatients or referred to peripheral health facilities as soon as they test negative for TB. On their return to these health facilities, MDR-TB patients are required to wear a mask. Some patients consider this to be a breach of their dignity. Situations were reported to the assessment team of patients being turned away by health care personnel because they had not complied with this practice.

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<sup>17</sup> Among key ministries are the Ministry of Health (responsible for norms setting, procurement and delivery of goods and medicines, health staff training, and raising and distributing international resources); the Ministry of Internal Affairs (responsible to oversee service capacity building and implementation at sub-national level, in cooperation with local authorities); the Ministry of Social Affairs (responsible for community capacity building and assistance to those in need for social support); and the Ministry of Justice and Human Rights (responsible for the formulation and, in theory at least, the monitoring and evaluation of the correct interpretation and implementation of these laws).



## **Human rights-related barriers to TB services**

### ***Stigma and discrimination related to TB***

In Indonesia, people diagnosed with TB are often stereotyped as infected because they come from lower economic backgrounds with low education levels. There is particularly poor information about TB and MDR-TB in Indonesia, resulting in people stopping treatment when they begin to feel better or refusing treatment altogether (FGD8, FGD20). According to in-country interviews, misconceptions about TB tend to increase stigma and discrimination towards people diagnosed with TB. Focus group discussion participants noted that people sometimes feel “disgusted and frightened” by people diagnosed with TB (FGD14). These phobias may remain even after a person has completed treatment (FGD25). Intense gossip about people’s suspected TB status increases fear of TB within communities (FGD14). In Makassar, it was noted that there were cases of families quarantining and neglecting family members diagnosed with TB (FGD25).

In-country interviews noted that TB is generally less stigmatized than HIV, as it is considered treatable. However, discrimination is particularly pervasive for people diagnosed with TB who are known to be HIV-positive and vice-versa (FGD20). In some cases, people diagnosed with TB refuse to take an HIV test due to fear of their potential status (FGD20). Focus group discussion participants noted that in Makassar, people do not often refuse TB testing. It was noted that usually patients feel unprepared for the consequences of a positive HIV test result, particularly after being diagnosed with TB (FGD25).

Overall, it is clear from in-country interviews that stigma and discrimination may heavily contribute to poor treatment adherence. Because of stigma, people may travel to access health services far from home and where they must pay (FGD24, FGD14). Focus group discussion participants noted that those who are too ashamed to access services or do not think they can be healed will do nothing or use herbal treatments as an alternative (FGD25). It was noted repeatedly that MDR-TB is more highly stigmatized than TB (FGD15, KII1).

### **TB stigma and discrimination experienced by women**

Females diagnosed with TB are reportedly more stigmatized than their male counterparts. In Bandung, it was reported that pregnant women with TB are particularly stigmatized due to the assumption that the disease and the medicine it requires could harm the baby (FGD27). Communities may ostracize women until they have completed their TB treatment (FGD27). Community norms are that women having contracted TB will be strongly discouraged to marry or found a family, at least until treatment completion if not beyond. Women with MDR-TB may be stigmatized even more severely because communities “don’t understand [MDR-TB] and are scared” (FGD27). Focus group

discussion participants also noted Indonesian culture prioritizes men in terms of receiving treatment first within a family where both men and women are sick (FGD24).

### **TB stigma and discrimination experienced by children**

Starting at very young ages, children are subject to serious stigma and discrimination if they are diagnosed with TB. Being diagnosed with TB was reported to result in instances where children were rejected by their families, were forced to stay in orphanages, or were forced to enroll in schools not in their home cities (“FGD Report: Community & Youth,” 2017; FGD24). One interviewee described a senior high school student in Bandung who missed his final exam because of the onset of TB symptoms. He was given another chance to take the exam and passed. He will have to complete his treatment before considering his later educational options and, in the interval, is volunteering as a TB advocate.

### **TB stigma and discrimination experienced by people who use drugs**

The desk review highlighted that people who use drugs experience stigma and discrimination at many levels, limiting their ability to access methadone as well as TB treatment as needed. In-country interviews highlight this as well, noting that, in general, health care workers tend to be suspicious of people who use drugs even when they are coming to access services (FGD8). In Makassar, people who use drugs are also not allowed to wait inside some Puskesmas to receive their methadone due to negative stereotypes of what people who use drugs will do, and in Bandung, despite hiring security, a local Puskesmas deliberately excluded people who use drugs from night-time services, for the reason that they were suspected to have stolen materials within the facility (FGD32, FGD17). Furthermore, it was noted that police in Surabaya are known to target rehab centers to arrest people who use drugs, further discouraging access to treatment (FGD19).

### **TB stigma and discrimination experienced by prisoners**

Prison inmates are systematically tested for both TB and HIV on admission—at least when supplies of diagnostics are available (FGD29). However, a lack of staff limits coverage. According to focus group participants, there is no funding for HIV-TB services in prisons and not all prisons have trained health staff (FGD19). Furthermore, when people are diagnosed prison staff often do not know what to do with them (FGD17). For TB care, prisons in Makassar are completely dependent on Puskesmas (FGD24). In addition, the only time cadres see people diagnosed with TB in prisons is when they were connected to them before they were incarcerated (FGD27).

Inmates needing treatment are cared for by prison physicians when available, with the support of periodic visits by specialists (two out of three prisons in Bandung) or by staff of the neighboring Puskesmas. Focus group discussion participants in Surabaya revealed broad stigma and discrimination from prison staff and other prisoners experienced by those diagnosed with TB (KII2). It was noted that prison staff and other inmates widely fear being infected (FGD 19). Because isolation space is limited, inmates diagnosed with

TB are often relocated to prisons with more space for isolation. Relocation causes disruptions in treatment and dropout from treatment as well (FGD19).

### **TB stigma and discrimination in health facilities**

People diagnosed with TB report that fear of stigma and discrimination from unfriendly health providers is often a deterrent to seeking treatment. For those who are diagnosed with MDR-TB, the stigma experienced at Puskesmas is particularly high (FGD15). In Bandung, it is reported that some patients have been turned away from some Puskesmas, but this was not widely noted (FGD27). Employees at the RSHS TB program widely felt that “stigma and discrimination do not affect the attendance of suspect TB cases to the clinic nor their adherence to the treatment,” despite the many reports of stigma and discrimination experienced by people from key populations diagnosed with TB (FGD29). This may simply reflect the difference between provider perception and the realities experienced by patients. It is also possible the TB clinic of the RSHS Hospital sees only people with suspected or confirmed TB, and this results in friendly staff behavior.

### **TB gender-related issues**

In-country interviews highlighted that people are well aware that men are more likely to become infected with TB via increased exposure from their jobs such as factory workers, truck drivers, and rickshaw drivers, for example (FGD14). Women, on the other hand, are more likely to be home ‘due to gender norms rooted in inequality, therefore have less risk of TB exposure to TB’ (FGD15). Importantly, treatment outcomes are not entered into management information systems in ways that differentiate females from males. It is therefore not possible to compare rates of treatment success, failure, or between men and women.

The desk review and interviews did not reveal information on gender-based violence in the context of TB in Indonesia.

### ***Availability and accessibility of TB services***

The most prominent provider of TB services is the government. Focus group discussion participants in Surabaya reported that DOTS is available *only* in government settings, although some people do receive treatment in private clinics (FGD26, FGD25, FGD20). In fact, it is estimated that close to 50% of TB care may be initiated in the private sector. All TB medicines are free from the government (FGD14, FGD20, FGD29). However, there was concern expressed by patients in Bandung that the number of doses patients receive each time appears to be random and not standardized, suggesting that there may be poor communication between the service providers and patients (FGD28). Many public-sector providers are trying to work with private doctors to have TB patients referred to their local Puskesmas or Dinkes, particularly because TB tests are free at Puskesmas (FGD25, FGD20, FGD8). Nonetheless, in Surabaya it seems high- and middle-class individuals will use private sector providers because they want to avoid being seen using public services.

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They also choose private services for the more comfortable setting that providers are assumed to have (FGD20, KII3).

On the positive side, PMO (companions for taking medicines) networks in many places accompany patients to their appointments and help to make sure they are taking their medications. In some places, they can also get medicines on behalf of patients (FGD25). Some cadres will take the medication to the patients' homes and find a local nurse to help administer the medication if needed (FGD25).

In addition to difficulties with staffing, the opening hours of most Puskesmas in Indonesia (8am-2pm) also make it very difficult to access needed services. Although focus group discussion participants in Surabaya reported that some Puskesmas have extended hours a couple days a week, limited hours are the case throughout most of the country. As noted in Bandung, TB services are only available one day a week within these limited hours (FGD14, FGD12, FGD28). There is also limited access to certain tests and technology as well as weak distribution, and monitoring and evaluation of TB supply chain management (Ministry of Health Republic of Indonesia, n.d.). A limited number of health care workers work in TB, which makes coordination in accessing services difficult for many patients (FGD27). In order to receive treatment, people diagnosed with TB must get a referral. However, TB doctors are not available every day, which requires people to come back for multiple visits (FGD28).

Accessing services may be especially difficult for MDR-TB patients who may need to visit a health care facility every day to access treatment. The treatment's side effects are reportedly also major deterrents to continuing treatment, especially when doctors do not fully explain all possible side effects (FGD14, FGD15).

### **Poverty and economic and social inequality relevant to TB**

In-country interviews identified poverty and economic inequalities as barriers to accessing HIV and TB services, in particular for key populations (FGD7, FGD21, FGD22). For those needing TB treatment, a hospital visit is required to confirm results to receive treatment (FGD27). The drugs that alleviate the negative side effects of treatment are oftentimes too expensive for those with no JKN. For MDR-TB specifically, one focus group stated that most people diagnosed are not employed and have limited education (FGD 14). Furthermore, individuals from low-income backgrounds may live in crowded living quarters with no ventilation (FGD14). For TB, there is greater allowance for providing several days or weeks of medicines to patients under DOTs programs.

## **Existing programs to address human rights-related barriers to TB services**

### ***Introduction***

TB programming in Indonesia has generally not had a specific or prominent focus on key populations. The National TB Program does not consider the terminology of ‘key populations’ to be particularly useful for targeting TB interventions. They consider the vast majority of the undiagnosed TB cases in Indonesia to be widespread across the general population. As TB remains a leading and first-appearing opportunistic infection associated with HIV, it may make sense to offer HIV testing systematically to newly diagnosed TB patients. This is policy in priority districts known to have high HIV prevalence. TB screening and testing is much more frequent among people diagnosed with HIV, but there are additional barriers to people living with HIV in seeking a TB diagnosis and enrolling in TB treatment. TB treatment should be and is normally prescribed prior to the uptake of ART by people living with dual infections. However, Isoniazid Preventive Therapy (IPT) uptake for PLHIV is very low, despite clear NTP directives. The longer-term implications of this approach for key populations remain to be understood.

In recent years there has been a major shift in how TB programs are implemented in Indonesia. As explained to the assessment team, TB programs have gone from a heavy, almost exclusive reliance on medical services-centered approaches to more NGO-centered approaches focused on working in and addressing community contexts. Up until 2006, there were few NGOs dedicated to TB work. The number of NGOs working on TB has increased dramatically, partly because of widened geographic areas engaging in TB elimination; the expanding population; the unabated spread of TB and the emergence of MDR-TB; and financing opportunities from the Global Fund and a handful of other international funding and technical assistance agencies (FGD9).

Generally, TB programming implemented by NGOs focuses on two specific areas: TB education and awareness for the general community and TB patient treatment compliance (FGD9), with little explicit attention to human rights. Most NGOs working on TB are attached to or running TB clinics and working directly with communities. Currently, TB-related clinical work is primarily performed by the Ministry of Health while TB-related community work is implemented through Aisiyiah, a faith-based organization and a current principal recipient of the Global Fund (FGD9), and from 2018, by LKNU as a sub-recipient under the NTP. Aisiyiah has been building the capacity of local groups through training on program management, fundraising, advocacy, and participatory techniques, all with aim of ensuring the sustainability of TB prevention efforts, but to date, with little expressed attention to human rights or ethics (GF grant agreement; Aisiyiah website).

As discussed below, while programmatic work is beginning to focus on mobilizing and empowering patient and community groups, human rights-related work in this area remains limited.

**BOX: Key implementing organizations for TB programs**

Aisyiyah is a faith-based, voluntary organization founded in 1917 as an Islamic faith-based women's organization under Muhammadiyah, one of the two largest Islamic organizations in Indonesia. An autonomous women's organization, 'Aisyiyah contributes to women's empowerment by strengthening women's participation in all aspects of social and economic life.; Their health program has included a dedicated focus on TB since 2012. Its programs have been revamped since GF support became available (Aisyiyah is currently a principal recipient). Amongst their other duties, Aisyiyah's cadres carry out advocacy with religious and community leaders, school administrators and teachers to promote non-discrimination and reduce community stigma related to TB.

LKNU is the health branch of Nadhlatul Ulama (NU), one of the two largest Islamic religious organizations in Indonesia, established in 1926. NU has an estimated membership of up to 45 million people spread across the country. As of 2018, LKNU is a Global Fund sub-recipient under the Ministry of Health TB grant. They were previously one of three implementers under the USAID-funded CEPAT program, which focused on increasing people's awareness of TB prevention and early detection, as well as fostering and facilitating local commitment to the national program.

Stop TB Partnership Indonesia is dedicated to supporting and strengthening the national TB response in Indonesia. It brings together a diverse membership of government, private sector, professional and civil society organizations, including groups that comprise and represent current and former TB patients.

Stop TB / TB REACH: Several Indonesian organizations, including most recently the MOH, Muhammadiyah and Menara Agung Pengharapan, have received grants from Stop TB under the TB REACH program.

***Reduction of TB stigma and discrimination***

In 2016, eight TB patient groups in Indonesia established a national network called POP TB (Perhimpunan Organisasi Pasien TB; Association of TB Patient Organizations) which "aims to provide a platform for the voices of TB patients, represent TB patients in national level discussions and forums, contribute to planning and decision making and to participate in monitoring the implementation of national policies. POP TB also aims to promote and facilitate the establishment of more local TB patient organizations all over Indonesia and to build the capacity of its members" (Ministry of Health Republic of

Indonesia, n.d; USAID).<sup>18</sup> As noted, ensuring more visibility and agency for those affected by TB in the national and local contexts is a necessary step to dismantle the continued stereotypes and stigma surrounding people diagnosed with TB. To date, there has not been a specific focus on human rights or human rights training but this would seem to fit the ethos of the organization and could be easily integrated into the work this network is undertaking.

One of the more visible programs for addressing stigma reduction is Ketuk Pintu (Door to Door), which is organized by Aisyiyah and DinKes and centers on a network of community cadres. The cadres use a community-based approach to facilitate access to TB testing and treatment and to reduce stigma and create a supportive environment. After training, the cadres work within communities to identify and locate suspected TB cases – knocking on doors of homes and referring suspected cases to health centers or encouraging diagnosed individuals to take their medicines (FGD5; FGD14). Cadres are assigned to specific Puskesmas– in Bandung city, for example, one or two Puskesmas in 15 Districts participate in the network with approximately 100 cadres assigned to them (FGD27). On average, a cadre refers 10 suspected TB patients per month to the Puskesmas. In cases of individuals younger than 60, the cadres also recommend an HIV test (FGD27).

Cadres receive incentive payments of IND Rps 15,000 (approximately US\$1.12) for each suspected TB patient they refer to the Puskesmas and IND Rps 40,000 (approximately US\$3.00) for each newly diagnosed case of TB or HIV (FGD27). While this would seem to suggest a potential for abuse, the assessment team heard no issues of concern during fieldwork.

Aisyiyah’s cadres also carry out advocacy with religious and community leaders, school administrators and teachers to promote non-discrimination and reduce community stigma related to TB (FGD25; FGD5; FGD14). The cadres engage family members, educating them and recruiting them to help monitor patients’ adherence to medication. As one cadre explained for a news article: “So we talk to them and try to convince them TB is not a curse, and not something to be ashamed of. It’s a serious disease but one that can be cured.”<sup>19</sup>

Aisyiyah reports seeing an improvement in communities as more people who are potentially infected with TB are detected and are less reluctant to visit the Puskesmas for sputum checks and access to treatment (FGD14). However, as a result of the cadres’ work to compel more people to get tested, key informants noted that some local labs had been overwhelmed with the demand and unprepared to accommodate the spiked increase in tests (FGD24; FGD14).

Key informants also described various initiatives that mobilize former patients to act as peer supporters and educators, to help reduce self-stigma and facilitate access to

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<sup>18</sup> [http://pdf.usaid.gov/pdf\\_docs/PA00MF82.pdf](http://pdf.usaid.gov/pdf_docs/PA00MF82.pdf)

<sup>19</sup> <http://www.irinnews.org/report/95632/indonesia-housewives-help-fight-tb>

information, services, and other supports. In Makassar, there are several patient support groups including Peduli TB (Care about TB), a community at Labuang Baji Hospital, as well as a network of TB patients called Kareba Baji. Kareba Baji is funded by the KNCV Foundation and had a model where former patients become motivators for new patients (FGD24; FGD25). However, because the funding has ended, the Kareba Baji network is no longer active (FGD24). In Surabaya, key informants pointed to REKAT, an NGO whose members are former TB patients acting as peer supporters and educators (FGD19; FGD15). According to the “TB Control Program” there are currently 8 TB support groups in Jakarta (PETA), Bandung (Terjang), Semarang and Surakarta (Semar), Surabaya (Arek Nekat), Malang (Panter), Makassar (Kareba Baji – but according to key informants this one is no longer active), Medan (Pesat) and Jember (Sekawan).” (Ministry of Health Republic of Indonesia, n.d.)

Importantly, focus group discussions revealed that people living with TB were generally not aware of support groups even if they did exist (FGD27). For example, in Bandung, during the focus group with TB patients, they all noted that this meeting was the first time they had met other TB patients. Interviewees shared that they had found the space and discussion very helpful and noted that it would be useful to start a support group (FGD27).

### **Opportunities to strengthen reduction of TB stigma and discrimination**

Despite important efforts by existing programs, TB patients emphasized that more sensitization and training is needed throughout society, from the community level through to workplaces, schools, and the media (FGD27). Moreover, as with volunteer-based programming generally, there is the concern of sustainability. Sustainability is a particular concern given the substantial time commitment often involved in community and/or patient outreach efforts that the cadres are involved in doing, and the fact that there is no or limited provisions for livelihood or financial compensation (see also e.g. FGD24, FGD17).

### ***Reduction of Gender-related barriers to TB services***

This is a program area in which neither the desk review nor did the assessment identify any substantial programmatic efforts.

### **Opportunities to strengthen reduction of gender-related barriers to TB services**

Despite evidence that people experience heightened discrimination in relation to a TB diagnosis, there do not appear to have been any notable documented efforts to incorporate gender perspectives as relevant to women, men or transgender populations into TB education, services, and/or advocacy efforts to address discrimination.



### ***TB-related legal services***

There is little known about TB-related legal services. Presumably, individuals could tap into many of the same legal services mentioned above in the context of HIV. According to key informants, violations are certainly happening, but to the best of what the assessment team could ascertain these violations are not yet being brought through the legal system (FGD21). There is also no record of paralegals working with TB patients (FGD10).

### **Opportunities to strengthen TB-related legal services**

As mentioned above, there appears to be limited available legal services and limited efforts to ensure awareness and access to existing services that might be of assistance in cases where individuals with TB suffer violations of their rights. There is also a lack of linkages between legal services and health services. For example, in a focus group in Bandung with Puskesmas staff, interviewees noted that while providers may hear reports from patients of violations of rights, they lack the training or contacts to help their patients and so even if they want to help they have to resort to just informal recommendations (FGD18).

### ***Monitoring and reforming policies, regulations and laws relevant to access to TB services***

Launched in 2013, the National Stop TB Partnership Forum appears to act as a pressure group for social and political action. The Forum seeks to ensure the development and proper implementation of policies to support TB control efforts and increase national and local government budgetary allocations for TB programs (Ministry of Health Republic of Indonesia, n.d.; also Stop TB website<sup>20</sup>). The Forum consists of 65 member organizations/institutions from the following sectors: government, community-based, academia, professional associations, private sector, health care institutions, international partners and individuals. The Partnership has a significant role across many of the above program areas. They embody a comprehensive approach to TB control that is generally supportive of human rights even if not yet a direct focus. For example, the Forum works to ensure access to effective diagnosis, treatment and a cure for all individuals, including key populations, as well as to reduce the inequitable social and economic toll of TB. Many of their partner organizations are active service providers.

The NGO Japeti, founded in 2013, is currently engaged in outreach and education in six provinces, where it also advocates for increased local funding for TB work but there does not yet appear to be an explicit human rights focus to their work (FGD9).

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<sup>20</sup> [http://www.stoptb.org/countries/partnerships/np\\_idn.asp](http://www.stoptb.org/countries/partnerships/np_idn.asp)

### **Opportunities to strengthen monitoring and reforming policies, regulations and laws relevant to access to TB services**

It could not be determined the extent to which current policy-related monitoring and advocacy encompass considerations of human rights.

### ***Legal literacy (know your rights) in the context of TB***

Neither the desk review nor assessment identified any substantial programmatic efforts in this program area (FGD14). In a discussion with program implementers at the national level, they suggested that the Patients' Charter for Tuberculosis Care (PCTC) might be useful to improve legal literacy and involve communities on TB issues. The Charter outlines the rights and responsibilities of persons affected by TB. However, it was noted that there is a need to improve available education materials related to TB and human rights, particularly so as to be better understood by staff, patients and community members from modest educational backgrounds (FGD9).

### **Opportunities to strengthen legal literacy (know your rights) in the context of TB**

Despite the declared need for rights literacy-related efforts, there appears to be a notable gap in programming. Key informants emphasized that many TB patients are not aware of their rights (or even do not have a sense that they are specifically entitled to rights). This lack of awareness pertains to such issues as their right to access treatment and medications and to be protected from involuntary isolation or other coercion, particularly in situations of limited financial ability, or when and where they can report violations (FGD17; FGD20). Moreover, in addition to gaps in knowledge, key informants also identified a gap in capacity. Interviewees noted that most organizations doing TB care are not equipped to deal with rights literacy or advocacy issues. This could perhaps be partially resolved by providing a list of referral organizations they could make available to patients (FGD27).

### ***Sensitization of law-makers, and law enforcement agents regarding TB***

This is another program area in which there appears to be extremely limited if any activity. Only some prison-related trainings were identified, albeit without apparently any specific focus on human rights dimensions of TB, or issues of stigma and discrimination.

It was noted that the Indonesia AIDS Coalition (IAC) has conducted human rights trainings for paralegals from NGOs and health workers involving representatives from HIV and TB clinics. More trainings from IAC are planned for other stakeholders (FGD19).

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In Bandung, government stakeholders<sup>21</sup> affirmed that prison officials/staff require substantial training, particularly on stigma and discrimination. What exists is usually done by NGOs (FGD17). However, they also emphasized that these trainings are limited in terms of whom they target and their human rights and/or TB focus (FGD17). In Surabaya, the key informants stated that there were no prison programs (FGD14).

### **Opportunities to strengthen sensitization of law-makers, and law enforcement agents regarding TB**

Given the apparently substantial gap in sensitization of law-makers and law enforcement agents, particularly in relation to rights, this is a program area in which there would need to be a concerted focus on both developing and evaluating new approaches.

### ***Training of health care providers on human rights and medical ethics related to TB***

At national level, the National TB Program has coordinated training (training of trainers) for health care workers from 34 provinces. These trainings include skills building for nurse on effective communication with patients about treatment and adherence (Ministry of Health Republic of Indonesia, n.d.) but without an explicit human rights focus.

In Bandung, service providers noted that there is a training for health care workers on some of the social dimensions of living with TB. Such social dimensions are defined to include personal and community relationships and issues with education, but details were sparse and there was apparently no explicit human rights content (FGD27). In Surabaya, program implementers referenced trainings for health staff on appropriate communication in the context of TB. Implementation was apparently limited and details were sparse (FGD14).

Ketok Pintu is a compelling model for mobilizing individuals to access TB services (primarily), yet cadres report feeling ill-prepared to respond to human rights concerns affecting individuals in the communities where they work. Given that these cadres, along with other community-based health workers, have direct, one-on-one contact with individuals affected by HIV and TB, their families and communities, they are an extremely valuable and untapped source of frontline support for identifying and responding to rights-related issues that might emerge in the lives of these individuals and groups. Some cadres interviewed referred to an earlier training on patient's rights but noted their lack of familiarity about how to apply this in practice, and asked to be provided with a guidance document they could carry with them when visiting patients.

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<sup>21</sup> Government stakeholders included representatives from KPAP, KPAK, the Provincial Health Office, the City Health Office, the Local Government Office, and the Law & Human Rights Office.

### **Opportunities to strengthen training of health care providers on human rights and medical ethics related to TB**

Overall, there seems to be a significant gap in this program area. Existing training efforts rarely, if ever, incorporate human rights and medical ethics and what exists is inconsistently implemented and limited in scale. Indeed, in conversations with national-level as well as local (e.g. Bandung) stakeholders and implementers, there was a consensus that service providers often avoid engaging in human rights issues even if raised by patients for lack information and comfort (FGD27; FGD9). However, it is important nonetheless to note an openness to this kind of work from those interviewed. In a focus group discussion with cadres in Bandung, for example, they expressed a strong eagerness for formal training which would help them be better prepared to support patients and families in relation to rights concerns. The cadres also emphasized the need for human rights-related training and sensitization of health care workers generally, including private care providers.

### **Ensuring confidentiality and privacy in the context of TB**

No relevant interventions were found.

### **Mobilizing and empowering patient and community groups in the context of TB**

No relevant interventions were found.

### ***Programs in prisons and other closed settings relating to TB***

No relevant interventions were found, but it must be noted the assessment team did not visit any prisons.

### **Opportunities to strengthen TB human rights programming in prisons**

Although not specific to programs within prisons or other closed settings, interviewees widely noted that a systematic referral to services for prisoners who have TB when they transition out does not exist. Depending on whether a person lives in an area with a service already linked to the prison, there is no mechanism to ensure they will not be lost to follow-up (FGD17). In Makassar, key informants described an ongoing collaboration between health facilities and NGOs to communicate about and collaborate on remedying cases of loss to follow-up. They reported that there is regular communication between LKB (Continuum of Care) facilities and local NGOs to discuss problems and follow ups for the NGOs to respond to. This model of communication and collaboration was described as very effective (FGD25).

## VI. Comprehensive programs to remove human rights-related barriers to HIV and TB services

### **Introduction**

Before turning to a description of comprehensive programs by which to remove human rights-related barriers to HIV and TB services, it is necessary to underline the insufficient coordination and where relevant integration of HIV and TB services. While such services should be of equal reach and quality, TB services have a longer history than HIV services and, as a result, were perceived to be ‘more dominant.’ Historically, TB care providers have applied biomedical and therapeutic standards relying heavily on health facilities while HIV programs have, from their onset, placed emphasis also on community participation, empowerment and capacity building. A further characteristic of HIV programs is that they are intended to extend support and services to disenfranchised, in some cases populations who live outside the law, which is not a prominent feature of most TB programs. Improving collaboration between HIV and TB services will require structural, strategic changes as well as some efforts to support adjustment in the sub-cultures of each of the two groups of practitioners. To note, the Ministry of Health has targeted 23 districts which will benefit from focused technical support from 2018 onwards in an attempt to establish them as centers of excellence where staff from other districts could receive education and training on integrated TB/HIV prevention, care and treatment. Ensuring that human rights are part of this education and training will be crucial to this effort.

Moving forward with a comprehensive, rights-based response requires not only training but strengthening coordination and integration among and between government entities and NGOs (WHO & Kementerian Kesehatan Republik Indonesia, 2017; Benarto et al, 2017; “PSM Presentation,” 2017; Subronto et al., 2017; “FGD Report - Provincial AIDS Commissions,” 2017). There are numerous important local government and/or NGO-led efforts related to addressing HIV and TB related barriers. However, many are working separately and independently of each other. This is particularly an issue from the perspective of key populations and individuals who are then left to negotiate an array of disconnected programs/services. There needs to be increased awareness amongst programs/services as to who is doing what, including across government services and between public and private sector services (see e.g. discussion above concerning Additional Barriers). Additionally, there is a need for those NGOs working on HIV and/or TB to better coordinate with other NGOs who are dealing with relevant issues for the populations they serve, such as violence against women and LGBT rights (FGD21), and more broadly with organizations dealing with health-related human rights issues for other vulnerable populations in Indonesia (eg. women, migrants, youth, urban and rural poor), In some cases, such broader approaches or coalitions could reduce the risk of inadvertently further stigmatizing those groups most vulnerable to HIV, who are currently subject to targeted campaigns of discrimination.

Recommendations specific to the seven program areas are included in the ‘Optimal Program Mix’ section below.

## **Optimal program mix for a comprehensive response to human rights related barriers to HIV and TB services**

This section describes, according to the seven key program areas that are the focus of this assessment, a comprehensive national response to human rights-related barriers to HIV and TB services. Prior to a summary discussion relevant to the activities, a table is provided which is organized by the primary program area where work is occurring. It is heartening to note that there are programs which can be scaled up in each of the seven program areas. To avoid unnecessary repetition, information is presented in one table under the relevant program area noting where it is applicable to both HIV and TB, and where the proposed activity is relevant to only one of these epidemics:

- The first column of the table notes the type of activity, and examples of what such activity could look like drawing on the information received through the assessment.
- The second column of the table notes the level of the intervention required (e.g. national, health facility etc.).
- The third column of the table notes the recommended scale of activity.
- The fourth column notes the type of institution most likely to take the lead in this work. Consultation will seek to identify specific organizations with the capacity, mandate and intent to implement such activities.
- The final, fifth column notes a few organizations which are currently doing this type of work and that were identified during the baseline assessment, when applicable.

<b>Activity</b>	<b>Level of intervention</b>	<b>Scale of intervention</b>	<b>Lead institution</b>	<b>Examples of who is currently doing this activity</b>
<b>Stigma and discrimination reduction for key populations (HIV and TB)</b>				
Carry out public education campaigns to increase knowledge: -about HIV, particularly in rural areas -about TB, particularly in schools and workplaces to dismantle stereotyping -about relevant human rights -about stigma and discrimination against key	National & community	National	Government & CSOs	Peer education (e.g. Spiritia and Aisyiyah);  Community education (e.g. GAYa Nusantara, KPA, and LBH);  Media engagement

<p>and vulnerable populations and its harms</p> <p><i>Examples for both HIV and TB:</i></p> <ul style="list-style-type: none"> <li>• Increase use of social media to counter negative messages with accurate information</li> <li>• Engage PLHIV and TB, celebrities, sports figures, traditional and religious leaders</li> </ul>				(e.g. KPAP South Sulawesi)
<p>Improve access to services for key populations</p> <p><i>Examples for both HIV and TB:</i></p> <ul style="list-style-type: none"> <li>• Transgender friendly services on specific days</li> </ul>	National level	National	Government	Surabaya (some Puskesmas)
<p>Support networks of key and vulnerable populations and NGOs to advocate for and monitor more user-friendly services and greater access as well as providing information on what sorts of services exist at different health facilities</p> <p><i>Examples for HIV:</i></p> <ul style="list-style-type: none"> <li>• Use websites and create guides to provide directories of where to access services, what services are covered etc.</li> </ul>	National level	National	NGOs	Spiritia and GAYa Nusantara
<b>Training for health care workers on human rights and medical ethics (HIV and TB)</b>				
<p>Ensure pre-service and in-service trainings of health care workers (medical and nursing educational curricula) and community workers, and to the degree possible, providing HIV and TB integrated training</p> <p><i>Examples for HIV:</i></p>	Health care training institutions, Health facility & Community	National	Government & CSOs	Human rights trainings (IAC); Integration of HIV and VAW (IPPI)

<ul style="list-style-type: none"> <li>• Conduct trainings on informed consent, confidentiality and privacy (followed by measures of accountability)</li> <li>• Explore patient-provider power dynamics</li> </ul> <p><i>Examples for TB:</i></p> <ul style="list-style-type: none"> <li>• Same as above plus accurate information about MDR-TB to reduce stigma and fear</li> </ul> <p><i>Examples for both HIV and TB:</i></p> <ul style="list-style-type: none"> <li>• Include training on rights of health care workers to safe working conditions, infection control</li> <li>• Provide trainings to decrease stigmatizing attitudes related to key populations</li> </ul>				
<p>Ensure health care workers are equipped to deal with rights and advocacy issues through development of workplace policies on nondiscrimination, complaint mechanisms and referral systems</p> <p><i>Examples for both HIV and TB:</i></p> <ul style="list-style-type: none"> <li>• Provide basic trainings on rights issues for key populations</li> <li>• Ensure health care workers are aware of and can provide a list of referral organizations where needed legal and other social services are available</li> </ul>	National and local	National	NGOs	None noted during the assessment.



<b>Legal literacy ('know your rights') and legal services (HIV and TB)</b>				
<p>Expand and support peer paralegals for key and vulnerable populations</p> <p>Expand and strengthen networks of peer human rights educators</p> <p><i>Examples for HIV and TB:</i></p> <ul style="list-style-type: none"> <li>• Peer educators to provide human rights and legal literacy and mobilization for advocacy around rights and laws</li> <li>• Paralegals to resolve disputes, assist with community discrimination, help monitor health provision</li> </ul>	Community	National	CSOs	<p>Community paralegals for people who use drugs (LBH Masyarakat)</p> <p>Paralegals in Makassar (KPAP and PKBI)</p>
<p>Build capacity of legal services to work on HIV and TB related issues and to work with key populations</p> <p><i>Examples for both HIV and TB:</i></p> <ul style="list-style-type: none"> <li>• Conduct inclusive trainings</li> <li>• Support lawyers engaging in this work for the first time</li> </ul>	Community	National	CSOs	None noted during the assessment.
<p>Expand / strengthen HIV, TB, and rights-related reporting and accountability mechanisms</p> <ul style="list-style-type: none"> <li>• Ensure accessible and appropriate mechanisms, including hotlines, web- and app-based systems, community monitoring of health services</li> </ul>	National & Regional Levels	National	Government	New legal & advocacy unit at KPAP in Bandung
<b>Sensitization of law-makers and enforcement agents (HIV and TB)</b>				

<i>For both HIV and TB:</i> Update curriculum and roll out training for police and officers (pre-service and in-service) on human rights/prevention as relates to HIV, TB and key and vulnerable populations, including the prevention/trx needs of police	National and regional levels	National	Government & CSOs	None noted during the assessment.
<i>For both HIV and TB:</i> Ensure (or when necessary, develop and evaluate new approaches for) in-service training of judges and select <i>pro bono</i> lawyers on human rights as relates to HIV, TB and key populations	National and regional levels	National	Government & CSOs	None noted during the assessment.
<i>For both HIV and TB:</i> Document and publicize cases of key populations experiencing rights violations that have been properly dealt with through official judicial/complaints systems	National, regional, and community levels	National	CSOs	None noted during the assessment.
<b>Monitoring and reforming laws, regulations, and policies (HIV and TB)</b>				
<i>For both HIV and TB:</i> Document and evaluate the impact of conflicting and regulations and policies at local levels on key populations' access to use of HIV- and TB-related services, including the National Health Card	Local level	National	CSOs	None noted during the assessment.
Support advocacy by civil society for improved policies and practices for increased access to services <i>Examples for HIV:</i> <ul style="list-style-type: none"> <li>Female sex workers who are not included in the "Treat All" Strategy</li> </ul> <i>Examples for TB:</i> <ul style="list-style-type: none"> <li>Track treatment success, failure or</li> </ul>	National and local level	National	Government	None noted during the assessment.

relapse differentiated by women and men				
<p>Support civil society efforts to monitor, improve and provide feedback to health services provision</p> <p><i>Examples for HIV:</i></p> <ul style="list-style-type: none"> <li>Tracking simplified and user-friendly pre-test counselling and informed consent guidance recently published by the Ministry of Health to see impacts on access and use of services</li> </ul> <p><i>Examples for both HIV and TB:</i></p> <ul style="list-style-type: none"> <li>Misuse of Government Regulation No. 25/2011 meant to facilitate access to treatment for drug users, where health workers may be forced to reveal names of clients and peers</li> </ul>	National, regional, and community levels	National	Government and CSOs	PITCH
<b>Reducing discrimination against women in the context of HIV</b>				
<p><i>Recruit and support peer educators and paralegals to provide human rights literacy and legal support for women in context of HIV and TB</i></p> <p><i>Expand positive engagement of traditional and religious leaders to support women by resolving disputes, addressing discrimination and violence</i></p> <p><i>Ensure integration of HIV and TB in national/local efforts against violence and harmful gender norms</i></p>	National level	National	NGOs	The Women's HIV Network  MAJU

<p><i>For HIV:</i> Support patients rights materials in MCH/PMTC facilities and policies against mandatory testing and forced sterilization of HIV positive</p>				
<p><b>Programs in prisons and other closed settings (HIV and TB)</b></p>				
<p><i>Support prison advocacy groups to integrate and expand HIV and TB related human rights activities for prisoners, e.g. legal literacy; efforts to reduce prison discrimination and violence, including that based on HIV and TB status; monitoring of quality of care</i></p> <p><i>For TB:</i> Support advocacy to reduce over-crowding and substandard conditions through justice reform Update referral lists for all provinces for prisoners upon release to access TB-related legal and other support services</p>	<p>National level</p>	<p>National</p>	<p>Government and NGOs</p>	<p>None noted during the assessment.</p>

### **Proposed program of activities**

This section elaborates on the activities listed in the table above. As previously explained in this report, the intent of sharing this proposed program is to engage all interested stakeholders in a more coordinated and comprehensive response. Consultation to further refine and engage a broad range of government and non-government actors in the implementation of this response, in the form of a 5-year plan, is one of the main objectives of providing this baseline information.

### ***Stigma and discrimination reduction for key and vulnerable populations***

Community public education and media campaigns which address gender and human rights concerns are needed at every level and in all parts of the country to reduce

discrimination and increase comprehensive knowledge about HIV and TB. Such campaigns should use various forms of media as well as community dialogues and discussion and should engage celebrities, sports stars, as well as representatives of key and vulnerable populations. They should deal with the prevalence and harm of stigma and discrimination, human and patients' rights, and the availability of health services and legal support.

Given that some of the current discriminatory beliefs about key and vulnerable populations are fueled by political agendas and populist movements invoking socio-cultural norms and beliefs, it is essential to intensify efforts to engage traditional and religious leaders (as some organizations have already been doing) to address community level stigma, discrimination and violence.

Moving forward, there are many notable efforts seeking to reduce stigma and discrimination at various levels on which to build. This includes peer education/support activities (e.g. Spiritia in the context of HIV and Aisyiyah in the context of TB). Existing efforts can play an important role and serve as useful models, but would need substantial support to be scaled up and to effectively coordinate.

### ***Training for health care workers on human rights and medical ethics***

In addition to expansion of the rights-oriented and medical ethics content of trainings, it is also crucial to consider issues of scale and sustainability. Existing health workers and their supervisors should be reached by integrating/expanding HIV/TB human rights and ethical concerns in continuing education with training focus on those health care workers delivering HIV and TB treatment. Additionally, training should include representatives of key and vulnerable populations and be done in conjunction with (a) the development of facility-level policies on nondiscrimination and friendly care (b) patient rights materials and (c) community based monitoring of health service provision. Administrative staff (guards and receptionists) should be included.

Training materials should also address the health-related rights of health care workers including the right to a discrimination-free and safe working environment with knowledge of and access to universal precautions as well as work-injury related compensation.

It is also important to develop and incorporate HIV and TB-related human rights sensitization into existing pre-service curricula for professional schools e.g. medical and nursing schools. While there would certainly be initial costs related to securing buy-in for these institutional approaches, the long-term costs would be relatively minimal with positive impacts beyond the contexts of HIV and TB.

### ***Legal literacy ('know your rights') and HIV and TB related legal services***

There is a need to strengthen, scale up, and better coordinate efforts happening in this area. Greater investment should be made into peer educators and peer paralegals for key and vulnerable populations resulting in strategic recruitment, training and support of strategic cadres in heavily impacted communities. These personnel can help to inform their communities of their rights related to HIV and TB, including their patients' rights, and can support affected communities to better mobilize around laws and regulations guaranteeing their health-related rights. These resources can also help individuals address community-level discrimination, resolve disputes, monitor the quality of health care provision and in the case of criminalized populations deal with illegal police activity through rapid response mechanisms of support. A good resource on which to build is LBH Masyarakat's work with people who use drugs.

Concurrent with scaling up paralegal education, it will be crucial to also increase the capacity of existing legal aid services to respond to any increased demand the paralegal programming may generate in all cities, not only in a few places. Such services will require specific training on the human rights issues in particular surrounding TB (as well as the intersection of HIV and TB).

Finally, but equally important, it will be necessary to improve the legal system's capacity and mechanisms for receiving and responding to human rights violations related to HIV, TB, and to issues affecting key populations more generally. In addition to building awareness about the Commission (e.g. via paralegal education), this will require training and support.

### ***Sensitization of lawmakers and enforcement agents***

Training of police, both pre-service and in-service, should be scaled up and paired with the following efforts: (a) identification of and nurturing of high level police staff or other Ministry of Justice officials to support such efforts; (b) development of policies and associated complaint and redress systems for those affected by illegal police activity and (c) joint activities by police with key populations in particular locales where it is most needed. Given the example of abuses perpetrated or tolerated by police in Surabaya and reported during the FGDs – as well as other examples since baseline fieldwork was conducted - it will be important to roll out efforts based on local experiences and concerns.

### ***Monitoring and reforming laws, regulations, and policies***

National and local NGOs should be provided increased funding to (a) assess which laws, regulations and policies are causing the most negative impact on access to services and (b) based on this, build local and national campaigns to change these laws/regulations/policies. Across locations, there is also a need to increase NGO capacity

to monitor health care provision, as well as to collect data on violations of human rights of key populations and to use this in their advocacy.

Support should be given to both civil society (for advocacy) and government (for sensitization and change) to address issues related to obtaining and using the national health card. This will require engaging in research and advocacy to address concerns such as the preservation of privacy (in the context of families/households), surmounting difficulties noted above particular key and vulnerable populations (e.g. children living and working on the streets, transgender persons) might face in obtaining the requisite national ID, and resolving complications for utilization by highly mobile populations.

Support should be given for civil society advocacy to reduce logistical and financial barriers for key populations to access HIV and TB services. Programs and policies are needed to ensure services and treatment are truly accessible to all, for example, through subsidies or more decentralized distribution of treatment. Additionally, there is need to advocate for harm-reduction programs to be more physically and financially accessible (e.g. devolved to more peripheral health facilities and covered by the national health insurance scheme).

### ***Support to implementation capacity***

The issue of capacity is a crucial one to moving forward. Although many of the key organizations currently working on these issues are very capable, they are also increasingly over-stretched. They will need substantial and sustained support to strengthen their research, planning, service delivery, operational, reporting and monitoring capacity with respect to their rights-based efforts. There will also likely be a need for targeted and sustained capacity-building to grow the necessary paralegal networks and related legal services and reporting mechanisms, as well as professional schools, and other entities, that seek to introduce and institutionalize new curricula on HIV, TB, and human rights.

### ***Monitoring impact of comprehensive programs to remove human rights-related barriers across program areas***

This baseline assessment is designed as the first step in a process that will include a mid-term and end-term assessment during the current 2017-2022 Strategy of the Global Fund. Baseline values will be provided for the indicators recommended to be assessed in each of two future, smaller scale assessments that are tentatively scheduled for 2020 and 2022.

Due to the broad range of barriers, key and vulnerable populations, and recommended programs and interventions, a corresponding range of indicators and data collection methods will be needed, including quantitative, qualitative and policy assessments, with a focus on the lived experience of key populations. Whereas some of the outputs to the recommended programs/interventions can be measured in numerical terms, many of the real changes in barriers to access to services will need to be measured in qualitative terms, examining and learning from the experiences of key and vulnerable populations. In the

longer term, changes to the legal environment and the test and treatment cascades for HIV and TB will also need to be examined and learned from.

### **Qualitative assessment**

Each assessment should repeat the major steps of this baseline assessment, including, but not limited to, desk review, key informant interviews and focus group discussions with key and vulnerable populations and other relevant stakeholders and community members in relation to both HIV and TB:

- The desk reviews should focus on identifying any new research or innovative interventions on HIV and/or TB-related barriers in Indonesia and evaluations of any programs to reduce these barriers, including those considered for or implemented as part of the comprehensive rights-based approach.
- Key informant interviews and focus group discussions should focus on changes in the programmatic, social, political and legal environment since the previous assessment, as well as capture diverse views from new interview participants on how the comprehensive approach is being implemented, looking for strengths and weaknesses. It is important to note that there may be people in the new focus groups who were not previously interviewed and have more general experiences and insights beyond recent project changes.
- Focus group discussions with key populations and other stakeholders may consider the following:
  - **Specific questions: HIV**
    - Is it now easier to access HIV services than two years ago? Why?
    - Has general knowledge about HIV changed?
    - How has stigma and discrimination related to HIV changed?
    - Do health care workers generally respect confidentiality related to HIV?
    - Is there pressure or coercion related to testing, treatment, or reproductive choices?
    - Is it easier to access HIV-related legal services than two years ago? If so, how? Are these services better equipped to deal with HIV-related cases?
    - (Showing the comprehensive approach) Have you been reached by or accessed any of these services? How useful were they?
  - **Specific questions: TB**
    - Is it now easier to access TB services than two years ago? Why?
    - Are TB services better connected to HIV services (e.g. testing)? If so, how?
    - Has general knowledge about TB changed?
    - Has stigma and discrimination related to TB changed? How about stigma and discrimination specifically related to MDR-TB?
    - Is it easier to access TB-related legal services than two years ago? If so, how are these services better equipped to deal with TB-related cases?
    - (Showing the comprehensive approach) Have you been reached by or accessed any of these services? How useful were they?
  - **Specific questions: related experiences of key and vulnerable populations**
    - Has stigma and discrimination related to your key or vulnerable population changed?
    - Have health worker attitudes and treatment towards your population changed?



- Have police attitudes and treatment of your population changed?
- Have media portrayals of your population changed?
- Has the legal environment impacting your population changed?
- Have community attitudes towards your population changed?
- Has your population's awareness about their rights changed?
- Is it easier for your population to report violations of human rights? If so, how?
- Is it easier for your population to access and use health services? If so, how?

### **Quantitative assessment**

The appropriate mix of quantitative indicators to assess implementation of the comprehensive package of services to address human rights barriers to accessing HIV and TB services can only be determined once the final package of services is agreed. Subject to revision once this package has been agreed, below are some illustrative indicators that might be useful to assess progress comprehensive services based on the programs/interventions:

- Number and profiles (age, sex, region, etc.) of individuals reached through awareness-raising among the general public
- Number of traditional and religious leaders engaged in public education
- Number and proportion of graduates from law, medical, nursing, and other relevant professional schools and programs who have been trained in HIV, TB, and human rights and medical ethics
- Number of practicing health care workers, police, judiciary, and media representatives who have been trained on HIV, TB, and human rights, including communicating with key populations and stigma reduction
- Number (percentage) of people living with HIV who know their status, disaggregated by gender and key population to the extent possible
- Number (percentage) of people who are testing for HIV and TB, disaggregated by gender and key population to the extent possible
- Number (percentage) of people living with HIV who are on ART, disaggregated by gender and key population to the extent possible
- Number (percentage) of people with TB who have been linked with treatment, disaggregated by gender and key population to the extent possible
- Number (percentage) of people who are lost to follow up receiving HIV services, disaggregated by gender and key population to the extent possible
- Number (percentage) of people who are lost to follow up receiving TB treatment, disaggregated by gender and key population to the extent possible
- Number of people who inject drugs and are involved in harm reduction programs, disaggregated by gender and key population to the extent possible
- Number of peer human rights educators and peer paralegals who have been trained in conducting legal empowerment, including in human rights (including representation of different key and vulnerable populations amongst this group)
- Number and estimated proportion of individuals from key populations trained in legal literacy

- Number of complaints/cases filed involving key populations and/or HIV and/or TB related; numbers of these complaints/cases resolved (in timely manner, to be determined)
- Stigma Index scores

### **Policy assessment**

Each assessment should include a systematic review and evaluation of relevant laws and policies to capture how the environment evolves over the intervention period. In addition to assessing the existence and content of laws and policies, it will also be important to collect programmatic and financial / economic data, where available, on implementation including, for example, budget allocation to human rights-relevant activities, expenditure of this budget, and creation/use of any structures to address or monitor human rights barriers to accessing HIV or TB services. This will all require a mixture of desk review and in-country data collection. New policy recommendations based on interventions above should be evaluated on their technical and political viability.

### ***Overarching contextual issues***

Along with the opportunities to strengthen programming noted above, it is important to note two larger issues which may impact the opportunities to strengthen human rights-related programming to improve access to HIV and TB services in Indonesia.

The first concerns the specifics of the organizations that will be taking on this work which is currently heavily donor dependent. This is amply illustrated by the emergence and rapid growth of NGOs engaged in HIV and TB across the country since 2016. The Global Fund began to fund these types of activities in 2016, and consequently few organizations at the time of the assessment were fully operational due to myriad administrative and other delays. Likewise, as a result, the creation of new NGOs has not always been accompanied by sufficient training (e.g. a sample of the 100 newly recruited and deployed TB cadres in Bandung acknowledged their lack of clarity about the scope of their work and best methods to deliver their community-based services). The issues of incomplete preparedness to fulfill their roles alongside the financial sustainability of these projects raises considerable concern about the impact over the medium and longer term in both the HIV and TB areas. There are encouraging exceptions, such as in Bandung, where some provincial funding complements GF resources made available to NGOs. In Makassar the provincial government is offering a grant to the Provincial Health Office for the same purpose. While these are important exceptions to note, the sustainability of programs moving forward is definitely an area to be given serious consideration.

Second, as discussed throughout this report, it is impossible to address issues of access to and use of HIV and/or TB services without attention to the increasingly punitive environment for key populations that has emerged in many settings in Indonesia. The environment has serious implications for the possibility of realizing the recommendations

contained here. Moreover, the current climate is making it harder for programs to reach specific groups – such as female sex workers, men who have sex with men, and transgender persons - because many people feel the need to further hide themselves. While Internet and social media may help bridge this in some way, these vehicles are insufficient (FGD21). There is an urgent need to increase overall awareness of the human rights of key populations and to push back through education, training and all means possible against the broader restriction or denial of rights, affronts to dignity and perpetration of violence to which people are now subjected.

Although the scope of this report is reducing human rights-related barriers to HIV and TB services, the ultimate success/impact of the recommended programming is inextricable from concurrent efforts to address the broader realities of vulnerability and discrimination, and the broader right to health, in the current social and political environment.

## VII. Conclusion

Populations in Indonesia continue to face a range of human rights and other related barriers to accessing and using both HIV and TB services. As affirmed by diverse stakeholders and affected individuals during the in-country work, prominent human rights-related barriers affecting uptake and use of services include stigma and discrimination, punitive laws, policies, and practices, and gender inequality. There are also significant barriers related to the availability and accessibility of services, structural and systemic coordination challenges, as well as poverty and economic and social inequality more generally. The increasingly punitive environment for key populations and the administrative and related issues surrounding the health card discussed in many sections of this report both significantly impact the lives of people who might wish to access and use HIV and TB services. Overall, the identified barriers tend to resonate across the country, and particularly amongst the various key and vulnerable groups who, within the Indonesian context, include female sex workers, men who have sex with men, transgender individuals, people who use drugs, people living with HIV and people living with TB.

In terms of HIV-related programs in the identified UNAIDS program areas, there have been many notable efforts that can serve as models to address human rights barriers to HIV services –however, much of the work has been small in scale with as of yet limited data on implementation details and effectiveness. For TB-related programs, while there has been a positive and major shift from clinic-centered to community-centered approaches in recent years, there are still significant gaps in terms of integrating human rights perspectives. Moreover, the siloed approach and limited coordination between HIV and TB programs remains a challenge for integrated delivery of these services and for the experience of people who use them, and raises new and important human rights-related barriers still to be addressed.

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Ensuring a comprehensive human rights-based response to existing barriers to both HIV and TB services will thus require a combination of scaling up existing efforts (e.g. peer support networks, community-based health worker and paralegal programs) as well as investing in new programs (e.g. institutionalized police training). Both will require substantial capacity-building and resource commitments to ensure that programs are able to achieve their necessary reach in each city and throughout Indonesia, and ultimately that organizations engaged in delivering these services will have the support necessary to be able to sustain their efforts.

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## IX. Annex 2:

**List of organizations participating in key informant interviews and focus group discussions*****Jakarta***

<b>INTERVIEW</b>	<b>ORGANIZATIONS PRESENT</b>	<b>DATE</b>
Courtesy meeting with HIV and TB Directorate	Ministry of Health	7/14/2017
Inception Meeting	TWG TB, TWG HIV	7/14/2017
Key Informant Interview	Stop TB	7/14/2017
CCM Representatives	CCM	7/17/2017
FGD with Development Partners	UNAIDS, UNFPA, UNDP, WHO, USAID, KNCV, LINKAGES, ASIA Foundation, Hivos, UNICEF, UN Women	7/17/2017
FGD with Government	Komnas HAM, Komnas Perempuan, Kemos, PMK, DirjenPas, KPPIA	7/17/2017
FGD PRs TB and HIV and SRs	Subdit HIV, Subdit TB, KPAN, Spiritia, Aisyah, IAC, UNFPA	7/17/2017
Interview Dinner	LBHM Representatives	7/17/2017
FGD with TB NGOs	Red Institute, PPTI	7/18/2017
FGD with people who use drugs	PKNI, RC, Karisma, Kios, Atma, LBHM, FM	7/18/2017
FGD with people living with HIV	IPPI, JIP, LAP, Kotex, FM	7/18/2017
FGD with men who have sex with men and transgender individuals	GWL-INA, our voice, Swara, YKS, YIM/YPJ, LBHM, FM	7/18/2017
FGD with sex workers	OPSI, PKBI Kajarta, Bandung wangi, YKB, FM	7/18/2017

***Surabaya***

<b>INTERVIEW</b>	<b>ORGANIZATIONS PRESENT</b>	<b>DATE</b>
FGD with HIV program implementers	Employees from NGO, support organization, CBO	7/17/2017
FGD with HIV beneficiaries	Key populations: people who use drugs, sex workers, transgender	7/17/2017

	individuals, men who have sex with men, people living with HIV	
Key Informant Interview	Orbit/East Java Action	7/17/2017
FGD with TB program implementers	Employees from NGO and Peer support group	7/18/2017
FGD with TB patients	N/A	7/18/2017
Key Informant Interview	Gaya Nusantara	7/18/2017
Courtesy Meeting with local health office; Interview with Planning Agency (Bappeda); FGD with Stakeholders	KPAP, KPAK, Provincial health office, city health office, local gov office, law & human rights office, social welfare office university or research agency	7/19/2017
FGD with TB and HIV service providers	Employees at HIV hospitals and PHC	7/19/2017

### ***Bandung***

<b>INTERVIEW</b>	<b>ORGANIZATIONS PRESENT</b>	<b>DATE</b>
Courtesy Meeting with local health office	Local government partners	7/19/2017
FGD with HIV and TB stakeholders	KPAP, KPAK, Provincial health office, City health office, local gov office, law & human rights office, social welfare office university or research agency	7/19/2017
FGD with TB and HIV Service providers	Employees at HIV hospitals and PHC	7/19/2017
FGD with HIV Program implementers	Employees from NGO, support group organization, CBO	7/20/2017
FGD with HIV beneficiaries	Representatives from key populations: people who use drugs, sex workers, transgender individuals, men who have sex with men, people living with HIV	7/20/2017
FGD with TB program implementers	Employees from NGOs and TB peer support groups	7/21/2017
FGD with TB patients	Representatives from affected populations	7/21/2017

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TB Program	Hasan Sidikin Hospital	7/21/2017
HIV Program	Hasan Sidikin Hospital	7/21/2017

### ***Makassar***

<b>INTERVIEW</b>	<b>ORGANIZATIONS PRESENT</b>	<b>DATE</b>
Courtesy meeting with local health office; Interview with planning agency (Bappeda)	Local health officials and Bappeda leadership	7/20/2017
FGD with stakeholders	KPAP, KPAK, Provincial health office, city health office, local gov office, law & human rights office, social welfare office university or research agency	7/20/2017
FGD with TB and HIV service providers	Employees from HIV hospitals and PHC	7/20/2017
Dinkes, South Sulawesi	Dinkes Leadership	7/20/2017
FGD with HIV program implementer	Employees from NGO, support group organization, CBO	7/21/2017
FGD with HIV beneficiaries	Representatives from key populations: people who use drugs, sex workers, transgender individuals, men who have sex with men, people living with HIV	7/21/2017
FGD with TB program implementer; FGD with TB patients	Employees from NGO and peer support group	7/21/2017

### ***Phone Interviews***

<b>INTERVIEW</b>	<b>ORGANIZATIONS PRESENT</b>	<b>DATE</b>
Key Informant Interview	IAC	7/7/2017
Key Informant Interview	Spiritia	7/7/2017
Key Informant Interview	UNAIDS	7/10/2017