

Social Barriers to Accessing Quality TB Service: TB Key Populations, Legal Environment and Gender Assessment

Revised by July 2020

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Acknowledgement:

The CRG Assessment & Recommendations was made possible with the support of the American People through the United States Agency for International Development (USAID).

About this Version:

This version includes inputs and recommendations discussed in report presentation to main stakeholders and published in December 2019. This version has additions in detail record of initial meeting results on key population, and additional one item at recommendation section about costed CRG intervention for the National Strategic Plan.

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Foreword

By Spiritia Foundation CEO

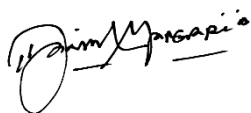
Spiritia Foundation is a national organization of people living with, and affected by HIV/AIDS in Indonesia, dedicating the works of supporting people in needs, starting with People Living with HIV since the beginning era of AIDS onsets in this beloved country to continue its service to those who suffered with Tuberculosis, and make the best of what we have as a basis to support people with the disease. Spiritia has been integrating TB in their program also working together with PLHIVs Catalyst and Peer Support Groups in the provinces and districts level. Spiritia Foundation is also actively engaged in TB advocacy at the national and regional level, including as part of the Steering Committee of Activists Coalition on Tuberculosis Asia-Pacific (ACT! Asia-Pacific).

In responding to the current situation where TB-HIV programming across the globe, and especially in Indonesia, faces significant challenges in case findings, strategies to define TB affected communities and groups of people with high risks to TB is essential. Understanding the obstacles of these vulnerable groups will highlight how we could improve our TB programme by bringing more people to quality services. We are fully aware that among many other factors, legal and gender issues often play an important role either in inhibiting or facilitating people to get proper services, from the prevention, diagnosis, treatment and care and psychosocial support. Thus, this is in very timely that the government of the Republic of Indonesia is hand in hand with TB affected communities, civil societies, professionals and other health service providers to further understand this significant matter.

The Spiritia Foundation took this initiative to conduct study on “Social Barriers to Accessing Quality TB Services” in order to look at the level of risks of two key populations (people living in high density poor areas and people living with HIV) and the relationship to legal and gender barriers for these populations. We hope that the results of this study can enrich the information that addressing bottlenecks or backstopping in TB elimination in Indonesia. This, in turn, may lead to policy and implementation improvements that enable multi-sector partners to remove the barriers faced by the missing people affected by TB in Indonesia, and especially at both districts selected in this study.

Spiritia Foundation appreciates the support we have received for all parts of this study: the funding agency, those who facilitated the process – in preparation, and in the data collection, as well as in the reporting – so that we can have this report. We again, would like to express our appreciation and sincere thanks to the Stop TB Partnership, USAID, the Ministry of Health of the Republic of Indonesia, the provincial and district/city health offices and all health services, affected TB people, communities and their organizations, and last but not least, to the Core Team and study staff.

Sincerely,



Daniel Marguari

CEO

By Stop TB Partnership Director

The tuberculosis (TB) response needs a paradigm shift – becoming people and community centered, gender responsive and human rights based. There is a need for country specific data and strategic information key, vulnerable and marginalized populations. There is a need to facilitate an enabling environment to effective prevention, diagnosis, treatment, care and support – which requires legal and gender related barriers to be analyzed, articulated and alleviated. The Stop TB Partnership CRG Assessments are the tool for National TB Programmes to better understand and reach their epidemics. With TB being the leading cause of infectious disease deaths globally, and with over 10 million people developing TB each year, this disease continues to be a public health threat and a real major problem in the world.

The Stop TB Partnership's Global Plan to End TB and the World Health Organization (WHO) End TB Strategy link targets to the Sustainable Development Goals (SDGs) and serve as blueprints for countries to reduce the number of TB deaths by 95% by 2030 and cut new cases by 90% between 2015 and 2035 with a focus on reaching key and vulnerable populations. The Strategy and the Plan outline areas for meeting the targets in which addressing gender and human rights barriers and ensuring community and people centered approaches are central.

Ending the TB epidemic requires advocacy to achieve highly-committed leadership and well-coordinated and innovative collaborations between the governments sector (inclusive of Community Health Worker programs), people affected by TB and civil society. Elevated commitment to ending TB begins with understanding human rights and gender-related barriers to accessing TB services, including TB-related stigma and discrimination. It has been widely proven that TB disproportionately affects the most economically disadvantaged communities. Intersectionality between poverty, low socioeconomic status and human rights results in legal, structural and social barriers impeding universal access to quality TB prevention, diagnosis, treatment, care and support services.

In order to advance a rights-based approach to TB prevention, care and support, the Stop TB Partnership developed tools to assess legal environments, gender and key population data, which have been rolled-out in Indonesia and in thirteen other countries. The findings and implications from these assessments will help governments to develop operational plans which can contribute to more effective TB responses and policy decisions as they gain new insights into their TB epidemic and draw out policy and program implications. These assessments and recommendations provide a strong basis for tailoring national TB responses carefully to the country's epidemic – the starting point for ending discriminatory practices and improving respect for fundamental human rights for all to access quality TB prevention, treatment, care and support services. The development of these tools could not be more timely, and the implementation of these tools must be a priority of all TB programmes. Without understanding and addressing the barriers that have been observed we will not be able to realize the global target of reaching 40 million people and end TB. We look forward to continuing to work with Indonesia at realize our shared commitment to a world without TB.

Lucica Ditiu,



Executive Director

Foreword from NTP Manager

The Government of Indonesia have a strong commitment to achieve the elimination of TB by 2030. This commitment was conveyed by delegations from Indonesia in various regional and global meetings such as (1) Regional meeting in New Delhi in 2017, (2) Ministerial meeting in Moscow in 2017, and (3) UN General Assembly in New York in 2018.

Indonesia's new National Strategy for Tuberculosis Care and Prevention 2020-2024 reflects this commitment and outlines crucial part that formulated using people centre framework approach adapted from WHO. The framework ensured all people have access to health services that are provided in a way that are coordinated around their needs, respects their preferences, and are safe, effective, timely, affordable, and of acceptable quality.

As the third highest burden country in the world related to Tuberculosis incidence rates, Indonesia is determined to ensure that this strategy will impact the acceleration towards TB elimination by 2030. According to WHO Global TB Report 2019, the incidence of tuberculosis in Indonesia in 2018 is 316 per 100,000 population; and of the 845,000 estimated cases of Tuberculosis in 2018, 32% were women. It is also estimated that there were about 98,000 deaths resulted from tuberculosis in 2018.

The CRG study presented a local understanding of social, legal, and gender barriers to address the current challenges of finding TB's missing people. It provides deeper understanding of which people are missing, where they are, and how they can be reached. TB is a disease that impacts people's lives in many dimensions hence, our response should also be mindful of these dimensions. It is not only important to restore people's health after TB infection, we need to also ensure that TB is not a stigmatized disease and that the people affected by it will not be brought down further by human rights and social implications.

I express my sincere appreciation to those who contributed to this report. We look forward to continuing to work together with stakeholders at all level to bring about a responsive change towards its effort in TB elimination, especially during and post Covid-19 Pandemic which disrupt TB services.

Jakarta, July 2020

Indonesia NTP Manager



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Additional technical support was provided by Stop TB Partnership.

List of Abbreviations

AIDS	: Acquired Immune Deficiency Syndrome
ART	: Antiretroviral Therapy
ARV	: Antiretrovirals
B / BKPM	: Balai (Besar) Kesehatan Paru Masyarakat/ Referral Community Lung Health
BPJS	: Badan Penyelenggara Jaminan Sosial/The Indonesian National Health Insurance System
CAT	: Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
CEDAW	: Convention on the Elimination all Forms Discrimination Against Women
CI	: Confidence Interval
CRC	: Convention on the Rights of Child
CRG	: Community Rights and Gender
DM	: Diabetes Mellitus
DO	: Drop Out
DOTS	: Directly Observed Treatment Short-Course
DPM	: Dokter Praktek Mandiri/Private Doctor
DUHAM	: Deklarasi Universal Hak Asasi Manusia/Universal Declaration of Human Right
Fasyankes	: Fasilitas Pelayanan Kesehatan/Health Service Facility
PHC	: Public Health Center
FGD	: Focus Group Discussion
FKRTL	: Fasilitas Kesehatan Rujukan Tingkat Lanjut/Advanced referral health facility
FKTP	: Fasilitas Kesehatan Tingkat Pertama/Primary health facility
Gerdunas TB	: Gerakan Terpadu Nasional untuk Pengendalian Tuberkulosis National Integrated Movement for Tuberculosis Control
GFATM	: Global Fund to Fight Against AIDS, Tuberculosis and Malaria
HAM	: Hak Asasi Manusia/Human Right
HCP	: Health Care Provider
HIV	: Human Immunodeficiency Virus
ICCPR	: International Covenant on Civil and Political Rights
ICEARD	: International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	: International Covenant on Economic, Social and Cultural Rights
IPT	: Isoniazid Preventive Therapy
JKN	: Jaminan Kesehatan Nasional/National Health Insurance
KDS	: Kelompok Dukungan Sebaya/Peer Support Group
KK	: Kepala Keluarga/Head of family
KTP	: Kartu Tanda Penduduk/Identity card
Kumis	: Kumuh Miskin/Poor Slum
Kupat	: Kumuh Padat/High populated Slum
Lansia	: Lanjut Usia/Elderly
LSM/NGO	: Lembaga Swadaya Masyarakat/Non-Government Organization
MDR/RR-TB	: Multi Drug Resistant/Rifampicin Resistant Tuberculosis
NAPZA	: Narkotika, Psikotropika, dan Zat Adiktif lainnya/Drugs
NTB	: Nusa Tenggara Barat

OAT	: Obat Anti Tuberkulosis/Anti TB Drug
ODHA	: Orang Dengan HIV dan AIDS (PLHIV)
PLWHA	: People Living with HIV/AIDS
PAMALI TB	: Pasien dan Masyarakat Peduli TB/Patients and Community Care for TB
PHBS	: Perilaku Hidup Bersih dan Sehat/Clean and Healthy Life Behavior
PHK	: Pemutusan Hubungan Kerja/Work Termination
PMDT	: Programmatic Management of Drug Resistant TB
PP-INH/IPT	: Pengobatan Pencegahan dengan INH/INH Prophylaxis Therapy
Puskesmas	: Pusat Kesehatan Masyarakat – Public Health Centre (PHC)
RAN TB	: Rencana Aksi Nasional Tuberkulosis/ National Tuberculosis Action Plan
RPJMN	: Rencana Pembangunan Jangka Menengah Nasional Indonesia/ Indonesian National Medium Term Development Plan
RS	: Rumah Sakit/Hospital
RSP	: Rumah Sakit Paru/Lung Hospital
SD	: Sekolah Dasar/Elementary School
SITT	: Sistem Informasi Tuberkulosis Terpadu/Tuberculosis Integrated Information System
SMA	: Sekolah Menengah Atas/Senior high school
SMP	: Sekolah Menengah Pertama/Secondary school
TB	: Tuberculosis
TB-HIV	: Tuberculosis – Human Immunodeficiency Virus
TB-RO	: TB-Drug Resistant
TB-SO	: TB-Drug Sensitive
TCM	: Tes Cepat Molekular - Rapid Molecular TB Test
TOSS-TB	: Temukan Obati Sampai Sembuh-Tuberculosis/ Find, treat up till cured- TB
UMK	: Upah Minimum Kabupaten-Kota/District Minimum Wage
UNAIDS	: Joint United Nations Programme on HIV/AIDS
UNDP	: United Nations Development Programme
UU	: Undang Undang/Act
UUD	: Undang Undang Dasar/Constitution
WC	: Water Closet
WDPP	: Warga Daerah Padat Penduduk – High-density area population
WHO	: World Health Organization

Summary

Background

In 2018, 10 million persons developed TB disease, 5.8 million of whom were men and 3.2 million women – 90% adults and 10% children. Indonesia has the third highest TB burden in the world and is one of eight countries that collectively account for two-thirds of TB cases globally. However, with an incidence rate of 319 per 100,000 population per WHO estimates, Indonesia ranks only 20th among countries globally. The difference between total burden and disease incidence reflects Indonesia’s struggles to detect and successfully treat cases of people with TB disease - as well as the barriers many people face to access TB prevention, diagnosis, treatment, care and support services they need. These struggles are also evident in the fact that the male/female case detection ratio in Indonesia (1.41) is far lower than the global figure (1.73) and that for the South East Asian Region (1.74).

In order to better understand the situation of national TB program implementation in Indonesia, a qualitative study was undertaken. The study was based upon the perceived need for more qualitative exploration that gives nuance for program improvements, from the program implementers, as well the TB affected communities’ point of view, so that their personal experiences and their perspectives on the roles in TB programs could serve as insights to contribute to and complement the work of the National TB Programme. The information sought focused on those who have a higher risk of being affected by TB – TB key populations (including persons living in high-density poor settings and PLHIV with TB co-infections), the types of legal, social (including stigma and gender-related among others), and economic barriers that people face in accessing quality TB services, and, what legal, policy and gender issues contribute to improving uptake of TB services among those people in need as well as the community in general. The data gathered for the study were analyzed through the lenses of gender equality and through a human rights framework with an eye toward suggesting ways to identify, mitigate and overcome legal, policy and gender-related barriers that people, including TB key populations, face in accessing TB prevention, diagnosis, treatment, care and support services in Indonesia.

It is hoped that this work can contribute to Indonesia’s efforts to reach to UNHLM on TB targets and commitments¹ – including those specific to communities, rights and gender (CRG).

Methods

The study was conducted in two sites, North Jakarta City and Sidoarjo District, during September-November 2018 using the Communities, Rights and Gender (CRG) tools developed by the Stop TB Partnership. A mixed-methods approach was used in collecting data for the study. Data collection activities including a Desk Review of relevant documents and collection of in-depth information from key stakeholders using several different data collection mechanisms.

¹ Stop TB Partnership UNHLM on TB Targets & Commitments (2018)
http://www.stoptb.org/assets/documents/global/advocacy/unhlm/UNHLM_Targets&Commitments.pdf

Twenty-one documents were examined in the desk review (7 international covenants, 1 constitution, 5 laws, 5 implementing regulations, and 1 other document). Data collection from stakeholders entailed key informant interviews (18 key informants from 18 institutions, 10 at the national level, 3 in Sidoarjo, and 5 in North Jakarta); 7 focus group discussions (1 national level, 2 in Sidoarjo and 4 in North Jakarta – 47 participants in total); and 44 in-depth interviews (29 respondents from North Jakarta and 15 from Sidoarjo).

Results

Legal and human rights issues

The Republic of Indonesia Constitution guarantees the protection of citizens' rights in accordance with the principles of human rights and gender equality, including regarding health. Six laws were identified in the review that mandate citizens Right to life; Right to the highest attainable standard of physical and mental health; Right to non-discrimination and equality; Right to privacy; Right to "informed consent"; Right to information; Right to be free from torture or cruel, inhuman or degrading treatment or punishment; and the right to participation. These laws imply the right to live a healthy life that is related to proper living conditions, access to health, and other regulations that limit people from living in "harmful" areas, including places that are susceptible to disasters (i.e. riverbanks, flooding, and slum areas).

Three specific TB-related regulations and an accompanying set of guidelines were also identified, one of which provides explicit support to TB communities. TB control guidelines in the Minister of Health's decree on TB control included articles closely related to legal aspects and gender issues: (1) protection, warranty and partisanship of the government to the communities and TB affected people including family members, communities and occupation; (2) Risk factor control that includes individual level (sex, age and environment – i.e. slum area) and community participation. Specifically, for the community participation, four key strategies to involve the CSOs and TB communities covers (a) engaging, (b) expanding, (c) emphasizing, and (d) enumerating. Particularly the expanding strategy, the guidelines clearly mentioned "specific populations", such as "manufacture workers, schools, hostels, incarceration, and sex workers" that are expected to have roles in former or currently TB patient engagement at the community level in case findings, and drug-resistant cases, also as treatment buddies.

However, there is no legislation that specifically regulates gender equality regarding TB. There are several laws and regulations to address specific gender-related issues (i.e., domestic violence, immigrants, marriage, etc.), but none specifically address TB (or HIV). Legally, the Indonesian health system cannot discriminate against people with TB. The Indonesian government expressly determines that all people in Indonesia have the right to access TB services for free, regardless of population sub-group membership or gender. The study found no clear finding of gender-based discrimination, however, this does not imply that there is no actual gender-based discrimination in the practice. While other study found that "10% of the marriages ended in divorce because of the female spouse diagnosed with TB (common among younger spouses); 25% of

women with TB, report being isolated and discriminated in their homes, and in 2% older couples marriage ended in divorce when the wife is diagnosed as a TB patient”.²

Further exploration on the gender issues perceived by the key informants and respondents leads to understanding that they are not using gender-responsive approaches in the area of provision of TB services. And this finding, of not capturing clear gender issues, directly or indirectly in itself, implies that there is gender awareness issues among health managers, health providers as well as in society. And, at both selected districts, those who do not have the subsidized health insurance nor local ID, are still able to access TB services because of the national TB program, when they reached health services.

Although the Indonesian legal framework was deemed to be based upon on human rights principles and adequate to support the protection of people with TB, implementation issues hindered access to quality TB services. Examples reported include delayed TB diagnosis and treatment; ineffective communications efforts leading to the TB community not being properly educated about TB or the rights of people affected by TB; self-stigma and self-discrimination due to misperceptions about TB; Lack of meaningful involvement of CSOs and CBOs to contribute to TB control; TB-affected households still seem prone to having catastrophic expenditure and impoverishment; and lack of sanctions for companies that terminate TB-infected employees.

Gender issues

The relationship between TB and gender relates to both prevalence of TB disease just as importantly, the way gender influences how men, women, boys and girls access TB and other health services. Although TB incidence is higher among men and women have relatively higher rates of TB treatment success, most study participants were unaware of any gender-related issues and doubted the existence of gender-related barriers despite knowing the significant data gaps between male and female. A MoH managerial-level staff person believed that more men were found to have TB than women because infections are occurring at workplace locations (e.g. mines, factories, convections) with higher levels of TB exposure where there are more men. A large proportion of male respondents stated that their illness was due to unhealthy working conditions. Women, on the other hand, tend to make greater use of health services. There were no reports of women or men feeling they were treated differently at health facilities providing TB services because of the gender – but there may still be opportunities to make services more responsive to gender preferences and behaviours. Further research is needed to understand TB in the context of transgender persons.

Significant gender differences were, however, reported regarding caretaking for people with TB. Among female TB survivors, or family members of TB survivors, conveyed that their husband mostly will take care of them, but in the contrary, their husband may have to struggle themselves because women had other things to do, including taking care of family business or children. Those who do not have a spouse usually have their family members to take care of them,

² Kanchan Srivastava, Surya Kant, Apoorva Narain, Jyoti Bajpai. 2018. European Respiratory Journal. Tuberculosis in women: A reflection of gender inequity

most likely their mothers. Cadres also play significant roles in encouraging people to take TB test and/supporting people with TB disease to return to the clinic and complete treatment. Caretakers of people with TB are usually female, either family members or cadres. However, men, who are former TB patients mentioned that their knowledge of TB are often shared among their fellow men in the neighbourhood or at work environment. Knowledge of TB was mostly lacking among respondents of both genders. The major difference observed in terms of knowledge was between TB patients and TB-HIV patients, with TB-HIV patients being more knowledgeable about TB.

Socioeconomic issues

In both study sites, poor “slum” conditions were observed by study field staff. Typical housing conditions included limited air circulation, one room with 3-plus families, the only door at the front that was closed most of the time, and an unhygienic toilet room right in front of the house. Confirmed cases of people with TB disease that were non-notified were recorded. Knowledge of TB, prevention and treatment was mostly lacking. Most residents had ID and National Insurance scheme (BPJS) membership cards, but that does not mean they would go to health services when they were sick due to personal inconvenience such as long waiting times at health facilities. Lack of knowledge leads to fear and stigma in these communities. TB MDR patients mostly had long histories on TB treatment. Daily transportation costs, especially those who need other family member to accompany them, take a significant proportion of limited family funds. These observations emphasise the need to continue to prioritise building sustainable and informed community systems especially in vulnerable and underserved populations.

PLHIV

Due to their compromised immune systems, PLHIV are vulnerable to developing active TB due either to direct contact with TB-infected person or because of latent tuberculosis infection. Although those on ART were used to adherence requirements, many were not keen to visit health services. Although issues around stigma or potential stigma were revealed in some of the discussions, most had never experienced stigma or discrimination from health providers. Self-stigma was, however, observed - a guilty feeling of being responsible for infections among loved ones. Side-effects and long waiting times at health facilities were factors that weighing them down in taking medicine, as well as the cost of nutrition.

Recommendations

Based upon the study findings, the following recommendations are made:

1. The inter-sectoral policies and joint programme for TB control are available, such as the TB control program at the Indonesian National Police (POLRI) health facilities, TB control guideline at the workplace which covers issues of access to TB services, but also freedom from discrimination. However, this is not strong enough to take sectoral collaboration to more effective wider coverage of TB programming in Indonesia. Regulation is necessary for robust multi-sectoral involvement, including TB key and vulnerable populations, TB survivors, civil

society, private sector innovators and the TB control program. This should be developed in a coordinated manner that necessitates the national planning and development coordinating body to lead the endeavor. This will include sub-national level planning and budgeting where the Ministry of Health provides technical support and mentoring during the process; and, advocating for parliament and the national planning agency related health and social development and infrastructure budgets both at national and sub-national levels. Moreover, the Government of Indonesia also needs to enhance and continue the implementation of UNHLM Country targets and accountability.

2. Understanding gender in the context of TB is nuanced. Advancing and strengthening gender responsive programming and facilitating an enabling legal and policy environment, including for women, girls and transgender persons, including in the National TB Strategic Plan should be a priority. To achieve that, the key is to have the strategy development team to get sensitization training on both gender equality and the interaction between gender and accessing services as well as enabling legal environment issues and opportunities. Multi-sectoral governance can serve as a channel as Indonesia is adopting Sustainable Development Plan, collaboration with Ministry of Women Empowerment and Ministry of Law and Human Rights would pave a way to a more sustainable TB response that is gender sensitive and completed with legal aspect review.
3. Capacity building in terms of gender sensitization for different stakeholders is one of the priorities as the awareness on gender-related issues, i.e. how gender, gender norms and traditional gender roles impedes universal access to TB services, is still lacking. Before the critical mass could begin with gender-related works for TB programming, they need to acquire understanding on gender-associated and related barriers and how gender hinders TB affected people accessing proper diagnosis and treatment. This is the gateway to TB programming improvements. As the study uses CRG tools as its basis, it is recommended that the recommendations are accepted and are operationalized as part of a national operational plan and ultimately in the National Strategic Plan.
4. As many of the decision makers are also not convinced of the importance of the relationship between gender and TB, advocacy and sensitization initiatives will be critical. And it will be very useful, if in the course of the capacity building the decision makers are involved in international movements/activities on gender, and at the same time are provided with guidance, tools and technical support to help them develop a more targeted or tailored programmatic development for specific key and vulnerable populations, including among men, women, boys, girls and trans populations. Training to assist identify evidence of gender-associated and related barriers and to develop gender equality indicators for various level of TB program will be important.
5. Capacity Building on diagnostics and treatment literacy and on rights literacy – including access to justice, at the grassroots level is critical for the health service providers, policy makers, patients undergoing TB treatment, TB survivors and members of populations vulnerable to TB in order to gain knowledge and confidence on TB prevention, diagnosis, treatment and care services. This includes the civil society, TB survivor community, TB-HIV

support groups and health professionals; to be able to provide support to TB patients to complete the treatment successfully.

6. The government, private sector and research institutions need to continue to conduct research to find diagnostic and treatment options that are more innovative, new technology, inexpensive and accessible to the public. For this reason, funding commitments from both the government and international development partners are needed to support the implementation of these studies and operational research.
7. The government must ensure that the supply-side of diagnostic tools, prevention and treatment including MDR-TB drugs for all health services including the private sector is available and affordable. TB affected communities must also be empowered to monitor availability of TB drugs and diagnostics including issues of side effects, stigma and stockouts.
8. TB strategies that are more detailed in the way they include and engage vulnerable, marginalised and TB key populations will have potentially higher yield of effective prevention, case detections, treatment initiation and successful treatment completion. It is recommended to prepare a list of “TB key populations” (including PLHIV, PWUD, prisoners and detainees, migrants and indigenous people) prior to next strategy plan development, together with representatives from each of the groups lists, to understand more about what effective TB prevention, diagnosis, treatment, care and support means to each of those groups, and to prioritise populations with higher risks to TB. By 2020, beside lessons learned from the on-going TB program implementation, new approaches should be taken into consideration.
9. It is important to strengthen the integration and collaboration of TB/HIV by conducting a TB screening program for all risk populations or the general population reached in HIV programs and referred to TB testing for those suspected of TB. This approach is cost efficient and can be implemented by educating outreach workers in TB screening.
10. Findings of this study on TB at slum areas, where access to services were relatively reachable and affordable, leaves a recurring problem of TB-reinfections that leads to drug resistance if TB survivors would have to be back to the slum areas. In relation to enabling legal environment and human rights, promoting rights to housing, and right to hygiene can be a relevant answer. This notion is relatively new to Indonesia, but there is an on-going movement at the global level to support this. Thus, capacity on how to create the demand needs to take place. Prior to this, a group of TB program staff needs to collect credible information using on disaggregated data to show how people living in poor, high-density area settings affected by hygiene and housing conditions. In turn, National TB Program will have to collaborate with related sectors to advocate and work in rights to adequate housing and safe workplaces, that not only significantly reducing transmission, but also increase the level of people’s welfare. More legislation is needed to further development, including holistic TB workplace policies as recommended by the ILO, UNAIDS and WHO.
11. Given the findings about people living in slums in urban environments, it would also be prudent to undertake a more thorough analysis of CRG issues impacting people living in remote and isolated environments, including some of the more remote islands of Indonesia It would also be valuable to understand more about the context of TB and universal access in other high-density living environments such as prisons and detention centers.

12. It is important to encourage the involvement of TB affected people to be involved in TB programs both in policy development, planning, implementation and evaluation. In addition, it is necessary to facilitate the establishment and strengthening of peer support system for the TB affected people from various parties including technical assistance and funding support. Furthermore, support is required for networks of people affected by TB to build independence and begin with empowerment through peer support groups.
13. The study also found several TB survivors who are never recorded as TB patients, due to migration or personal reference on health facility that are not having integrated information system. This condition leads to recommendations to improve reporting and recording system by including all facilities, public and private to the national management information system – irrespective of migration status and where they move within Indonesia. This, in turn, will enable people found not completing the treatment to get back to treatment, and the system would allow community to take roles as treatment observer to ensure every TB patient completes treatment. Further analysis of the experience of documented and undocumented migrants in other regions of Indonesia is recommended to understand how to overcome this challenge.
14. The study found considerable barriers for TB people and their families to get comprehensive knowledge on TB – whether it be prevention, diagnosis, treatment, care and support. What might constitute a violation of their rights to health is also not widely known and understood whether it be the right to privacy, rights to information, right to liberty, right to freedom from stigma and discrimination among others. Correct information provided in timely manner, particularly from peers, would, in part, address this lack of knowledge on cause, transmission and prevention, and especially those of in higher risk to TB. Hence, a communication strategy, including a know your rights component and a legal support component, ought to be scaled up in Indonesia.
15. Communication, coordination and engagement strategies reaching the grass roots communities and increasing CSO/CBO's/TB survivor networks skills and knowledge must be a priority focus for overcoming barriers to TB universal access.
16. Use of IEC materials for health workers (e.g., 10-minutes video or a longer refresher training) would be efficient ways to increase health personnel readiness to deal with TB and to understand the broader human rights and gender equality issues that are a challenge for many of the people who are affected by TB.
17. Closer TB and MCH program integration is urgently needed to increase capacity in diagnosing and referring pregnant women to TB care.
18. Strengthening public-private partnership and communication, often among clinicians will be significant in ensuring prevention as well as timely diagnoses, treatment, care and support.
19. It is further recommended, that a package of costed CRG interventions be developed based on these findings and recommendations. This package should be reflected in the National Strategic Plan and upcoming Global Fund funding requests or re-programming initiatives.

Background

TB is one of the top ten cause of death and the leading cause of a single infectious agent, worldwide. Each year, approximately 10.4 million people develop active TB disease. About 4 million (40%) of them go undetected or unreported. Many of the “missing 4 million” are among **key, vulnerable or underserved populations**. Globally, in 2017, an estimated number of 1.3 million TB related deaths were reported among HIV negative people and another 300,000 among PLHIV. A number of 10 million people develop TB disease (5.8 million men and 3.2 million women), 90% adult and 10% children, where two-thirds were living in 8 countries, including Indonesia. No specific TB-related information among transgender people available at the moment.

There are 30 highest burden countries accounting for 87% of the world TB infections. Drug resistance continues to be an urgent challenge as a public health crisis, where 558.000 people develop TB resistance to Rifampicin, and 82% of them had Multi-drug resistance TB (3.6% of new TB cases and 17% of previously treated cases). Among people with MDR TB, 8.5% were estimated to have XDR-TB. Aside from that, currently, the world highlights an estimated 1.7 billion people are having latent TB infection, that makes up 23% of the world population. The progress report shows a reduction of the proportion of deaths from TB from 23% in the year 2000 to 16% in 2017, and that the incidence rate is falling at about 2% per year. The table below shows the burden of disease, globally, in South East Asia Region and in Indonesia year 2017 (WHO Global TB Report 2018)

TABLE 1. GLOBAL, REGION, AND INDONESIA TB EPIDEMIOLOGICAL DATA

	Global		Regional South East Asia		Indonesia	
	# (thousands)	Rate (per 100,000 pop)	# (thousands)	Rate (per 100,000 pop)	# (thousands)	Rate (per 100,000 pop)
Mortality (exclude HIV pos TB)	1.270	17,0	638	32,0	107,0	40,0
Mortality (HIV pos TB only)	300	4,0	28	1,4	9,4	3,6
Incidence	10.000	133,0	4.440	226,0	842,0	319,0
Female	3.680		1.620		349,0	
Male	6.360		2.820		492,0	
Incidence (HIV+TB only)	920	12,0	152	7,7	36,0	14,0
Incidence (MDR/RR-TB)	558	7,4	192	9,7	23,0	8,8

The male/female ratio in Indonesia (1,41) is lower than that at the Global (1.73) and South East Asia Region ratio (1.74). However, to date, there is no further official explanation on why and how such difference occurred. Significant progress is evident when DOTS program was expanded starting by the end of last century up until current “end TB strategy” era. The table below shows the results of such efforts up to December 2017, and their gaps.

TABLE 2. GLOBAL, REGION, AND INDONESIA TB PROGRAM ACHIEVEMENT

	Global		South East Asia Region		Indonesia	
Total Cases Notified	6,708,123		2,965,311		446,732	
Total New and Relapse	6,444,278		2,826,486		442,172	
Known HIV status		60.0%		55.0%		29.0%
Known HIV status who are HIV pos	464,633	12.0%	61,832	4.2%	7,729	6.0%
Who are HIV pos on ARV	377,040	84.0%	42,191	68.0%	2,244	29.0%
TB Treatment Coverage (notified/incidence)		64.0%		64.0%		53.0%
Treatment Success Rate (cohort 2016)						
New & relapse cases	6,084,986	82.0%	2,599,452	75.0%	364,671	86.0%
Previously treated cases	291,057	68.0%	183,312	71.0%	2,002	71.0%
HIV pos TB Cases	427,886	77.0%	60,809	73.0%	4,470	64.0%
Preventive treatment (IPT)						
PLHIV		300%		12.0%		16.0%
Children <5		23.0%		14.0%		8.5%
Financing						
Domestic		62.0%		54%		34%
International		16.0%		22%		16%
Unfunded		22.0%		24%		49%

The WHO Global Tuberculosis (TB) Report 2018 shows a total estimated number of incidences of 842 thousand in Indonesia annually. This large number puts Indonesia at third position among the highest burden countries after India and China. However, with the incidence rate of 319 per 100,000 population, Indonesia ranked 20th among countries of highest incidence rate globally. Apprehending that Indonesia holds specific importance contributing to global TB programming, efforts to improve effective implementation at all levels in Indonesia are fundamental. Not only that it will meet the national and sub-national targets, but in turn, it will have a significant impact to the global goals set at the United Nations General Assembly summit in September 2018 in New York, where Indonesia is actively participating in this initiative.

While the sense of urgency abovementioned is real, on the other side of this situation, Indonesia also reported a fairly good success rate of TB treatment, that in the year 2017 it reached 86% out of 842 thousand estimated incidences, and a number of 443,704 cases (52.7%) were notified receiving TB treatment.

Looking further to the TB Control Program Strategy (2017-2020), Indonesia puts forward six main strategies that aim to increase TB case detection of the people who have not detected or accessed to TB facilities and to increase TB notification of people who have identified TB but not recorded in TB program information system as well as to improve the quality of the services and the program.

Why we need this study?

Given the considerable gap of TB case finding (53%), and the fact that 86% success rate has left around 14% patients not having proper treatment results, and with the TB mortality rate of 107 thousand (WHO-Global TB Report, 2018), there is a strong indication of social barriers to accessing TB service. While, the last Inventory study conducted in 2016, figured out that the under-reported cases (detected but not notified) percentage was at the size of 41% (36%-46%), while the proportion of undetected was 18% (15%-21%). The result of this study illustrates the magnitude of missing cases across the country is reaching 50% of the incidence. Therefore, we need to find out the cause of these gaps, and whether among others, gender and legal aspect, including human rights, are contributing to such gaps.

Such figures above are leading to a consideration to explore more innovative actions that may contribute to strategy implementation in finding more missing cases, and at the same time bringing more people to quality TB services. In order to do that, it is primarily important to comprehend what are determinant factors to TB case findings and successful treatment. Therefore, the study is needed to explore and describe conditions that are attributable to finding people affected by TB and maintaining them in treatment, to generate information for TB program improvements.

Some studies shined lights on determinant factors influencing TB case finding and TB treatment success, and are applicable for Indonesian programmatic context. However, we need more qualitative exploration that gives nuance for program improvements, from the program implementers, as well the beneficiaries' point of view, so that their personal experiences and their perspectives on the roles in TB programs could serve as insights to address issues in TB program implementation. The information highlight: those who have a higher risk of transmitting/getting TB, what and who encounters barriers related to gender factors in receiving quality TB services, and, what legal and gender issues contribute to improving uptake of TB services among those people in need as well as the community in general. This study is a qualitative study to understand the situation of TB programs implementation better using gender analysis as well as legal environment assessment analyses, referring to 3 guides as follow:

1. Stop TB Partnership. September 2017. **Data Action for Tuberculosis Key, Vulnerable and Underserved Populations**. Working document.
2. UNAIDS and Stop TB Partnership. 2016. **Gender Assessment tool for national HIV and TB Responses. Towards gender-transformative HIV and TB responses**.
3. UNDP. Stop TB Partnership. 2017. **Legal Environment Assessment for Tuberculosis: An Operational Guide**.

TB Key, Vulnerable and Underserved Populations

No single definition of TB key populations currently exists, every country has their specific key population. The Global Fund defines key populations as those who experience both increased impact from disease and decreased access to services (The Global Fund to fight AIDS, TB and

malaria (2018).³ Key and vulnerable populations for TB are further categorized by the Global Plan to End TB 2016–2020 as the most vulnerable, underserved, and at-risk populations. The Stop TB Partnership additionally features people living with HIV (PLHIV), rural populations, and healthcare workers in their series of key population briefs.

For Indonesia, the national TB control strategy⁴ mentions several groups of having higher factors for TB infections and illness, including (1) Diabetes Mellitus patients, (2) children (<15 years), (3) elderly (> 65 years), (4) urban poor, and (5) people living with HIV and AIDS (PLHIV). The core team use the guide developed by Stop TB Partnership at al. a list of 14 groups of people at higher risk of TB⁵, while the five groups listed in the Indonesian TB National Strategy are included in the list. The group in the long list is currently called the TB key population, which includes mobile people, miners, prisoners and, PLHIV (See Annex 2 for the Key Population Exercise). We came to 3 potential groups. However, due to budget and time constraints, we selected two highest ranked that covered relatively wide range of background on how people were exposed with TB and have lower access to services, have intrinsically vulnerable to TB infection, and faced with behaviour risk as well as stigma and discrimination.⁶

Despite possible multiple determinant factors of people to develop TB disease and how patients seek treatment and uptake the treatment, we will focus this study on the two areas of key, vulnerable or underserved populations as follows:

1. People living in high density area (“poor slum area”). The group is chosen because the people living in such situation will be highly exposed with various communicable diseases including TB. The areas are usually situated in a poor slum housing, at urban areas, and especially in large cities.
2. People with HIV and AIDS (PLHIV), have a higher risk of TB due to due having HIV virus in their body that is weakening the immune system, and that such internal condition heightened the risks of getting TB.

Data from countries worldwide show evidence that TB prevalence among people living in slum area is 4 to 7 times higher than those living in other urban areas, where the barrier identified among this population is more likely due to weak patient-finding approaches, and underutilization of public health services. PLHIV are 16 to 27 times more likely to develop active TB as compared to people who do not have HIV and are four times more likely to die during TB treatment, with identified barriers of stigma, nutritional deficiencies, and a persistent lack of service integration that cause difficulties for PLHIV with TB co-infection to access collaborative care.

³ Key Populations. On line at <https://www.theglobalfund.org/en/key-populations/>

⁴ Minister of Health Republic of Indonesia. National Strategic Plan of Tuberculosis Control. 2016-2020.

⁵ Stop TB Partnership. September 2017. Data Action for Tuberculosis Key, Vulnerable and Underserved Populations. Working document.

⁶ Based on Figure 11 (P39) of “Data for Action for Tuberculosis Key, Vulnerable and Underserved Population, Working Document, Stop TB Partnership, September 2017. We have determined PLHIV, urban poor, rural poor prisoners, miners, elderly, children, mobile populations, as priority TB key population in Indonesia.

Gender Analysis

Gender analysis, as any analyses on diseases, would require completion of several stages, including (1) preparing for gender assessment of the national TB and HIV response, (2) knowing the national TB and HIV epidemics and context, (3) Knowing the national TB and HIV response and (4) using the findings of the assessments for a gender-transformative TB and HIV response, that is focusing on redefining and shaping the new norms and relationships between genders to reduce gender imbalances.⁷

To date, gender issues are not put as one of the highlights in Indonesian documents, and mostly in strategic document, that it leads to notions that there are no significant gender-related problems laying in the implementation of TB programs, despite reports explicitly suggest more issues occurred with male than female (i.e. higher number of case findings, lower percentage of treatment success). Information related to gender factors that will be obtained from this study is to provide nuances of how TB program implementers and beneficiaries at the district and national levels see gender aspects in the national TB program.

Legal Environment Analysis

Legal environment analysis aims to identify and examine the important legal and human rights issues affecting all people in a country. For TB, LEAs also have several objectives including review laws, policies and implementations that might hamper access for people with TB; Identify populations vulnerable to TB; Determine whether the rights of people with TB are recognized and if they are violated in practice; Involve stakeholders in harmonizing laws, policies and practices within the framework of human rights and gender equality, as well as; Plan the allocation of resources (politics, human and financial resources) to make changes.

Legal environment analysis starts with a literature review of legal documents and stakeholder consultations in understanding the legal situation that might have effect programmatically and/or individually to whether the legal aspect is supporting or hindering uptake of quality TB services. Analysis on whether the rights of people with TB are recognized and if they are violated in practice. This includes the course of program implementation as to identify issues in relation to law and policies.⁸ In addition to a broad perspective using the method of literature review and stakeholder consultation, this study will also look at a narrow scope, namely, on how the beneficiaries perceived the TB services throughout the course of diagnosis, treatment and complying the treatment, that has relations to legal and policy. Similar to the gender and key population assessments, legal environment assessment also starts from knowing the TB epidemic after having the stakeholders mapping, and consultation to complete the analysis.

Based on these three guides, the study aims to do the analyses as to answer:

1. Know the epidemic

⁷ UNAIDS and Stop TB Partnership. 2016. Gender Assessment tool for national HIV and TB Responses. Towards gender-transformative HIV and TB responses.

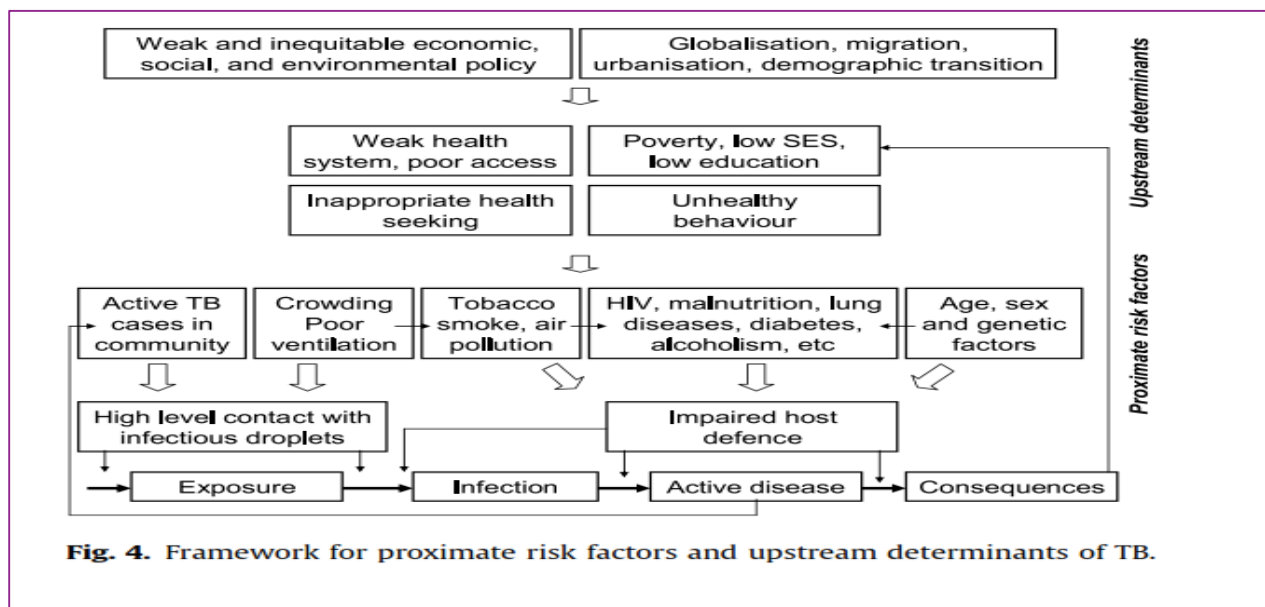
⁸ UNDP. Stop TB Partnership. 2017. Legal Environment Assessment for Tuberculosis: An Operational Guide.

2. Know your response
3. Identify determinant factors
4. Identify factors related to health seeking behavior
5. Identify Gender and Legal Environment related Issues
6. TB Key Population: Are they in higher risk of TB morbidity?

Barriers to TB Services

Study done by Lönnroth (2009) in Indonesia discussed the drivers of TB epidemics as follows⁹:

FIGURE 1. DRIVERS OF TUBERCULOSIS EPIDEMICS: THE ROLE OF RISK FACTORS AND SOCIAL DETERMINANTS



The figure above shows the dynamics of the situation starting from inequitable economic conditions, combined with the transition in demographics, where this results in poor access to the health system, low socio-economic status, inappropriate health seeking behavior and unhealthy behaviors. This affects the transmission among people in the community, the slum situation with poor air ventilation in densely populated condition, smoking behavior, malnutrition and various diseases that weaken the body's immune system (HIV, diabetes), and also specific age and sex of

⁹ Lönnroth, K. *et al.* (2009) 'Drivers of tuberculosis epidemics: The role of risk factors and social determinants', *Social Science and Medicine*, 68(12), pp. 2240–2246. doi: 10.1016/j.socscimed.2009.03.041

more susceptible to transmitting/getting TB as a result of high exposure to Mycobacterium TB (MTB) and vulnerability among people with specific disease as hosts for MTB.

Taking into consideration above findings, and also looking to other literature review using the keywords "TB" and "determinant factors", this study selects 4 main factors that are relevant in the Indonesian context to explain hindering factors to utilization of quality TB services: (1) gender related factors, (2) legal related factors, (3) health system factors and infrastructure factors, (4) socio-economic factors.

Gender related factors

Horton et al.¹⁰ mentioned: "TB prevalence is significantly higher among men than women in low-and middle-income countries, with strong evidence that men are disadvantaged in seeking and/or accessing TB care in many settings. Global strategies and national TB programs should recognize men as an underserved high-risk group and improve men's access to diagnostic and screening services to reduce the overall burden of TB more effectively and ensure gender equity in TB care."

Tan et al.¹¹ conclude that women with TB have longer delay in seeking healthcare than men after onset of TB-associated symptoms; while men with TB have significantly more severe lung lesions (Cavities and healing associated features) and higher bacterial counts compared to women with TB.

Kanchan et al.¹² mentioned "10% of the marriages ended in divorce because of the female spouse diagnosed with TB (common among younger spouses); 25% of women with TB, report being isolated and discriminated in their homes, and in 2% older couples marriage ended in divorce when the wife is diagnosed as a TB patient.

Legal related factors

Legal environment assessment, including program policies that has direct relation with human rights issues in TB program implementation, are critically needed to understand how the national level policies could support district level institution to provide services to the communities, and whether TB program at local level is sustainable and matched with the national TB strategy. Understanding legal factors may not directly relate to better TB response, however, absence of supporting legal factors will hamper implementation of national TB strategies. Sufficient legal support for TB would enable not only the health facilities and providers to optimize

¹⁰ Horton, K.C et al. PLOS Medicine. 2016. Sex Differences in Tuberculosis Burden and Notifications in Low-and Middle-Income Countries: A Systematic Review and Meta-analysis.

¹¹ Tan, W. et al. 2018. BMC. Sex influences the association between homeostasis and the extent of lung lesions in tuberculosis

¹² Kanchan Srivastava, Surya Kant, Apoorva Narain, Jyoti Bajpai. 2018. European Respiratory Journal. Tuberculosis in women: A reflection of gender inequity

their roles, but also to encourage communities to take significant part in TB program implementation. Local regulations would enable district health office in managing TB in health system mechanism, and taking responsibility in providing necessary resources.

Enabling environment is one of the strategies set out in the TB Ending Strategy (WHO, 2015) ¹³, where it is a call for different Institutions to take responsibility for implementing the TB program.

Health system factors, and infrastructure factors

Using Poisson regression models, Godinho de Seixas Maciel et al., (2018) ¹⁴ were able to identify the association between drop out from anti-tuberculosis treatment and the human development index and the social development index. The result shows that economic conditions, infrastructure, and the tuberculosis control quality of surveillance were associated with treatment adherence. This study demonstrated that the scenarios of socio-environmental precariousness found in the districts of Rio de Janeiro were able to identify populations with an increased risk of default treatment from anti-tuberculosis.

Socio-economic factors

A study was done in Pakistan (Khan et al., 2017) suggest that low education, unawareness of TB, crowded population, poverty, high treatment cost and distance to public health facilities, have a strong correlation with TB prevalence. This study also reported factors such as the poor attitude of family members, colleagues, society, and health care professionals were major social factors leading to non-compliance and denial of TB treatment. Poverty is strongly associated with TB incidence even after controlling for smoking and other risk factors. Excluding income losses, direct out-of-pocket treatment costs (medical and non-medical) accounted for 55.5% of average annual household income, and most TB cases fell into massive debt. The DOTS cure rate was 91%. When DOTS was incomplete or not done, mortality was high (Jackson, 2006).

Amidst different factors indicated above, the study will look more deeply on gender and legal aspects to determine whether these two factors have a contribution in hindering people to be detected for their TB suspect, and to get proper diagnosis and treatment, including for those who have MDR-TB, and for the community support that will play important parts in the overall TB programming.

The school participation rate among girls and boys aged 16-18 years may serve as indication of gender imbalance in socio-economic factors should they differ significantly. The Indonesia central bureau of statistics reported that total school participation rate at year 2009 is

¹³ WHO. The End TB Strategy. Global strategy and targets for tuberculosis prevention, care and control after 2015.

¹⁴ Godinho de Seixas Maciel, EM., et.al. 2018. Social determinants of pulmonary tuberculosis treatment non-adherence in Rio de Janeiro, Brazil. Plos Medicine.

55.16% where boys are at 55.90% and girls at 54.37%. Total rate is continuing to grow that the national level of school participation of population 16-18 years old is at 70.83% in year 2016. The girls have relatively higher rate since 2012 onwards, at 2016 where boys are at 69.62% and girls are at 72.11%. Education Expectancy Rate (in year) of boys are 12.84 years and girls are 12.99 in year 2018, while the average length of education time for boys are 8.62, while girls are 7.72. These data show that more girls participating in school but quicker to getting out of school. This is indicative that there is gender imbalance for girls and boys in getting the education, and it continues to getting the occupations.

Objectives

The general objective of this study is to describe identified determinant factors that hinder TB related case findings, case notification and access to services among:

- People living in poor, high density area settings.
- People Living with HIV who were TB Co-infected and have completed TB treatment as recorded in select Hospital and PHCs.

The study would answer to a question of what barriers encountered by people in order to access to TB-related quality services, and whether the gender and legal aspect are amongst these barriers.

Specific Objectives:

1. To explore possible determinant factors for people affected by TB to seek care and treatment
2. To identify factors affecting people affected by TB to health seeking behavior
3. To explain factors related to gender and legal aspect in the course of diagnosing, care and treatment as well as supports
4. To describe possible key populations among people affected by TB and those who have higher risk to morbidity related to TB, in order to formulate recommendations for improvements on TB case findings, case notification, and access to services.

Methodology

A qualitative study conducted at North Jakarta City and Sidoarjo District from September to November 2018.

This study is using the CRG (Community Rights and Gender) tools as a reference, guides that are developed by the Stop TB Partnership in collaboration with the Global Fund and WHO in the Strategic Initiative, UNDP and UNAIDS.

Information and data are collected employing six main activities: (1) Stakeholder mapping; (2) Literature review; (3) In-depth interviews with respondents and key informants; (4) Focus group discussions; (5) Multi-stakeholder community dialogue and (6) Validation workshop. The literature review includes those for legal analysis, analysis of disaggregated data of routine and survey data for gender analysis, as well as for study background, in particular regarding TB determinant factors.

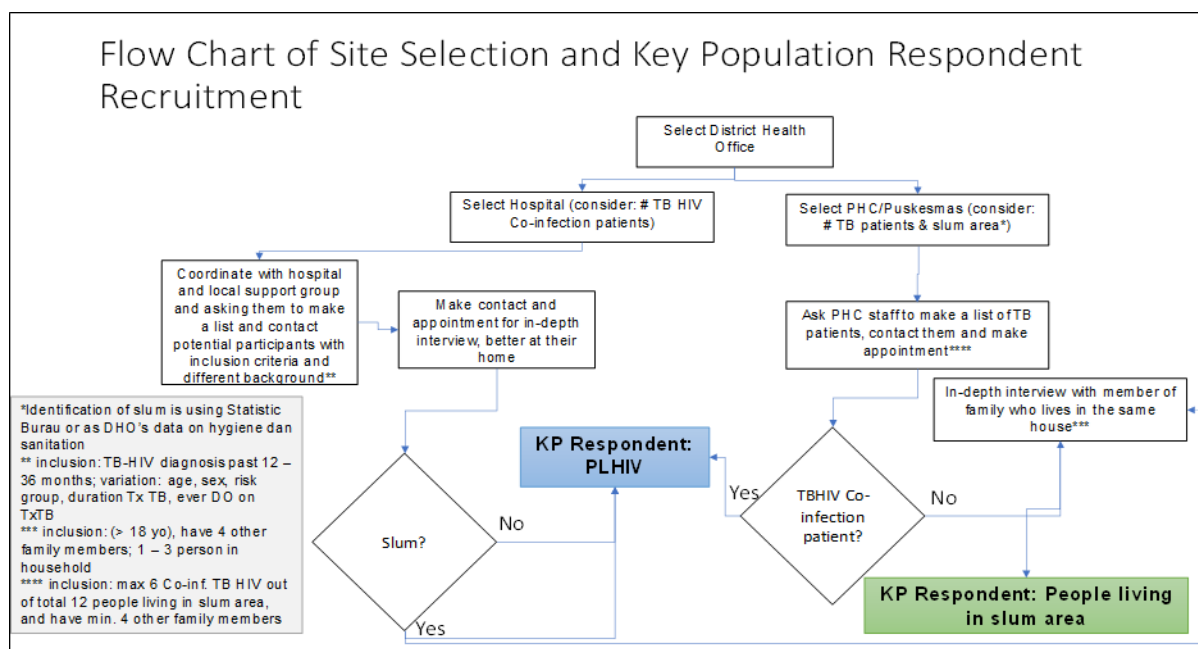
The study plan, the results of the interim analysis and the final results of the study were consulted with the advisory team to validate the overall findings in particular: (1) the results of the initial key population description of TB, (2) the results of gender analysis, (3) the results of legal assessment study, (4) review recommendations.

Data Collection

The study team received ethical approval from the Atma Jaya University Ethics Committee. All respondents and key informants were given informed consent before the interview and asked for their permission to an audio recording. The observation was carried out to depict surroundings and situations that show an increased risk of TB transmission. Expanded notes from in-depth interviews, records and results of observations were collected and organized during the study to prepare for the analysis process to answer the study questions.

A maximum of 30 respondents of key populations both PLHIV and people living in the high-density area at each site or total peak of 60 respondents were recruited using the flow chart below.

FIGURE 2. FLOW CHART OF SITE SELECTION AND KEY POPULATION RESPONDENT RECRUITMENT



SITE SELECTION

Selection of the villages was based on the calculation of scoring on several variables related to density and poverty. Some of the variables used are population density, average members per family, rural/urban areas, level of family welfare or housing's physical condition. This data derived from the National Bureau of Statistic, the year 2017 and 2018. Each variable has the same weight. Data are arranged sequentially based on score calculations, starting from the highest to the lowest score. However, because the variety of availability of data in each village, the variables used for a selection also correspond to the availability of variables. The village with the highest total score will be recommended as the candidate for assessment. The final decision on the selected villages have discussed among the research team and the local District / City Health Authorities.

Key Informants And Respondents

Below is the data collection statistics about this study:

1. **Total stakeholders mapped:** 18 key informant interviews of 18 institutions (10 at the national level; 3 in Sidoarjo, and 5 in North Jakarta)
2. **Total documents reviewed** for legal aspects: 21 documents (7 international covenants, 1 constitution, 5 laws, 5 implementing regulations, and 1 other document)
3. **Total FGDs conducted:** 7 groups (1 national level, 2 in Sidoarjo and 4 in North Jakarta with a total of 47 participants).

4. **In depth interview with respondents:** 44 people (29 from North Jakarta and 15 from Sidoarjo)
- a) **Key Population TB:**
 1. Total respondents of people living in slum area: 33 people (18 people from North Jakarta and 15 people from Sidoarjo)
 2. Total respondents of TB-HIV co-infection former patients: 10 people from North Jakarta. Interviews of former TB-HIV co-infection patients in Sidoarjo are not carried out until the writing of this report.
 3. There is 1 person not recorded by demographic data
 - b) **Gender:** Of a total of 43 people identified, 16 were men and 27 were women
 - c) **Age:** Of 43 people identified, 4 people aged 18-24 years, 7 people 25-34 years, 22 people 35-44 years, and 10 people 45 years or more.
 - d) **Education Level:** high school graduated (19 people), junior high school graduated (11 people, and elementary school (9 people), the rest did not pass elementary school (3 people), did not pass junior high school (1 person), and 1 person is not identified.
 - e) **Income:** out of 43 people identified as income, 42 people earn below district standard of income, and 1 person above district standard of income.

Literature review is done on legal documents, program and survey reports, some journals and other strategy/policy documents.

Legal And Policy Framework

The study of the legal environment related to TB is carried out through an analysis of the national legal framework and policies of TB in Indonesia through a hierarchical approach to Indonesian legislation and international instruments that have been ratified in state legislation relevant to TB. This study aims to identify the extent to which the legal and human rights framework and its enforcement in Indonesia creates an enabling environment for access to and uptake of quality TB services; it will also identify gaps in the TB programme based on the legal assessment and requirements.

International Covenants and Charters	Constitution of Indonesia	Human Rights Act	Health Law Act	Occupational Safety Act
Major Labor Act	National Security System Act	Medical Practice Act	Hospital Act	MOH Regulation on TB Control
TB Management Guidelines 2016	National Strategic Plan of TB Control 2016-2020	TB Control in the Workplace Guideline 2015	Health System District of Sidoarjo Regulation 2013	DKI Jakarta Governor Regulation on TB Control 2018

Summary of Laws, policies and guidelines reviewed in this assessment

Results

A. Know your Epidemics

This section will put forward the discussion on published epidemiological data, in a brief overview as well as in disaggregated data analyses. This study is able to obtain disaggregated data by sex, by co-infection with HIV, and age. However, disaggregated data on the “slum area”, or poor setting, high density area, were not available to this report writing phase, and this data is considered gaps for further analyses.

i. The Overview

The estimated TB case incidence reported in 2017 was 842 thousand (767 thousand - 919 thousand), including co-infection with TB-HIV, or a number of 319 (291-348) people per 100,000 population. The mortality caused by TB alone (outside of TB-HIV co-infection) is 40 (38-43) per 100,000 population, or around 12.5%, while the MDR / RR-TB incidence in 2017 reached 8.8 (6.2-12) per 100,000 population, or 2.8% of the total estimated incidence.¹⁵

By sex, the estimated incidence among male is 492 thousand (458 thousand - 526 thousand) and 349 thousand (329 thousand - 370 thousand) among women, or male group is 1.4 times higher than female. More detailed information can be found in Appendix 1. Latest TB Epidemiology Reports in Indonesia.

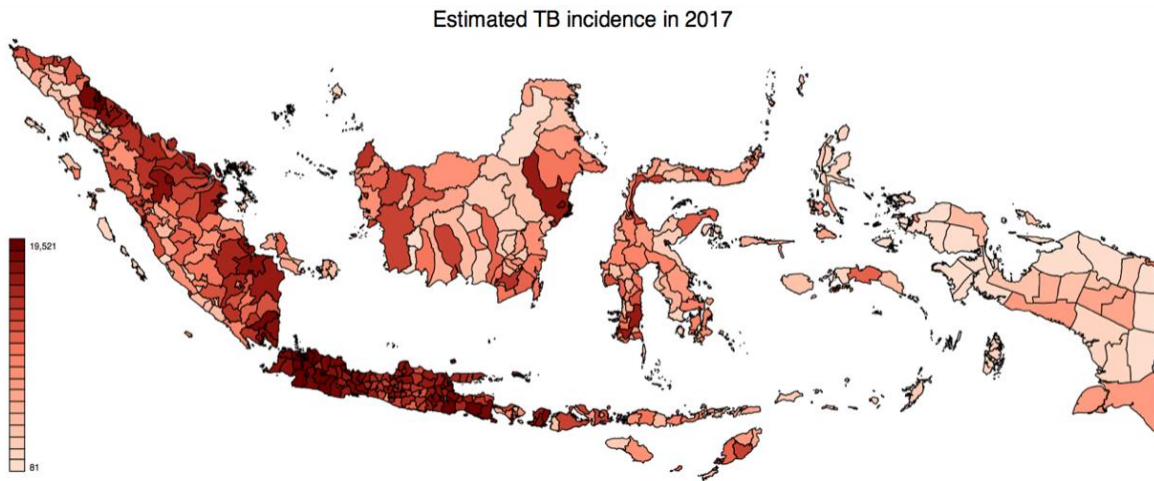
Of the total estimated 842 thousand incidents in 2017, the total number of TB cases found and reported was 446,732 people or 53%, while those receiving treatment were 444,704 people or 52.7%.

There are 7,729 people who know their HIV-positive status, with the size estimates of 49,000 HIV incidents in 2017, and 36,000 TB-HIV incidents (source: UNAIDS, 2018). Of TB patients who knew of their HIV-positive status, a total of 2,244 (29%) received ARV treatment.

Below is the geographical information system TB epidemic distribution in all (514) districts of Indonesia using the absolute numbers of estimated incidence.

¹⁵ TB Global Report, 2018

FIGURE 3. ESTIMATED ABSOLUTE INCIDENCE IN 514 DISTRICTS IN INDONESIA. 2017

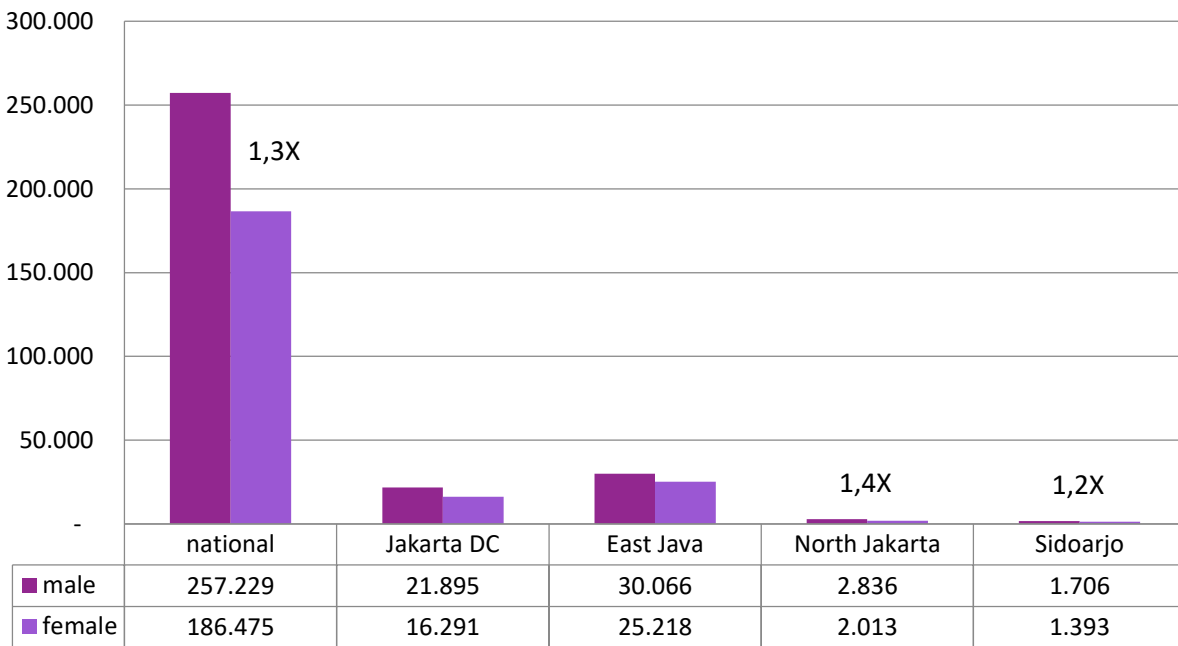


The figure 3 above indicates that in terms of absolute number of TB incidence, Java and Bali, West Nusa Tenggara, and Sumatera, then Kalimantan and Sulawesi are consecutively having highest TB burden.

ii. TB by Sex

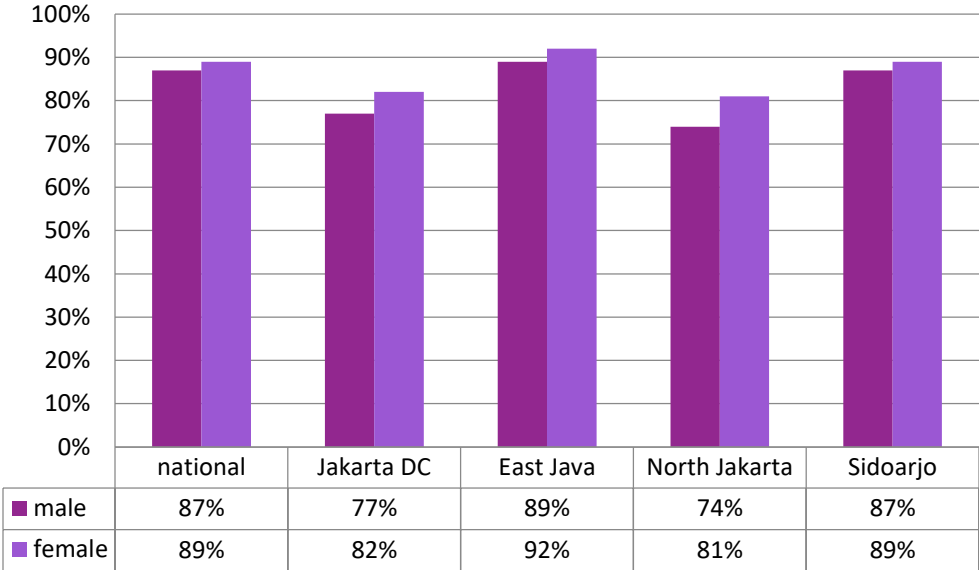
Figure 4 below shows that at the national level, male are 1.3 times higher than female, while both, North Jakarta and Sidoarjo, has the same pattern.

FIGURE 4. TOTAL NUMBER OF TB CASES REPORTED BY SEX, 2017



While for treatment success rates based on sex as seen in the figure 5 below appears a tendency for female to have a slightly higher rate of success in TB treatment than male, but statistically may not be significantly different.

FIGURE 5. TB TREATMENT SUCCESS RATE BY SEX, 2016



iii. TB by co-infection with HIV

In order to see the situation of TB treatment in HIV positive patients compared to HIV negative patients, figure 6 below suggests that TB treatment success among HIV-positive patients is consistently lower than HIV-negative patients, and difference reaches 24% at the national level, and even higher at North Jakarta, reaching 31%.

This condition shows higher susceptibility among HIV-positive patients as compared to HIV-negative patients to achieve successful TB treatment. However, it seems that the difference could be minimized at Sidoarjo.

FIGURE 6. PERCENTAGE OF TB TREATMENT SUCCESS RATE BY HIV STATUS, 2016

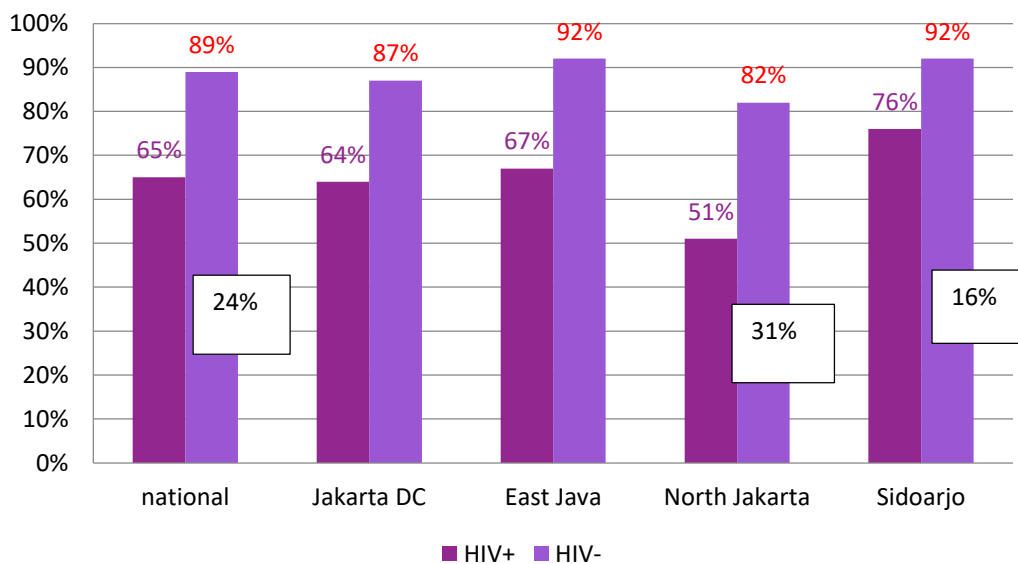
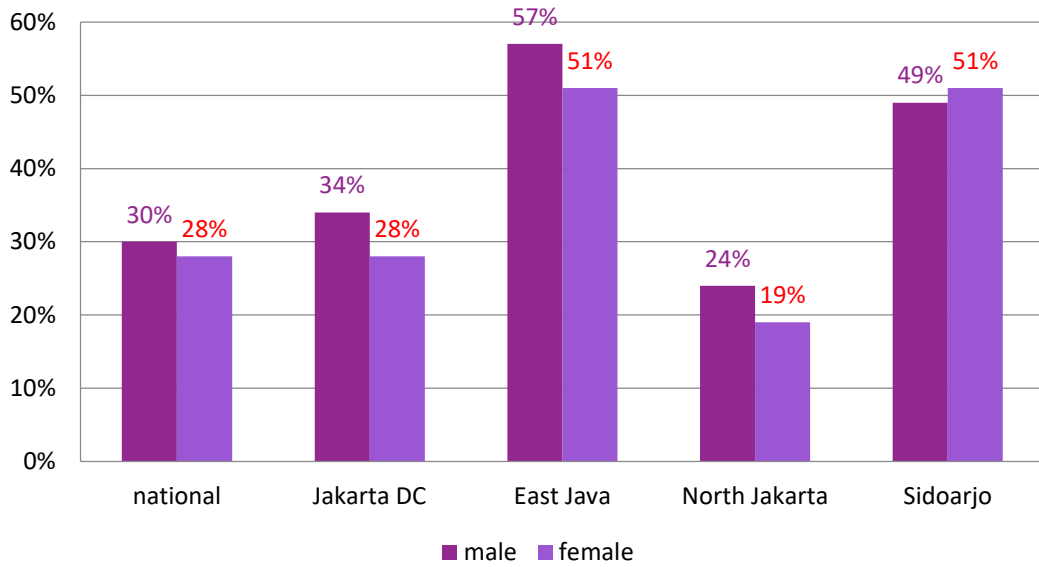


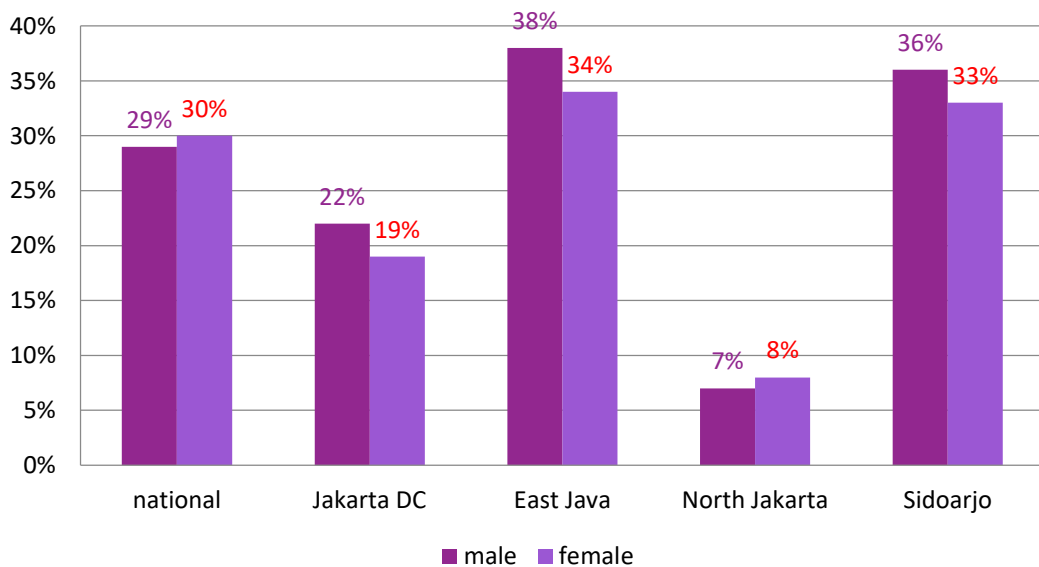
Figure 7 below shows that nationally, and also at province level, DKI Jakarta and East Java, as well as district level, North Jakarta and Sidoarjo, more male patients know their HIV status than female. However, the differences between male and female do not seem to have a significant difference.

FIGURE 7. PERCENTAGE OF TB PATIENTS KNOWING THEIR HIV STATUS BY SEX, 2017



A total of 2,244 people or 29% of TB-HIV co-infection patients receiving ARV treatment nationally and the graphs shows a slightly higher portion among female than male group. However, at the province and district level in this observation, male groups seem to have a somewhat higher proportion than the female group, that indicates no significant difference in receiving ART among co-infected TB-HIV male and female patients.

FIGURE 8. PERCENTAGE OF TB-HIV CO-INFECTION PATIENTS RECEIVING ARV TREATMENT BY SEX, 2017



iv. TB by Age

Disaggregated analysis by age can be seen in figure 9, 10, and 11 on TB treatment success rate, TB patients who know their HIV status, and TB-HIV patients who receive ARV treatment, respectively. Children, or under 15 years of age patients, tend to be more successful in TB treatment than adult patients (15 years and above), but smaller proportion of TB patients in children who know their HIV status, and tend to be smaller in proportion to ARV treatment (See Figure 9, 10 and 11 below).

FIGURE 9. PERCENTAGE TB TREATMENT SUCCESS RATE BY AGE, 2016

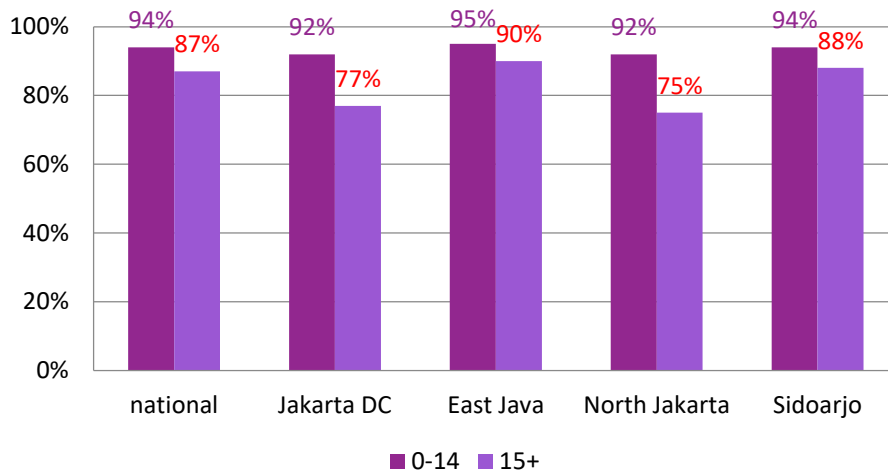


FIGURE 10. PERCENTAGE OF TB PATIENTS KNOW THEIR HIV STATUS BY AGE, 2017

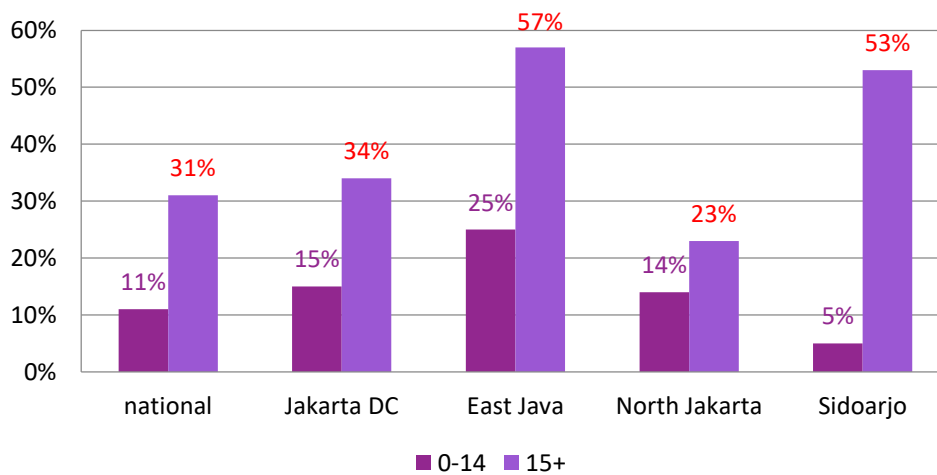
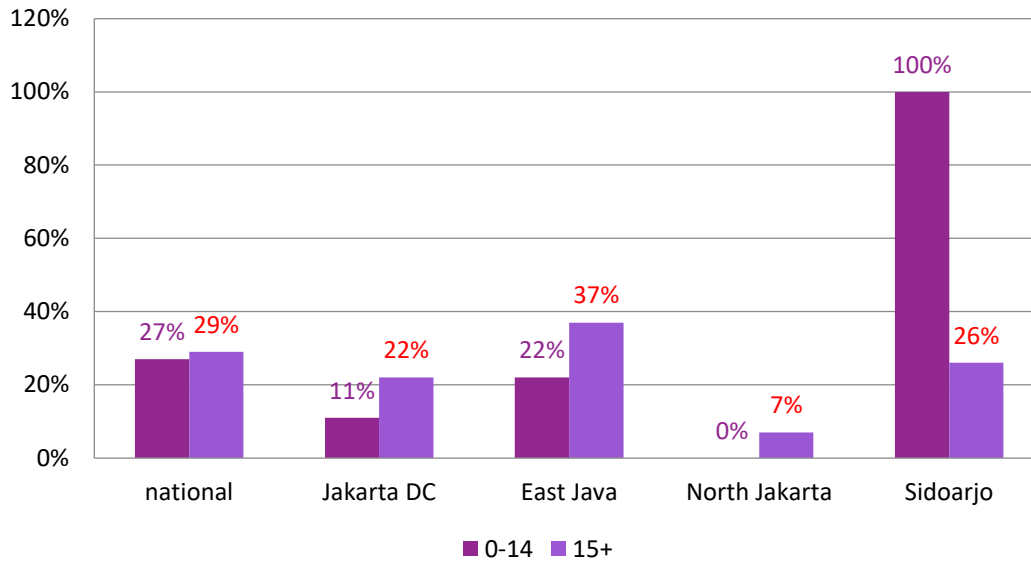


FIGURE 11. PERCENTAGE OF TB-HIV CO-INFECTIONS PATIENTS RECEIVING ARV TREATMENT BY AGE, 2017



B. Know Your Response

In order to briefly describe the country response, below are situations that cover important areas of the TB control program and implementation, and those are available legislation and policy, data and information management, National TB program strategies, health systems and quality TB service delivery, and main challenges in effective TB programs implementation. The following is the description.

i. Legislation

Legislation is all legal documents that describe the rules and regulations, as well as other policies of the Indonesian government to ensure the availability of services and the protection of the rights of citizens to obtain quality and dignified TB services. Under the constitution of the Republic of Indonesia below are several legislation levels of implementation comprising of regulations, guidelines, and other documents.

a. Regulations

1. The Ministry of Health Regulation No. 67/2016 on TB Control;
2. Ministry of Health Regulation No. 43/2016 on Minimum Service Standards in the Health Sector;
3. Minister of Health Regulation of the Republic of Indonesia No. 39/2016 on Guidelines for Implementing a Healthy Indonesia Program with a Family Approach;

4. Decree of the Minister of Health No. 1278 / Menkes / SK / XII / 2009 on Guidelines for implementing collaborative control of TB and HIV diseases;
5. Circular Letter No. HK.03.03 / D1 / III.I / 951/2016 on Increasing TB Case Findings;
6. Circular of the Minister of Home Affairs No 440/4838 / Bangda on Support for the Acceleration of TB Control;
7. Ministry of Health Strategic Plan 2015 – 2019;
8. National Strategic Plan of TB Control 2016-2020, Ministry of Health of the Republic of Indonesia;

b. Guidelines

1. Guidelines for National TB Control, Ministry of Health 2016;
2. Guidelines for Tuberculosis Control in the Workplace, Ministry of Health and Ministry of Manpower 2015;

ii. Data and **Management** Information System

Data and information are managed in an integrated monitoring and evaluation system, comprises of information systems for routine program implementation, surveillance, and further analyses of routine data and surveillance to get an overview of the country-level situation on the implementation status and effectiveness of TB programs in Indonesia. Data and information Management include:

- SITT: routine data of facility-based recording and reporting, verified and summarized by district level for the national information system (SITT) on TB program.
- The national TB prevalence survey carried out in 2013 - 2014
- One of the recommendations from the results of the 2014 TB Prevalence Survey, is the implementation of an inventory study. Based on these recommendations, the TB Sub-Directorate in collaboration with the Research and Development Agency of Ministry of Health Republic of Indonesia and WHO, conducted an Inventory Study that aims to calculate under-reporting TB cases. This study published the under-reporting TB cases in Indonesia amounted to 41% (95% CI 36% -46%). Further analysis of the inventory study, came out with published incidence rates of Indonesia in 2017 that is 842,000 (95% CI 767,000-919,000) or 319 per 100,000 population (95% CI 291-348).

iii. The National **Strategic** Plan of TB Control 2016-2020

The National Strategic Plan of TB Control 2016-2020 (NSP TB) is structured with reference to the National Medium-Term Development Plan (RPJMN) 2015-2019 and Strategic Plan of the Ministry of Health 2015-2019 where TB control became integral part of the broader strategy on disease control and environmental health. The NSP TB will become a reference in the implementation of TB control across all sectors of government, private and public, and also can

be used as reference in formulating action plans and proposed budget at each province and district / municipality as the fulfilment of decentralization laws.

The National Strategic Plan of TB Control (2016-2020) provides the policy directions on TB program implementation, formulized in 6 strategic areas:

1. Strengthen leadership in TB Program Management at district level
2. Improve access to quality services using “TOSS TB” (Find TB Cases, Treat them to completion)
3. Manage and control risk factors
4. Improve TB Partnerships through the Coordination Fora
5. Increase community involvement in TB control
6. Strengthen the Health System

No citation on gender or human rights in the national TB strategic plan. The strategic plan is focusing on making the implementation effective through tackling different health system rather than paying detail attentions on legal and policy development as well as specific intervention to “identified” people with higher risks of TB: older and younger people, TB-HIV coinfection, people with Diabetes Mellitus, people in poor-high density area, and people in incarceration. No specific strategies translated into smaller strategies as per population, only mentioning “integrating services” with DM or HIV clinics. Even in one of the statements on the increase of community involvement in TB control states that patients have rights and responsibility as an individual as the centre of TB control, unfortunately there are no recognitions that address the challenges and strategies on human rights issues and legal barriers for people with TB .

iv. Health System in practice and **Provision** of quality TB Services

TB control in Indonesia is carried out in accordance with the principle of decentralization within autonomy framework with districts/municipalities as the focus of program management, which is including: planning, implementation, monitoring and evaluation and guarantee availability of resources (funds, personnel, facilities and infrastructure).

TB control is implemented using the DOTS strategy as the basic framework and considering the global strategy for controlling TB (Global Stop TB Strategy). Policy strengthening is aimed at increasing local commitment to TB control programs. Strengthening TB control and development aimed at improving the quality of services, easy access to case finding and treatment so as to be able to break the chain of transmission and prevent the occurrence of drug resistant TB.

The findings and treatment in the context of TB control are implemented by all Primary Health Care Facilities (FKTP) and Referral Health Facilities (FKRTL), including: Puskesmas (Sub-District level Public Health Center), Government and Private Hospital, Lung Hospitals (RSP), Community Lung Health Center (B / BKPM), Medical Clinic and Private Practitioners (DPM).

Basic TB diagnosis and Treatment (without complications) was provided by the Primary Health Care Facilities (Puskesmas, Clinics and Private Practitioners). More advance TB Treatment is referred to FKRTL (Fasilitas Kesehatan Rujukan Tingkat Lanjut- referral health facilities). TB

control program includes health promotion using cooperation and partnerships among government, non-government, private and community sectors under the National Integrated Movement for Tuberculosis Control (Gerdunas TB).

Among people affected by TB reported in 2016, only 8% of the estimated 32,000 MDR-people affected by TB were diagnosed. Up to 2017 issues of delays in confirmation of drug resistance status, limited access to centralized PMDT facilities, fear of side-effects, and long duration of treatment has led to high initial and early loss-to-follow up and high death rates, despite the fact that the government had provided significant referral centers across the country (37 PMDT referral centers, 32 sub-referral centers, and 1,217 satellite centers).

v. Major Challenges in **National** TB Program Implementation

One of the challenges in TB response in Indonesia is most people affected by TB go to private sector for initial care seeking (80,000-100,000 providers of which 78,597 are registered as medical doctors) and only 495 private practitioners, 63 private hospitals, and 225 private clinics engaged on notifying people in year 2016. Although the patients are treated in similar method, these private care providers contributed only a very small case notification: 4,952 (1,5%) private practitioners, 26,547 (8%) private hospitals, and 5,505 (1,5%) private clinics people affected by TB.

Private sectors, as much as this is challenging at this period, are in progress to betterment with the roles of professionals and coalitions. Legal wise, private roles for TB are regulated through protection of human rights, default of workplace, misconduct against the workplace regulation, misconduct against health services, and misconducts against rights to housing and healthy living environments. This legal offense would be processed through report mechanism.

Recent available drugs and diagnostic method for all people who need that. The main challenge in relation to this is that the MoH is not necessarily adopted the newest WHO guidelines. The patent drug may need to face the law no. 4/2001 about patent, that article 1 stated that patent is and exclusive rights given by the country to inventors. Exclusive rights hold the meaning that no other party takes and use the benefit of patent without patent holder's permission. The Indonesian constitution, UUD 1945 law, article 28H, and Law of Health, also International stipulation at Paragraph 4 Doha Declaration on TRIPs Agreement and Public Health, come to "TRIPs Agreement does not and should not prevent members from taking measures to protect public health", and that Indonesian government tends to curb HIV epidemic by producing the second grade ARV, registered with patent. Indonesian government applied compulsory licensing through patent registration which is regulated in law No. 14/2001. In producing drugs of generic type, the Indonesia FDA (BPOM) is responsible to oversee drugs publicly distributed in Indonesia. Tight regulation on drug registration and distribution clearance of a product (drug), the Government of Indonesia is taking responsibility on quality/efficacy and safety. The warranty is expressed in Article 36, 106, 107, and 197 of Law No. 36/2009 about Health.

In workplace, Law No. 1/1970 about Work safety, and law No. 13/2013 about workforce are regulating health measures created by the owner (institutions) and workers. Tb is included in these both laws that covers health and healthy environment for workers, specifically on:

- rights to health and work safety

- rights to social security and health insurance
- owner's responsibility to prevention and control measures of diseases-related works physically and psychologically.

At least six legislation at constitutional level cover protection towards TB community: (1) UUD 2045 (the constitution), (2) Law No. 39/1999 about Human Rights, (3) Law No. 36/2009 about Health, (4) Law No. 1/1970 about Work Safety, (5) Law No. 40/2004 about National Social Security System – SJSN, and (6) Law No. 13/2003 about Workers/Manpower. These laws provide warrants and protection to people rights to health, health service, and social security. Taking it further, these laws imply the rights to live in healthy life that is related to proper living condition, access to health, and other regulation that prevents people to live in “harmful” areas including places that are susceptible to disaster (i.e. river banks, flooding, and slum areas). Such regulations are available at district level. TB-related regulations available are (1) Minister of Health Decree No. 67/2016 about TB Control, (2) Minister of Health Decree No. 13/2013 about Guidelines on Comprehensive Management of TB-MDR control, (3) Director General of CDC Decree No. 2088/2015 on CDC Program Action 2015-2019, (4) Attachment of Minister of Health Decree No. 67/2016 about TB Control about the Guideline. Among those 4 regulations, only the latest issuance, the decree and its attachment, have clear support to TB communities, however there is no legislation that specifically regulates Gender equality in Indonesia, particularly regulations which address issues on women and girls, men and boys, transgender people and key affected populations in relation to HIV, TB, HIV/TB, or MDR-TB.

C. Identify **Determinant** Factors

i. Key Population

No single definition of TB key populations currently exists, every country has their specific key populations, and generally, the key population is defined as a risk and vulnerable group of populations. The association of a risk marker with TB may be confounded with other factors, but it is still valid as an identifier for having a high risk of TB. A risk group for TB is any group of people within which the prevalence or incidence of TB is significantly higher than in the general population. A risk group may be a group of people sharing a specific individual-level risk profile, for example, being in close contact with a person who has active TB; or living with HIV or having diabetes; or being a migrant. (WHO, 2013). The literature on meta-synthesis of 468 TB screening studies done by a group of experts defining more than 20 groups indicated as populations at-risk for TB on the preparation of the WHO guideline of Systematic screening for active Tuberculosis: Principles and Recommendations.

The Global Fund defines key populations as those who experience both increased impact from disease and decreased access to services (Key Populations, The Global Fund ATM, 2018). Key and vulnerable populations for TB are further categorized by the Global Plan to End TB 2016–

2020 of Stop TB Partnership as the most vulnerable, underserved, and at-risk populations. The Stop TB Partnership additionally features people living with HIV (PLHIV), rural populations, and healthcare workers in their series of key population briefs

A risk group can also be defined as all people living in a specific geographical location associated with a high burden of TB (for example, all people living in an urban slum) or a particular type of institution, such as all prisoners in a country. Increased risks are stemmed from close contact due to housing condition with high-density population, and almost always aggravated with poor environment settings, the presence of untreated infectious transmitted disease, i.e. TB or of underqualified treatment of that disease. This study is carried out in two districts, at the areas with such above mentioned characteristics.

1. High-density Area

Both at North Jakarta and Sidoarjo, the study staff depicted the poor condition of the house at “slum” area where they were collecting the data. The physical housing condition includes no air circulation, one room with more than three families, the only door at the front which is closed almost all time, and an unhygienic toilet room right in front of the house. A house of a participant that is situated above the "river", with a very damp condition of the house and dusty carpets, where a female sex worker living with her four young children is living. An observation of study staff on someone introduced later as a TB patient surround the slum area at North Jakarta was hanging out with neighbors without using a mask.

People infected by TB living in the same household with TB survivors, and not recorded in the closest health facility as TB survivors were found in the study. She self-reported as a drop-out TB patient and mentioned two people in the neighborhood who as well as a child under five who has TB.

“... I am having a cough... I think I am re-infected... with TB... and going through TB treatment now... This is my third sickness ... they (neighbors)... and the child too (got TB) ... I think... also TB can be spread because of a closed weather... or never got the sun shine...”: **IDI, slum area, female, North Jakarta.**

“... TBC is more severe than TB... a kind of cough sickness... TB is not too severe (compared to TBC), only coughing in 3 months but not getting better... I got the drug, but at night I feel a fever, and when I was really dropped, I went straight to the doctor... And people with TBC has to be injected... ya, my brother got TBC, now he’s well. I also got TB, and my brother is my reminder (of TB drug taking daily)... I just rest if I don’t feel well... or I consult my brother, or other family member, and if I am still sick, I go to the doctor. I do have ID and BPJS, and doctor is nice, but I don’t like queuing...”: **IDI, Slum area resident, Male, North Jakarta.**

Both study participants are not registered as patients from the near-by Puskesmas, nor seen in the facility record. They live with another family member who were recorded as ex TB patients. This may be also indicative of the non-notified patients.

Below shows how knowledge of most of participants from the slum area are also lacking. Misconceptions on the cause, transmission and prevention of TB are very common, and this strongly leads to isolation, stigma, dan discrimination, not only at the household but also at the community. This would lead TB people to develop low self-esteem, lack of motivation, and hindering them in getting supports from other people, physically and psychologically.

“... never really understand TB, but I guess that must be contagious... if we drink from the same glass of some sort. ... My Grandpa used to have TB and had been medicated. ... I never had TB... I will go to Mama if I don't feel well... and will go to the doctor if still feeling unwell the next morning...”: **IDI, Slum area resident, female, North Jakarta.**

“... I am having a cough... it may be flu... just drank ice... I heard about TB, but I don't really understand what it means... it can be genetically obtained... it can be spread through blood, air, sexual intercourse... shared food, and spitting. My late father had TB ... he died a year ago...”: **IDI, Slum area resident, female, North Jakarta.**

“... Never know TB... probably you are not allowed to smoke, not allowed to eat anything hot... it can be because of dust (abu), or wind at the night... Son in law was TB... he was staying at home, but it was very long time ago...”: **IDI, Slum area resident, female, North Jakarta.**

“...TB?... I saw it in tivi... I don't understand though... I think it's because of drinks... because of smoking... from the air... they say it is infectious... they say if we eat or drink using the same utensil... we'll get infected if at the same room... my child was TB person... already completed the medication though...”: **IDI, Slum area resident, Male, North Jakarta.**

“I didn't know anything about TB before I got infected... I remember seeing a poster, but I have no idea what that means... there is also people coming to houses, taking blood pressure tests and anything.” “... it must have come from the manufacture... lots of dust...” “I used to drink ice...” “the diet is unhealthy...” “I immediately tell family members so they could use masks...” “...and I wash my own clothes...” “...neighbors then make a distance because of fear of getting infected...”: **FGD, Former TB patients, Puskesmas Sukodono, Sidoarjo.**

Almost all of them had ID and BPJS membership card (the two documents required for the people to access services provided by the government and their national insurance system), but that does not mean they would go to health services when they were sick.

“... my husband was TB, and we have different utensils. He had completed the treatment... and I wasn't infected... if I feel unwell, I just say it to my husband, and the day after I went to Puskesmas... I actually did not have money, but I got ID and BPJS...”: **IDI Slum area resident, Female, North Jakarta.**

“... ya, my wife had TB... she had TB treatment, and completed... I too had an X-ray, but not getting TB... I seldom go to the doctor... Mostly I just rest if I don't feel well... I do have ID and BPJS, and the Puskesmas is close, the doctor is also nice...”: **IDI Slum area resident, Male, North Jakarta.**

And lack of knowledge leads to fear-based stigma, that is common among the community.

“... been having a cough and losing appetite and the doctor gave me medication for both causes... TB... is very infectious... if TB person is drinking, don't ever use the same glass... it's so much infectious, not like AIDS or HIV... this is more dangerous... it is much more contagious... it is from the air of the mouth... when we talk... can be when we drink... just don't drink from the same glass... Yes, I lived with my uncle who had TB, and had underwent medication for 6 months... back when I was still a teenager... actually TB disease, even though it is infectious, but there is treatment... what most important for the patient is that we have to live in healthy life, follow the doctor's advice, don't drop out of medication and live in healthy environment... I'd go to Puskesmas if I got sick, they have treatment, and why not.... We have BPJS... and they also provide good service...”: **IDI, Slum area resident, female, North Jakarta.**

Socio-economic factor – nutrition. Support to TB people is critical, not only when they just started treatment, but also in maintaining them in treatment. The stopping of medication seems to be a recurring theme, most common was because they have felt better. Good counseling, knowledge on TB treatment will help them stay in treatment, however, stopping the treatment despite having a good knowledge on TB treatment is also recurring. The patients may experience severe side-effects but usually would know how to handle that after a week of treatment. The companion role is critical support TB people when starting treatment, however, supports in terms of transportation cost and nutrition supply are still critical afterwards.

“... because within a year I could not work... and I need to get good nutrition to get better, so I sold anything valuable to buy food...” *“... the company did not fire me and give me the salary until I recovered from TB... then they fired me*

because of TB... they do not know my HIV status” “... my (current) husband was backing me up fully... when I was dropped... people said I would die very soon... but at that time I only knew I was TB infected, not HIV infected... it was my late (previous) husband who had gland TB”: **FGD Ko-infection TB-HIV, Puskesmas Sukodono, Sidoarjo.**

“... I was drunk (with alcohol) and eat santan (coconut milk) meal... then I got sick with TB... but stopped the medication... 5 years later I got it again then I got to the Puskesmas and they sent me to a quarantine hospital (Sulianti Saroso Hospital)... I got injected every day in months in Puskesmas Cilincing, but taking drug orally at home”: **FGD, Ex TB patient, Male, Jakarta.**

Those of the TB MDR patients mostly have a long history on TB diagnosis and treatment, such as below.

“... I took and brought 6-month drugs from Lampung to my home town... three hours from Medan, and finished all...but when I get to Medan, I got again cough with blood... the second times I had TB treatment for 6 months... I took the drugs orally, and awaiting the midwife (who gave TB injection) after she finished her work... then I just knew that 8 hours distance between drug orally taken and injection is incorrect treatment... then I went to Semarang... 3 years later, I got relapse with cough with blood... and since the doctor said that I have a rare lung disease, I was referred to Salatiga... they also gave up, and then they provided me a choice to choose where I could get better medication, Surabaya or RS Persahabatan Jakarta... I pick Persahabatan... it took 3 months for me to get the result after I gave the sputum... and while awaiting I just took any vitamins that is sold in the market... at that time, those vitamins is relatively cheap... then I got the result that I might have TB resistance disease... I should have 26 months treatment, but I finished in 18 months... I am okay till now”: **FGD, Ex MDR TB, Male, Jakarta**

“... I was pregnant with second child... I got cough... and the doctor said it was okay... and the doctor also said that his wife also coughing when pregnant... then another doctor from another clinic said that too, pregnant women coughing is okay... after I gave birth this child... I was diagnosed with TB... regular TB... very expensive for me (private hospital) 4 months treatment, I felt much better, then I stopped the medication... after months I got coughing again, and this time I went to Puskesmas... They told me I got regular TB, but will need to get injection... all 5 months out of total months I got the injection, and I was informed that I was recovered... but then I got another cough and out of breath (asphyxiated)... then I went to that same Puskesmas, and received steam treatment... then I was referred to a private hospital (RS Muhammadiyah Mayestik), and the result within hours... then brought the result to Puskesmas, and referred to RS Persahabatan (public hospital). I only Rontgen and blood checking... it was quick, after that...”: **FGD, Ex MDR TB, Female, Jakarta.**

The experience of both Ex MDR TB patients above, shows issues in counselling, and misdiagnosis, and possible negligence at hospital or lack of referral mechanism when TB patients found at other polyclinic. Both spent big amount of out-of-pocket money getting to effective medication and this implies issues of navigating TB people in the health system. Neglected twice from different doctors at clinical setting to this pregnant woman's symptoms is showing a gender related issue of TB and approach of healthcare workers to pregnant women.

Daily transportation cost, and especially who needs other family member to come with, will take a big chunk of their daily needs.

“...even though it is easy to get to Puskesmas... transportation cost is hard sometimes, because every day I have to pay for 2 persons to come to Puskesmas... times 3 months...”: **FGD, Ex TB patient, Male, Jakarta.**

The findings above confirm the depiction of housing and surrounding situation of slum areas that are considered as a factor that increases risks of TB transmission and morbidity. However, despite this disadvantage situation they face daily, more people living in this environment are not sick. They are aware that they could go to the nearest public health facilities when they need, and they will not have issues accessing health services because they know they have insurance (BPJS card – as a member of national insurance system) at hand. Or if the closest health facility is seen not to close, they still could get there easily by any means of transportation whenever they are sick.

They may only have to pay transportation cost to get to Puskesmas (PHC), and that might be difficult if that has to be done on a daily basis, and mostly has to pay at least one companion from home. Practice at one of Puskesmas (PHC) at North Jakarta with a very dedicated doctor and supported by cadres who know almost all members of the area (kampung) had just shown how the TB program at sub-sub-district level could run well and provide access to the community, even when at that time there were no NGOs in the structure yet.

2. PLHIV with TB

Due to their low immune system, PLHIV are vulnerable to getting infected and developing active TB, either direct contact with TB person, or because of existing dormant TB within their own system. At some geographical areas in Indonesia which is in relatively higher TB prevalence rate, the higher their risks of transmitted/getting TB.

Some of study participants shows lack of knowledge on TB.

“... I don't know what causes TB... but I think it is infectious... through drinking or meal utensil... My ex-husband got TB when we were not together anymore... I go to the hospital and puskesmas when I get ill, and usually I have someone with me... ya... (the health facility is) close enough, they are nice, and I have ID/BPJS...”: **IDI, TB-HIV Co-infection ex patient, Female, North Jakarta.**

“... I think TB is lung... spot in lung... and it is caused by smoke (of tobacco), dust, dirty environment, pollution, and weaken immune system... like I did when my immune system is weak... ya... through air, or shared utensil ... no, I don't have other people for a reminder (of taking drug). I did remind myself... and my children did not get infected... I am so independent... I went to the doctor by myself...”: **IDI, TB-HIV Co-infection ex patient, Female, North Jakarta.**

The health seeking behavior may have been modified when they first diagnosed with HIV and needing to adhere taking medication before getting TB infection. However, there is always chance that they may not so keen to come to the health service.

“... was getting TB at my window period... Finished my treatment now... I don't have a reminder, I am used to be with myself, and motivate myself... if I got sick, I just get rest, I just sleep... I am a navy (kuli), mostly I was just exhausted... and I could always consult my buddy (HIV support group)...”: **IDI, TB-HIV Co-infection ex patient, Male, North Jakarta.**

Some study participants who were former TB-HIV Co-infection group patients came from the middle to upper socioeconomic level. But, because they had TB, they need to move to a house closer to the service. Although at some point they also face with socio-economic factors they were more likely to be able to arrange their location to deal with their health issues better. And, it was clear that those who are also PLHIV, have a better understanding in getting group support and information from different various sources than those who are only TB patients.¹⁶

“... I used to live in Tangerang, and I have to get to RS Persahabatan everyday (2-hour trip one way) ... so after a month, I decided to get some a 'half-way house' so get near to the hospital”: **FGD, Ex MDR TB, Male, Jakarta.**

Issues around stigma or potential stigma are also reveals in some of the discussion, however, not recently, such as:

“... Been checking sputum, and at the forth times, using Genpart (GeneXpert) and Rontgen then I was diagnosed positive ... used mask everyday ... my husband smokes very much ... My parents, Umi, and Abah passed away because of TB, and they vomited blood more than a cup ... both of them... at that time, this disease had a very bad name, people are getting isolated, I mean, really isolated, and people thought this couldn't be treated, this disease was for people who did “something” ... but now, the puskesmas has giving information and people know that this can be treated... now what we need to do is drink lots of water, eat fruits... if unwell go to puskesmas... and if really not good, we could ask a

¹⁶ IDI Respondents TB-HIV Co-infection, North Jakarta

*steam... my late parents did... I never did... But my husband would bring me to the emergency unit, and Thank God... the staff will respond quickly... ”: **IDI, TB-HIV Co-infection ex patient, Female, North Jakarta.***

“... when I was having medication, I could not go to work, then they suggested me to focus on the medication, then they gave me severance pay”: **FGD, Ex MDR TB, Male, Jakarta**

But many of them also never receive any stigma and discriminating conducts from others, and from health providers

“... all are free of charge... from diagnosis to end of treatment... I was just paying for diagnosis, lab and Rontgen at first, because I went to private hospital. ... they gave me sufficient information... the doctor... the Puskesmas staff came to my house, even my room to check whether the air ventilation... never receive stigma or discriminate conduct...”: **FGD, Co-infection TB-HIV, North Jakarta (Puskesmas Koja)**

And some seems to be indicative of self-stigma, and a guilty feeling to be potentially a source of infections for loved ones.

“... I heard about TB and it was horrible... and I have wife and children, and if there is no good ventilation in our house, they surely will be infected. Luckily, they aren't infected. I know the solution I went out when I cough... TB was caused by staying nights, smoking, and when I used drugs (narcotics)... it is spread through breathing, saliva... when we spit, the saliva will evaporate and all the people in the room will get infected... my wife is my reminder of TB medicine daily... at 9... and always at 9... I have to go to the doctor because I want to be healthy, I have them, and my children are still very small...”: **IDI, TB-HIV Co-infection ex patient, Male, former IDU, North Jakarta.**

“... I got pulmonary TB... I was so insecure (minder – Indonesian terminology) with my family... actually I have used the mask... but I don't know why I felt that I was being isolated... fortunately my wife was fully supporting me...”: **FGD Ko-infection TB-HIV, Male, Puskesmas Sukodono, Sidoarjo.**

“... our rights?... we have to be aware of ourselves... if their suggestions were right... why not follow...” “at polyclinic Puskesmas... we are isolated... I feel we are different...” “if I pay more... I might get faster services...” **FGD, All Male Ex TB Patients, North Jakarta.**

“... and my wife didn't sleep with me...”: **FGD, Ex MDR TB, Male, Jakarta**

The above participant was also an ex-IDU, of HIV key population, who also an overlapping members of slum area and of PLHIV.¹⁷ They have issues similar with people in slum area, that is mostly the transportation cost, but key population who have been reached by the outreach workers are more knowledgeable than most people living in that area. The problems that are found with this participant with poverty is earning a living.

“... no... there is no hindering matters at all ... (giggle) they were just amazed with my look... because they call me S (male name)... actually... if they got upset because I had problem with drug taking previously. I was so naughty... the drug is too many... 4 pills ... I was struggling to take medicine because I didn't use to take medicine... I used to be an anti-drug... for myself... so when I felt better, I just stopped taking drug... I was naughty... ”: FGD, Co-infection TB-HIV, Transgender, Puskesmas Sukodono, Sidoarjo.

Side-effect, and long-time awaiting time is factors that weighing them down in taking medicine.

“... the side effect is unbearable (Female participant)” “I was working so the needs for taking TB drugs each 2 weeks was really hard, because I wasn't always allowed to go in working hours (Male participant)... Puskesmas Koja didn't open clinic at Saturday... and the queue... Gosh... came at 8AM and just got to the room at 2PM (Female Participant)... ”: FGD, Co-infection TB-HIV, Puskesmas Koja, North Jakarta.

Cost of nutrition for the patient is significantly increases.

“for sure... we have to have more money for nutritious food when in TB medication...” “... there is a product... TB Honey... I sell that too it is very effective... or soya milk... any diary milk... especially the B... Brand... or Green Coconut water... however, if milk we need to put 3-hour distance to drug taking... and it is better to just take directly milk powder...” “... I need to take fruits, and everything delicious... (giggle)... ah ya.. parking fee and gasoline...”: FGD, Co-infection TB-HIV, Puskesmas Koja, North Jakarta.

However, a Diabetic patient showed his understanding on how to manage his diet when taking TB medicine.

¹⁷ IDI Respondent TB-HIV Co-infection, North Jakarta

"... good nutrition ... and I have diabetes... kinda contra-indicative... so, I have to very careful... because I get fatter and fatter (giggle)..." **FGD, Co-infection TB-HIV, Male, Sidoarjo.**

ii. Gender

Disaggregated data analysis by sex using routine and surveillance data shows that the male population is higher in numbers compared to women in terms of:

1. Estimated TB incidence and case notifications of all age groups (See Figure 13¹⁸)
2. Estimated TB mortality among HIV-negative people at age groups 25 and above, and under 15 (See Figure 14¹⁹)
3. Estimated TB prevalence per 100,000 population aged ≥ 15 years (See Table 1²⁰)
4. The male to female Ratio of bacteriologically confirmed adult TB cases detected in prevalence survey (See Figure 15²¹) (See annex 3 for further information)

However, percentage of TB underreporting cases between male and female are not significantly different (See Table 2²²).

Graphs and visualization of disaggregated data above can be seen in Annex 2: Supporting Data on Gender Factor Analysis.

This study found that almost all key informants see no meaningful issues related to gender among TB patients, and also, on TB epidemic context. Thus, the barriers to access to quality TB services do not have a direct link to gender factors. A programme manager level at MoH²³ said that the reasons why more men were found than women, is because the infection is taking place at locations with higher level of TB exposure, and that is where more men are standing in daily basis. Such locations are mostly working place which need manual labor or difficult work situation, and consequently, are the male-dominated workplace. And in slum area, men are more susceptible to TB illness because of their unhealthy behavior, such as smoking and alcohol drinking.

This assessment also recorded a large proportion of men who stated that their illness, which was later known to be TB, was obtained in an unhealthy working environment.²⁴ These conditions include, closed air circulation, working with chemicals (printing, painting), working in a very humid air, or the room was only equipped with a small fan. Nevertheless, not all unhealthy workplace are male-dominated, and that is why not only male workers are in higher risks to TB

¹⁸ Global TB Report, 2018

¹⁹ Global TB Report, 2018

²⁰ TB Prevalence Survey Report, Indonesia, 2013-2014

²¹ Global TB Report, 2018

²² TB Inventory Study, MoH RoI, 2016-2017

²³ FGD, National Stakeholders (MoH, NGOs, TB Networks)

²⁴ IDI, North Jakarta, Slum Area

illness, but also female workers, such as in printing company with more than a hundred employees.²⁵

“... I did not want to get back to the port, painting ships... it was hard... and I feel weaker now...”: **FGD, Ex TB patient, Male, Puskesmas Kalibaru, Jakarta.**

A male TB patient stated that the status of having been exposed to TB caused him a stigma, and for him coming from the management persons from his previous workplace where he first having TB suspect symptom.²⁶ Some other men said they preferred not to return to his previous worksite for he was afraid to get re-infected there, and the other man gave a reason of having much weaker physical condition after TB illness, even after recovered.²⁷

“... They gave the gesture of closing their nose when I got back to my previous work location, just to visit... then I thought... I might as well not come back...”:
FGD, Ex TB-MDR patient, Jakarta.

“... I worked at computer rental... only with small fan... the customers are smoking for hours I was there... I didn't want to be there where I first got TB...” :
FGD, Ex TB patient, All Male, Jakarta.

However, among female ex-TB patients, or family members of ex-TB patients, conveyed that their husband mostly will take care of them, but in the contrary, their husband may have to struggle themselves because women had other things to do, including taking care of business or children.

“... When my husband got TB, he went to Puskesmas alone... I did not go with him... I'd better be at home... take care of our little store...”: **IDI, Slum area resident, female, Sidoarjo.**

“... my husband was very supportive... he took me to the hospital every day... and when I vomited at the hospital, he cleaned that... we handed in hand taking care of the children”: **FGD, Ex MDR TB, Female, Jakarta**

“... I never had TB. My husband did, and he had completed the medication... If I don't feel well, I just say it my husband, and took a drug (from the small closest store).. I usually get well soon enough... I don't really make time to go to puskesmas, because I am busy taking care of the children... Ah... ya... I have ID and BPJS, and actually the transportation is easy. The doctor is also nice...”:
IDI, Slum area resident, female, North Jakarta.

²⁵ Observation and IDI, North Jakarta, Sidoarjo, Slum Area

²⁶ FGD Puskesmas Kalibaru, FGD NGO Former MDR-TB patients

²⁷ FGD Puskesmas Kalibaru

“... My husband got TB, and I got TB from him, we had completed the treatment, and we had reminder. My husband used to take me to the emergency unit if I was sick... I got BPJS...”: **IDI, Slum area resident, female, North Jakarta.**

No problem with gender, but more on health seeking behavior.

“... I hope the existing support (from TB NGO – not PLHIV) is really supporting, not only take data on us. That is why the community (PLHIV) support makes us feel more comfortable because the information on what puskesmas providing specific services is more update ...”: **FGD, Co-infection TB-HIV, Puskesmas Sukodono, Sidoarjo.**

“... my brother... and he had completed the medication, I wasn't getting TB... I just take the drug (from the small store nearby) if I feel unwell... and go to the midwife if still unwell... I don't like to go to the doctor... too far... no easy transportation, and the queue is very long, while I still have to take care of the children. I do have BPJS and ID, and they are all actually nice...”: **IDI, Slum area resident, female, North Jakarta.**

iii. Legal

A. TB, Legal and Policy Review

Indonesian government has ratified several international and regional instruments, including the covenant, action plans and universal declarations considerably. It reflects the effort and commitment of the Indonesian government towards the promotion, protection and fulfilment of human rights in this country. The process of ratification of international instruments on human rights aspect signifies the commitment of the Indonesian government to improve the scope, quality and coverage of basic health services, covering promotional efforts, prevention and treatment of TB that is affordable by the community, including TB key populations. Additionally, these international instruments are of a robust fundamental framework, holding government accountable for their implementation. Thus, human rights, gender equality, and community involvement are key aspects of the laws and policies that apply to TB programs in Indonesia.

Some of the principles of human rights that are relevant and significantly affecting the implementation of the TB program, reliable to TB patient protection, and stated in various domestic ratification of the covenants and regulations are, among others, Right to life; Right to the highest attainable standard of physical and mental health; Right to non-discrimination and equal; Right to privacy; Right to "informed consent"; Right to information; Right to be free from torture or cruel, inhuman or degrading treatment or punishment and Right to participation.

Table 1. International Instruments of Human Rights ratified by Indonesia

No.	International Instrument	Ratification
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1.	International Declaration of Human Rights	Act No.39/1999, 23 September 1999
2.	International Convention on the Elimination all Forms Discrimination Against Women	Act No.7/1984, 24 Juli 1984
3.	International Convention on the Rights of Child	Presidential Decree No.36/1990
4.	International Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	Law No.5 /1998, 28 September 1998
5.	International Convention on The Elimination of All Forms of Racial Discrimination	Law No.29/1999, 25 Mei 1999
6.	International Covenant on Economic, Social and Cultural Rights	Law No.11/2005, 28 Oktober 2005
7.	International Covenant on Civil and Political Rights	Law No.12/2005, 28 Oktober 2005

In the constitutional system in Indonesia, a hierarchical system in legislation applies. The 1945 Constitution of Indonesia is the highest legal basis which is the reference of all laws and regulations. The bill that is under the Constitution is the Law. Handling TB problems and those related to TB is found in several laws. The several laws included in this assessment are:

1. Human Rights Act No. 39/1999
2. Health Act No. 36/2009
3. Medical Practice Act No. 29/2004
4. Hospital Act No. 44/2009
5. National Security System Act No. 40 / 2004
6. Occupational Safety Act No. 1/1970
7. Major Labor Act No. 13 / 2003

The Indonesian government has shown a high political commitment to TB control efforts and launched an accelerated elimination of TB in 2030. The government's commitment is embodied in several regulations and circulars to support TB programs, including:

1. The Ministry of Health Regulation No. 67/2016 on TB Control;
2. Ministry of Health Regulation No. 43/2016 on Minimum Service Standards in the Health Sector;
3. Minister of Health Regulation of the Republic of Indonesia No. 39/2016 on Guidelines for Implementing a Healthy Indonesia Program with a Family Approach;
4. Decree of the Minister of Health No. 1278/Menkes/SK/XII/2009 on Guidelines for implementing collaborative control of TB and HIV diseases;
5. Circular Letter No. HK.03.03 / D1 / III.I / 951/2016 on Increasing TB Case Findings;
6. Circular of the Minister of Home Affairs No 440/4838 / Bangda on Support for the Acceleration of TB Control;
7. Ministry of Health Strategic Plan 2015 – 2019;
8. National Action Plan for TB Control 2016-2020, Ministry of Health of the Republic of Indonesia;
9. Guidelines for National TB Control, Ministry of Health 2016;
10. Guidelines for Tuberculosis Control in the Workplace, Ministry of Health and Ministry of Manpower 2015;

B. TB and Access to Diagnostic and Treatment

Right to life as the fundamental right is listed in the International Covenant on Civil and Political Rights (ICCPR) Article 6 (1), which is then ratified as Law No12 of 2005, dated October 28, 2005. As has been outlined in the 1945 Constituent of Indonesia Article 28 A, which states that "*Everyone has the right to live and to defend life and the life*". Therefore, people with TB have the right to access services, including diagnostic services, care, support and treatment to improve their health status and save his/her life.

Based on the Minister of Health Regulation on TB No.67/2016, Tuberculosis Management-hereinafter referred to as TB Control-organized through health promotion activities; TB surveillance; controlling risk factors; discovery and handling of TB cases; vaccine administration and provision of preventive medicine (article 6). TB case management consists of TB treatment and treatment of side effects in health care facilities; monitoring compliance with swallowing drugs; monitoring treatment progress and treatment outcomes; and tracking loss to follow-up cases. In addition to this, the National Tuberculosis Management Medical Guidelines (Decree of the Minister of Health No: HK.02.02/MENKES/305/2014) has adopted the International Standard for Tuberculosis Care (ISTC) which complements the guidelines for TB control programs that are consistent with WHO recommendations.²⁸

According to Chandrashekhar (2014), studies show that the diagnosis of TB is often delayed. Delays in diagnosis and treatment of TB patients are estimated to be on average 31 and 2.5 days, respectively. Repeated visits to the health facilities and non-specific antibiotic therapies become one primary reason. A significant risk factor for prolonged health system delay is when initially seeking care from private health care providers (HCP). Also, first visiting to non-allopathic HCP and consultation to multiple HCPs, both were associated with diagnostic and treatment delay. Development of new strategies is needed to reduce patient delays and diagnostics by involving first contact health care providers.²⁹

From the field assessments, TB diagnoses were reported by some respondents to have different time frames. This is due to problems people having to get TB diagnostic.³⁰ Some, because of limited availability of TB test kits at health services, particularly at PHCs at district level. Currently, diagnosis in health services can be obtained through two methods, namely bacteriological examination using a microscope and rapid molecular test (RMT) using GeneXpert

²⁸ ISTC is a standard procedure for tuberculosis management in the process of diagnosis, treatment, medication adherence, the role of prevention, and proper management of TB and HIV and Hepatitis that appear together.

²⁹ Chandrashekar et al, Delays in diagnosis and treatment of pulmonary TB in India: a systematic review, 2014

³⁰ FGD National Stakeholders, Jakarta

MTB/RIF. The microscopic examination is more widely used in PHCs because the number of RMT devices is limited and currently only available in the referral hospitals. Though the accuracy of RMT is higher (around 98%) than microscopic test (or about 50%), and the time required for RMT is faster than bacteriological tests. RMT procurement is limited because the equipment is expensive, and most patients come to PHC in already very sick conditions, so microscopic tests are considered effective.³¹

A respondent of HIV TB co-infection in North Jakarta stated that he needed as many as six visits to the primary health care (PHC) to get clarity about his TB diagnostic. In Sidoarjo, a respondent reported that when he first came to the PHC, the doctor only gave him cough medicine before eventually the doctor referred the patient to the laboratory to be tested for TB. The process of establishing a diagnosis is reported to take almost one month.³²

Hassle also occurs at diagnosis of patients with MDR-TB. A doctor will refer MDR-suspected TB patients at the PHC to the referral hospital for RMT testing. If the RMT results show positive results, the patients will get TB drugs for two weeks from the hospital side, then decentralized to the nearest health center for continuation of MDR-TB treatment. For patients who have known negative RMT test results, the patient is returned to the previous PHC to continue drug-sensitive TB treatment. After being given TB medication and cured, then there was a recurrence, the patient was immediately referred to the hospital for the next RMT test.³³

The types of TB treatment available in PHC in general are TB category 1, category 2, pediatric TB drugs and TB prophylaxis (INH). All kinds of treatment provided by the government and given free to TB patients who access TB services at public health centers and hospitals.³⁴ This study reports that there are no obstacles to accessing TB treatment related to financing, because all types of treatment are given free in public health facilities from the government. However, some respondents had to spend cost of transportation to health services and to buy nutritious food in order to gain weight and recovered from TB, even though the amount of money they spend was relatively small. Almost all respondents both in North Jakarta and Sidoarjo had national health insurance initiated by the government, namely JKN, through both paid and unpaid premiums. Even though patients do not have an ID card or health insurance, TB treatment is still given free of charge at the PHC.³⁵

While in treatment of MDR-TB, the patients will need to be referred first to the hospital before continue their treatment at PHC. One of key informant expressed that she had to come to health

³¹ FGD National Stakeholders, Jakarta

³² FGD TB Patient, Sidoarjo

³³ IDI TB survivor, Jakarta

³⁴ FGD National Stakeholders, Jakarta

³⁵ FGD Co-infection TB-HIV North Jakarta

services to get her TB-MDR medication every day and she also experienced side effect from TB medication.³⁶ Most of the respondents either in Sidoarjo and in North Jakarta also reported experiencing side effects from TB medication. The side effects experienced by the patients, in general, are nausea, vomiting, and bone pain, while others said about hearing loss and experiencing depression during taking TB drugs. Some respondents reported side effects as one of the reasons for treatment drop-outs, and other was due to prolonged treatment periods, economic problems and having to move from one place to another. Most patients received additional treatment for their side effects because TB treatment were covered completely by national health insurance.

In conclusion, delayed diagnosis and treatment of TB may have a detrimental effect in the form of material loss on the part of the patient because they have to spend transportation costs every time they visit a health service. In addition to losing patients because of the uncertainty of the test results can increase the rate of transmission of TB; even death due to late TB patients being treated. There are needs for new strategies development to address delayed diagnostic and treatment for both sides, the first clinics (PHC) and TB patients. Additionally, the provision and equitable of diagnostic tools with good accuracy and conducting research to address diagnostic delays and treatment can find a way to solutions.

C. TB and Information

Right to information as listed in ICCPR article 19 (2) and ratified as Law No.12/2005, in 28 October 2005 to ensure people with TB have the right to access information. Article 52 of Medical Practice Act stipulates that TB patients are entitled to get all the information about TB services including about financing; TB patients to obtain clear understanding in timely manner regarding their state of health, treatment and effects of treatment; TB patients to know drug names and doses and the actions entailed as well as the consequences that may occur and affect the patient's condition; TB patients to get information about their medical records when required by the patient; and the right to share the experience with other TB patients and other patients as well as voluntary counselling, in array of diagnosis to completion of treatment.

Grace Wambura et al (2018) found that a lot of misperceptions among TB patients. Patients perceived TB as a serious infectious disease that is difficult to diagnose and treat. Most patients associate TB with smoking, drinking alcohol, dust exposure, cold air, witchcraft, chest trauma, contact with livestock and heredity. They believe that regular contact with TB patients and sharing equipment can transmit TB. According to Grace (2018) The national TB program must pay

³⁶ IDI TB survivor, Jakarta

attention to strategies to improve patient knowledge and emphasize efforts to correct misinformation about the causes and transmission of the disease.³⁷

Similarly, from field assessments, patients' knowledge about TB from symptoms, illness, modes of transmission, and treatment, including patient rights is still low. Some respondents reported that information about TB that was first obtained mostly from a doctor or a nurse. Knowledge on TB in greater depth is obtained by patients from health community cadres, HIV peer supporters or PLHIV communities.³⁸ The provision of information is still lacking due to massive TB campaigns carried out only one a year at TB day, limited service time at PHC due to the large number of patients and the level of education of patients.³⁹ In addition to this, information about the rights and obligations of patients (Patients Charter) has not been well socialized and allegedly caused some of them were experiencing economic problems because of leaving the jobs due to TB illness.⁴⁰ Even though there is regulation to keep people with TB in employment.

Awareness on Tuberculosis is important to achieve successful national program of tuberculosis. The development of effective communication strategies at all levels must be carried out to ensure implementation at every aspect of the program, and to have the people understand correctly about TB problems, especially that are affecting perceptions of TB in the community.

D. TB, Stigma and discrimination

The 1945 Constitution of Indonesia guarantees the right to equality and justice under article 28 H paragraph (1) that every person has the right to acquire facilities and special treatment to obtain equal opportunities and benefits to achieve equality and justice. The Human Right Law No 39/1999 article 3 regulates and underlines the obligation of the State to guarantee the protection of Human Rights and human freedom of every citizen of Indonesia without discrimination, which includes matters relating to TB problems. As stipulated in article 3 Paragraph (2), the Human Right Act also guarantees that every person has the right to recognition, guarantee, protection and fair legal treatment and obtains legal certainty in the spirit before the law. Specifically, the Medical Practice Act Article 51 guarantees that a doctor or dentist in medical practice implementation oblige to provide a medical service according to professional and procedural standard including medical needs of the patient. Furthermore, as an effort to eliminate stigma and discrimination against TB patients, The Ministry of Health Regulation No. 67/2016 on TB Control focuses on aspects of health promotion through education that also involves the community, as stated in article

³⁷ Grace Wambura et al, Knowledge and perceptions of tuberculosis among patients in a pastoralist community in Keya: a qualitative study, , 2018

³⁸ FGD Co-infection TB-HIV North Jakarta

³⁹ TB National Dialogue Forum, Jakarta

⁴⁰ TB National Dialogue Forum, Jakarta

25 paragraph (1) The public can participate in efforts to control tuberculosis by: b. strives not to stigmatize and discriminate against TB cases in the community.

According to Sushil (2007), *“the principal effects of stigma and discrimination associated TB in developing countries are social isolation of patients, both outside the family, where the person may be avoided by former friends and acquaintances, and inside the family where the patient may be forced to eat and sleep separately”*. Sushil et al also suggested that causes of self-discrimination include fear of transmitting TB to others, and avoiding gossip and the potential to be alienated by family or community. In addition, causes of discrimination by the community members including fear of the risk of infection; perceived links between TB and poverty and low social status; perceived links between TB and improper conduct; the perception that TB is a punishment from God. The patient feels discriminated by health workers. Comprehensive intervention packages, which are tailored to local wisdom, will be needed to address the causes of discrimination.⁴¹

The field assessment of this study found that stigma and discrimination against people with TB in TB services were not reported in this study. Some of TB HIV coinfecting respondents reported that when they came to TB services they never felt the stigma and discriminatory treatment of health workers at TB services. However, it was reported that stigma was still felt when TB patients access HIV services^{42 43} and other health services. This was reported by a key informant when she referred a patient to the dentist in the same health facilities. Initially, the dentist hesitated to treat the TB patient, but after the dentist received a full explanation from another colleague, the dentist finally agreed to treat the patient.⁴⁴ Self-stigma still seems to occur frequently in people with TB. Fear of transmitting TB to children and their families is one of the causes of self-stigma.⁴⁵ There is no reported discriminatory treatment from family members, but people with TB still feel the stigma and discrimination from the surrounding environment, especially from neighbors and coworkers.⁴⁶

Right to be free from torture or cruel, inhuman or degrading treatment or punishment is an affirmation of appropriate TB diagnostic, proper care and treatment and ensuring a healthy environment for people with TB. This right is listed in CAT⁴⁷ article 16 (1). Although the current cases of forced isolation are almost never found in tuberculosis patients in Indonesia, is extremely

⁴¹ Sushil C Baral et al, Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study, 2007

⁴² FGD Co-infection TB-HIV North Jakarta

⁴³ FGD Co-infection TB-HIV Sidoarjo

⁴⁴ IDI PHC Cilincing

⁴⁵ FGD TB patient PHC Sukodono, Sidoarjo

⁴⁶ FGD TB patient PHC Sukodono, Sidoarjo

⁴⁷ Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

important to protect the rights of people with TB to be treated humanely and dignified both during hospitalization or for a person with TB who are in prisons or detention centers. From field findings, no cases of forced isolation in patients with TB were reported from the study results. For MDR-TB patients, shelter homes are provided for patients in need, so patients can complete treatment until they recover.

People with TB still experience stigma and discrimination especially from non-TB health services such as HIV services and dentists. The right alignment of information about TB needs to be given not only to the community, but also to health workers and doctors in health services. Access to complaints to the chair of the honorary panel of Indonesian medical disciplines regarding stigma and discrimination or malpractice experienced by patients should be opened and informed as widely as possible by including access to legal assistance needed by victims according to Medical Practice Law Article 66 paragraph (1) and paragraph (2).

E. TB and Key Population

Ministry of Health Regulation No. 67/2016 states several factors that can increase the risk of TB disease are factors of age and sex, endurance, behaviour and socio-economic status. TB can affect any age, or class, but patients are mainly poor, and more men are affected than women. Urban areas are more affected than rural areas. The malnourished, prisoners, and people already sick with compromised immune systems, including HIV and diabetes, are vulnerable to TB.⁴⁸

According to Global fund, key populations is *“those who experience both increased impact from one of the diseases and decreased access to services. Widespread stigma and discrimination, state and non-state violence and harassment, restrictive laws and policies, and criminalization of behaviours or practices put key populations at heightened risks and undermine their access to services.”* In the context TB, The Global fund key populations including miners; migrant miners; displaced people; prisoners and detainees; people living with TB/HIV, people who inject drugs and children in contact with TB cases.⁴⁹

This study assesses two populations, which is people infected with HIV due to their immune system and the risk of developing TB is estimated to be between 16-27 times greater than among those without HIV infection⁵⁰; and populations in densely populated and slum housing environments, with an increased risk of transmission due to rooms with poor air circulation and no sunlight. This study indicates among two focus populations there is a strong relationship between

⁴⁸ http://www.searo.who.int/indonesia/topics/tb/tuberculosis_jemm_2017_for_ino_website.pdf

⁴⁹ <https://www.theglobalfund.org/en/key-populations/>

⁵⁰ <https://www.who.int/hiv/topics/tb/en/>

human rights of every citizen with health problems, especially of those who live in slums area. Article 40 of the Law on Human Rights states that everyone has the right to live and live a decent life. In this case the DKI Jakarta Government in particular has issued a Regional Regulation on Prohibition to build settlements or reside on the banks of the river (one of the portraits of slums) for security reasons in the event of natural disasters and health. But in practice there are still many violations found and no sanctions are known if the violation is committed. Therefore, it indicates that the government has not met the needs of decent settlements for its citizens.

One particular population that is also vulnerable to TB transmission is among workers (factory workers) and residents in densely populated settlements, which is closely related to the characteristics of the Sidoarjo regency which is an industrial area. The characteristics of the study area (Sukodono District) are Industrial areas and densely populated areas, based on the health profile of the District. Sidoarjo in 2017, Population Density in the coverage area of Sukodono Health Center covering 19 villages is included in the top 10 of the total 26 PHCs that exist, this situation has not been balanced with the existence of special policies at the local level regarding efforts to protect workers especially in occupational health issues (either in the form of health insurance provided by the company and / or protection of other workers' rights related to health issues).

Key population-specific program strategies are essential to be developed to achieve national TB elimination. Each key population has different needs and approaches in TB control programs. Further studies need to be conducted to analyse gender and legal barriers of other key populations, including for prisoners and detainees, indigenous people and migrants.

F. TB and Community engagement

People with TB have the right to establish an organisation or a group of people with TB to seek the support of health workers and other key stakeholders. People with TB have the right to actively participate in the planning, development, monitoring and assessment, both in terms of policy and implementation of the TB program. Right to participation is guaranteed by the 1945 Constitution and Regulation of the Minister of Health No. 67 of 2016 concerning TB Control stated in article 7 paragraph 4, “*Community Empowerment carried out through activities to inform, influence, and help the community to play an active role in preventing TB transmission, increasing clean and healthy living behaviour, and eliminating discrimination against TB patients*”.

Patient Charter for TB Care which was initiated by patients and communities caring for TB around the world to describe the rights and obligations of TB patients has been adjusted and developed by the Indonesian TB Patients and Community Care Association (PAMALI TB INDONESIA) into Charter of TB Patients' Rights and Obligations. This Charter was compiled in reference to Law No. 29/2004 on Medical Practice and is in accordance with the National TB Strategy Framework with patient-centered approaches. The purpose of this charter is to empower

TB patients and the community and build better relationships and beneficial competitiveness between patients and the community and the health care.

According to Christa Dewi (2015) “promoting community involvement and local initiatives and engaging health care providers were important elements in the community-based TB program implemented”. Christa et al found that community involvement through asset-based interventions can produce positive changes in increasing community knowledge about TB and producing changes in overcoming diagnostic delay and treatment. In addition, sustainable education programs are needed to reach the wider community and maintain the changes that have been achieved.⁵¹

From the field assessment, civil society organizations (CSOs) have not been effectively involved in TB programs in prisons/detention centers, or for Diabetes Mellitus (DM) integration TB programs. Even though there is an integration program for TB and HIV programs, coordination between TB CSOs and HIV has not been well developed.⁵² In the field, cross-referrals between patients by field workers from CSOs have not been effectively carried out, this is indicated by the low number of people with TB accessing HIV testing, and vice versa.⁵³ Similarly, community-based organizations (CBOs) for people with TB have not been fully involved at both the national and regional levels. TB CBOs have not had an influence and have not been able to participate ideally both in the planning, implementation, monitoring and decision-making processes related to the TB program. Participation of TB survivor community-based organizations is currently limited to testimonials and peer support for TB patients especially for MDR-TB patients. Even though this peer support activity has a high risk of susceptibility to transmitted back for field officers who provide support, especially for patients with MDR-TB. Whereas CBOs has a strategic position in providing input on improving TB programs, because they have experience in living with TB, and knowing the needs of TB patients.⁵⁴

TB control programs should pay attention to the political and cultural structures in program planning involving local communities. Government support, funding commitments, support from health professionals and the local community are very important in efforts to meaningfully engagement of CSOs and CBOs in contributing to the implementation of the TB control program.

⁵¹ Christa Dewi et al, Improving knowledge and behaviours related to the cause, transmission and prevention of TB and early case detection: a descriptive study of community led TB program in Flores, 2015, Indonesia

⁵² IDI CSO, North Jakarta

⁵³ National dialogue forum, Jakarta

⁵⁴ IDI TB survivor community-based organization

G. TB and Financing

People with TB have the right to health to enjoy the highest standards that can be achieved for physical and mental health. The right to health includes economic, social and health determinants including food and nutrition, access to clean and healthy drinking water, adequate sanitation, healthy and safe working conditions and a healthy environment. Through the 1945 Constitution, the protection of the right to health for citizens is regulated in general in the use of the terminology "physical and spiritual prosperity" in which health is included in the definition of physical well-being. This commitment is reaffirmed by explicitly stating the right to live and get a good and healthy environment and obtain health services, and this affirmation is a commitment to protect health problems where one of them is a TB problem. Through this Constitution, there are also rules regarding the obligation for Country to develop social security systems and the provision of appropriate health care facilities. Therefore, National Security System Act No.40 / 2004 is regulating on health insurance system as part of the form of State responsibility to its citizens mandated by the Constitution. Regarding the issue of TB and its funding, this Law is a reference to the implementation of health financing in Indonesia. According to this Law, the health insurance provided by the State is not only limited to citizens who can pay premiums but also include inadequate citizens and workers who are also protected by the National Health Insurance. Importantly, health insurance coverage now reaches 82,64 % of the population and provides free of charge health services to the poorest in society. The insurance covers the essential elements of TB care provision by both public and private providers including diagnosis and treatment. This is a major step towards universal access to TB care.

TB treatment is borne by the Indonesian government and provided free through PHCs and government hospitals. All respondents reported no obstacles to accessing TB services both from the time of diagnosis, hospitalization to outpatient care related to financing. However, Ahmad Fuady et al (2018) found that households affected by TB are still at risk of further catastrophic expenditure and impoverishment regardless of the availability of national health insurance in Indonesia. In addition to ensuring access to health services, cost mitigation policies and additional financial protection must be provided by the government to protect the poor and reduce income loss.⁵⁵

From the field assessments, related costs outside of TB treatment, respondents reported spending needed for transportation to health services and the cost to buy nutritious food for goodness accelerate weight loss and health recovery from TB.⁵⁶ Some respondents also indicated that transportation costs incurred were not too high because they used motorbikes, and the distance between home and health services was quite close. Almost all respondents both in North Jakarta

⁵⁵ Ahmad Fuady et al, Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of Universal Health Coverage, *Infectious Diseases of Poverty*, 2018

⁵⁶ FGD TB HIV patient, North Jakarta

and Sidoarjo have health insurance initiated by the government, namely the National Health Insurance (JKN) through both paid and unpaid premiums.⁵⁷ A co-infected respondent chose to finance without insurance while being treated due to the complexity of financing arrangements through the JKN mechanism. Key informants from health services in Sidoarjo reported that even if patients did not have a resident identity card (KTP) or JKN, TB treatment was still given free of charge at the PHC.

People with TB, including MDR-TB are prone to the risk of falling into deeper poverty. JKN is not the only way to solve the situations of catastrophic total costs, especially when people with TB are the breadwinners and lose their jobs of their TB. Efforts beyond free medical care are needed to reduce the financial burden of households affected by TB and reduce the occurrence of diagnostic delays and treatment can be considered as one of solution.

G. TB in the Workplace:

The Occupational Safety Act and the Major Labour Act of Indonesia recognize the rights of each worker to occupational health and safety as well as the obligations of workplaces in ensuring worker's health and safety. This law also guarantees that companies are prohibited from terminating employment because the worker is unable to enter work because of illness according to the doctor's statement, as long as the period does not exceed 12 (twelve) months continuously. In the Guidelines for Tuberculosis Control in the Workplace, Ministry of Health and Ministry of Major Labor, 2015 requires the implementation of Directly Observed Treatment Short-Course (DOTS) strategy in the workplace so that the implementation of TB programs in the workplace is following the standards. The purpose of this guide is that TB prevention and control in the workplace can be integrated with the implementation of occupational health services in particular and the implementation of occupational safety and health programs in general.

According to guidance provided by the ILO, UNAIDS and WHO (See: https://apps.who.int/iris/bitstream/handle/10665/44833/9789241503228_eng.pdf?sequence=1) , *“in the case of TB, workplaces can increase disease transmission, as people spend long periods of time in close proximity. Also, a number of barriers to accessing TB and HIV services are linked to work-related concerns such as loss of wages (or fear of wage loss), health facilities not accessible outside working hours, stigma and discrimination, mobility (e.g. truck drivers), etc.”* The guidance recommends the adoption of TB workplace policies that should address the following principles of the ILO Code of Practice & the Occupational Diseases List (2010) i.e.

- recognition of TB and HIV as workplace issues;
- bipartite approach (working with management and workers representatives);

⁵⁷ FGD TB patient PHC Sukodono, Sidoarjo

- gender equality;
- protection of the rights of workers;
- non-discrimination;
- confidentiality;
- continuation of employment;
- prevention;
- treatment, care and support.

In the past two years, there have been no cases of employees being dismissed due to TB that have led to any formal litigation. Even so, the lack of sanctions applied in the regulation on the protection and prevention of TB in the work environment is considered not to cause a deterrent and compliance effect for the Company to comply with the Act.⁵⁸ However, the issue of employment and particularly the continuation of employment emerged repeatedly in the FGDs. For instance, from the FGD in North Jakarta, a respondent said that when he had TB for six months, the company did not fire him but asked him to restore his health. However, he was informed that if he got TB again, he would be asked to resign. Another respondent reported that he decided to leave his job for fear of getting TB again from the same workplace where he was exposed to TB raising the question of whether work places where there is a risk of TB transmission are putting in place effective infection control measures. One of the participants at North Jakarta said that daily attendance at health facilities for 9 months to receive treatment made him unable to go to work, although he admitted that partly also due to their health condition.⁵⁹ The patients are more likely to lose jobs because things were getting complicated.⁶⁰ And at the same time, they are in need for financial supports, and especially for transportation cost to the health service. They mentioned that the support from family members (to accompany to services, as providers / help with meals, or reminders of taking medication) are of big helps for them to be able to deal with problems related to their illness.⁶¹ One respondent who has a long history of TB diagnosis and treatment, said that working from home, or using an online trading platform is the only option to earn income while still on treatment. The respondent also mentioned that this business was quite promising and suggested the TB program, especially that for a community support add this skill building for TB patients, and especially for MDR-TB patients.⁶²

With the specific policies governing TB in the workplace issued by the Ministry of Manpower in collaboration with the Ministry of Health in 2015, the government is currently focusing on TB

⁵⁸ IDI, Key National Stakeholder

⁵⁹ FGD, North Jakarta, Men group

⁶⁰ FGD, North Jakarta, Puskesmas Kalibaru

⁶¹ FGD, North Jakarta, Men group

⁶² FGD, NGO, Jakarta, Former MDR TB Patients

programs in the workplace on coaching for companies to protect workers through extension activities, workshops, training capacity building and so on. Based on the findings of the FGDs, it would be important for TB workplace policies to be holistic as recommended by the ILO, UNAIDS and WHO and particularly address issues related to the continuation of employment and the provision of reasonable accommodation for people with TB. Accurate information regarding when a person with TB is infectious and what sort of measures need to be taken during that period should also form part of workplace TB awareness programmes.

iv. Health System Factors and Infrastructures

The description on the health system at section **Result B. Know Your Response iv. Health System in Practice and Provision of Quality TB services** shows how the national TB control program has been integrated to the national health system, and whereas per national strategy, all TB-related services at different facility level had been designed, in terms of its referral system, to address the epidemiological situation that TB has spread across all regions of the country, however effective the service provision is. Issues in case findings, treatment success, as well as notification are still the major challenges faced at all level in Indonesia, and this suggests continuing improvements are still the mainstay of the national TB control programming.

Geographical distance between to health care facilities is known as one of problems related to infrastructure, and that is widely discussed in the TB program overall in Indonesia. However, for this study, the site selection is not allowing discussions on this factor, as both are of relatively easy-to-reach districts.

vi. Health Seeking Behavior

This section is describing findings on any aspects that are behavior related, and that described as having effects on the health seeking behavior among those who are affected by TB. Although each of the factors may have both inhibiting and facilitating factors, this description will look further on how these behaviors limiting their access to TB case finding, diagnosis, treatment and treatment success.

Lack of knowledge is a common condition among people living in the slum area, especially those of non-TB patients. However, some of people living with HIV interviewed also mentioned incorrect information on TB.

- Former TB patients concluded their statements with the message that it took a long time for him to really understand about TB.⁶³ He realized that the health workers had given them information, but he did not comprehend it at that time. Talking and discussing with their fellow patients while in daily treatment phase helped them to understand more about what is, the dos and the don'ts afterwards. He also mentioned that through this way he could then provide correct information to their family members who played important roles to help him in the treatment period.
- Health workers⁶⁴ emphasized the importance of repeat messages about TB to their patients. Some information is hard to digest, and that may cause problems. Silent reactions of the patients mostly indicate lack of understanding.
- Most of the people interviewed do not answer questions about TB correctly, especially those who are living in slum area, and are not TB patients but live at home with TB patients.⁶⁵

In the course of diagnosis, treatment, maintaining compliance of patient's treatment, several behaviors that may delay case finding and success treatment are as follow.

- Delayed diagnosis, especially among those who prefer to do “domestic traditional medication” when they are not feeling well. A common terminology “not feeling good” (tidak enak badan/masuk angin)⁶⁶ is regarded as ordinary sickness that only calls for massage therapy (pijat or kerokan/scrapings using coin to the upper back body area). The study found that this kind of self-medication is very common, and not until they feel really sick that they get to the clinic. Indirect case finding is also found when his young daughter was treated at inpatient ward and her pediatrician confirmed her father was the source of her sickness⁶⁷. Cases where they got to the health facilities before really sick were also found when a cadre and a friend (who has ever had TB) suggesting them to see the doctor due to TB suspect symptoms.⁶⁸
 - The time of first visit to the doctor and getting a diagnosis ranges between 24 hours to 2 weeks for patients who came ill.⁶⁹ The former MDR patients may have to wait for 2 to 4 weeks. An MDR case, has undergone years of TB treatment in more than

⁶³ FGD, North Jakarta, Men

⁶⁴ IDI Key Informant, health worker, North Jakarta; FGD, Puskesmas Kalibaru, North Jakarta

⁶⁵ IDI Respondent, slum area, North Jakarta; IDI Respondent, slum area Sidoarjo

⁶⁶ FGD North Jakarta Men; FGD Puskesmas Kalibaru; IDI Slum North Jakarta; IDI Slum Sidoarjo

⁶⁷ FGD Puskesmas Kalibaru

⁶⁸ FGD Puskesmas Kalibaru

⁶⁹ FGD Puskesmas Kalibaru; FGD North Jakarta Men

one places, and the last time he was diagnosed MDR took more than 3 months before he moved to another city.⁷⁰

- A company usually has its own clinic, and employee who found the cough medication non-effective, usually asked by the doctor to do the X-ray before getting proper TB treatment at referral public health facilities.
- Delayed treatment. This study is recruiting participants of patients who completed their TB treatment. People who revealed as drop-out patient is found by chance. However, among those who eventually completed the treatment, some have stories to tell about the long history to treatment completion.⁷¹
- Challenges in compliance of treatment. A former TB patient conveyed her experience of the hardest 2 first months of her treatment. Other former patient also mentioned feeling bored to go to health facility on daily basis, beside the transportation cost that is burdensome.⁷²

Summary of Findings

Referring to the general objective of the study, the section above is describing why and how to some extent gender-related factors, legal-aspect, health system factors and infrastructures, socio-economic factors and health-seeking behavior as determinant factors. While the study clearly confirms the socio-economic factors and health-seeking behavior at some extent explain whether they inhibit or facilitate people accessing to TB services, and that health system factor is closed to the expectation of either program implementers and end beneficiaries, the gender-related factors and legal aspect findings of the study shows no strong indication that reflects both gender and legal issues occurs along the course of TB diagnosis to treatment. Both genders as respondents (of FGD and in-depth interview) do not see gender-related aspect as having an inhibiting effect or barrier to access to quality TB service.

In alignment with the gender aspect findings, the legal aspect findings also lead to a conclusion that there no identified specific problems related to the legislation at the constitutional level, programmatic level as well as individual level. The study finds that legal aspect at the level of regulation, guidance, and chart has enabled the programmatical needs accommodated in management and community elements, such as protection of human rights, protecting patients from stigma and discrimination, and the community support and involvement.

⁷⁰ FGD NGO Former TB MDR Patients

⁷¹ FGD NGO Former TB MDR Patients

⁷² FGD Puskesmas Kalibaru; FGD North Jakarta Men

All patients mentioned that they could access TB services if they came to the Puskesmas just by showing their ID (KTP).

The findings of the study, on how people are explaining their experiences are also in alignment with Lönnroth study (2010) that cigarettes, malnutrition, diabetes, HIV and alcohol are of the most significant contributors to a TB risk factor. See Appendix 3: Supporting Data Analysis of Factors Affecting Health Seeking Behavior related to TB.

Description of factors revealed from the qualitative study among both, those living in poor settings - high-density area, and people living with HIV who were TB Co-infected reflects their specific characteristics as well as the common phenomenon that other vulnerable population apart from those selected two key populations might also undergo.

All in all, the specific objectives to explore possible determinant factors for TB affected people and how that affects their health-seeking behavior has been addressed. However, how gender-related factors and legal aspect affecting people who are in risk of TB, who are getting sick of TB, and who are receiving TB-related services need to be discussed further in the next section. So are the recommended formulation for the end program improvements in Indonesia - TB case findings, case notification, and access to services

Discussion

1. Gender issues exist, but in a subtle way.

The results of this study found that neither service providers or TB patients saw any gender-related factors in providing or receiving TB services. The policy documents, reflecting the stakeholders' point of view, also show insignificant concerns related to gender factors. The epidemiological data and program data consistently show that more men are at higher risk indicated by the level of burden (higher prevalence and incidence among male than female) and the level of success rate (lower rate among male than female), and that this phenomenon is actually in line with that of the regional and the global situation.

However, if we look further on the global, regional, and national figures, when male to female ratios accounted for 1.8, 1.7, and 1.4 respectively, it is clear that Indonesian ratio is significantly lower than the ratios of the surrounding countries. This maybe indicative that less gender issues laying at Indonesian's situation.

And yet, if the national estimated burden male to female ratio is up to 1.4, the national case finding ratio, which is the program output is only at the level of 1.1, and this is indicative that more male cases are not found. In other words, missing cases among male is more likely occurs in Indonesia. And if this "loss" is combined with the reported successful rate that more male is not successful then we could infer that male is more "disadvantaged" than female, in terms of both case findings and treatment.

This discussion is consistent with the CRG tools used for the study⁷³ page 37: *"Women and men have very different needs in terms of access to TB services. Male-specific risks of acquiring and becoming ill with TB include larger networks of social contacts, employment in high-risk settings, smoking, possible higher rates of alcohol consumption, and limited health-seeking behavior. Female-specific risks include higher stigma, delayed diagnosis, less access to treatment services, and the previous WHO policy of passive case finding. High rates of extrapulmonary TB among women also mean that they are harder to screen and diagnose. Furthermore, gender harmful policies and practices make it more difficult for women to access and receive services in most settings. While TB in women is more difficult to diagnose and they might encounter challenges and delays at the various stages of seeking help for TB, men seek help at later stages of the disease."*

⁷³ UNDP. Stop TB Partnership. 2017. Legal Environment Assessment for Tuberculosis: An Operational Guide.

This study also portrays how male is likely having to be responsible for their treatment success, when they need to go to the health facility on daily basis alone. Male is still the breadwinner of the family, and that women who live with them will be more likely having to be responsible also for others, and mostly their children. While, on the other hand, when women are sick with TB, their husbands would play an important role to ensure the wives getting the proper treatment. And yet, in Indonesian context, culturally, and especially at both selected districts, this phenomenon is not seen as gender imbalance.

However, it is also found that women tend to delay coming to the health facilities because of their busy domestic life, and if they are feeling unwell, the first thing they do is consult the husbands rather than immediately going to health facilities.

2. A consistent perception among program implementers and end beneficiaries that no gender issue happens in the course of diagnosis, care and treatment.

Irrespective of their gender, respondents and key informants are convinced that there is no need to focus on gender while improving the TB program. Thus, it seems that awareness on gender-responsive actions can only be achieved if those who are the policy makers, program implementers, and service providers are more gender-sensitive.

The reason behind the tendency of not considering gender-related issues in policy making as well as in implementation, may stem from a notion that TB is not related to sexual and reproductive health which is harder for people in general to connect the gender issues with the nature of the disease. And, the fact that generally in Indonesia, gender issues at all sectors are still in progress, those who works in health sectors will need to increase their capacity on gender-sensitive response.

3. A fear-based stigma and self-stigma stemming from lack of knowledge may lead to further spread of TB, treatment default or worse, unnecessary mental issues or concrete discriminations.

Incorrect, lack of, or incomplete knowledge and understanding of TB (symptoms, disease, modes of transmission and treatment) may be the underlying cause of not only practicing behavior that increases the risk of transmission and treatment failure, but also of fear-based stigma. The study finds considerable possibilities that the needs for simple, easy to understand information given to TB patients and their family members are far from sufficient. Normally, it takes time for TB patients and their family members to digest the information, and especially for those who have just been diagnosed.

Proper information will help affected TB people not only to avoid harmful practices in terms of preventing new infections, but also to feel secured knowing that they can protect themselves and their family members from transmitted/getting TB infection. Fear of getting

infection or infecting TB to other people, at some point causes isolation, feeling neglected, and less access to support from the significant people. Hence, this stigma or self-stigma could cause a depression, that is weighing down the recovery process.

Thus, this study also finds that lack of understanding on TB treatment will affect negatively people who face challenges when they start treatment. Drop-outs tend to happen when they feel better, and this non-compliance leads to more TB-MDR, which is also one of major challenges in Indonesia.

- 4. Although inter-sectoral regulation for TB program is available, but this is not strong enough to take sectoral collaboration to a more effective wider coverage TB programming in Indonesia.**

The inter-sectoral regulation for TB program has been made with General Directorate of Incarceration, Ministry of Labor, Indonesian Doctor Associates – a professional oration, and at some institution, an action plan has been issued. However, as seen by the National TB Control Program point of view, the existing collaboration is not strong enough to take the program implementation to the optimum level, where many more sectoral government offices could play more critical moves not only covering the employees but also those as institutional target groups. And for this, a ministerial level regulation – as the existing one, from the Ministry of Health – will need stronger regulation, preferably of a higher level issuance to be able to reach other ministries for sectoral TB-program planning and budgeting.

- 5. Although we have the Minimum Standard of Services at Health Facilities in district Level (*Standar Pelayanan Minimal*), and that we have regulations enabling district level to develop comprehensive TB-related programming⁷⁴, the planning and budgeting process would take more than regulation to make it a real budgeted action plan.**

Planning and budgeting process in the mechanism led by local Planning and Development Bureau (Bappeda) requires a task force involving different sectors, including civil society, and the community to develop and safeguard the fiscal year plan and budget up to district level. Support for the works of task force is usually not available, not only for the coordinating body but also for the operational cost. And if these requirements are available there is still a need for a superior body to ensure the plan is in line with the national TB strategy and action plan.

This study finds that both districts have limited budget to support national TB program. At North Jakarta, the budget is mostly for the meeting activities, and the situation is more or less

⁷⁴ Minister of Domestic Affairs Regulation for Developing Sub-National Planning and Budgeting, annually.

the same with that at Sidoarjo. This depicts how the National Strategy is not fully referred to for their planning and budgeting process.

- 6. It is timely to put forward meaningful community involvement into TB as well as TB-HIV program implementation, but lots of works need to be done.**

Lessons learnt from HIV programming, this study finds that the end beneficiaries would need more than the existing stakeholders at grass root level to make the TB and TB-HIV program run better. The role of TB survival community/organization, and the CSOs, needs to be highlighted and coordinated with local TB and TB-HIV program managers, including those from the government agencies, the private sectors, health professionals and the planning-development bodies. This study finds that TB affected people are either not aware of their rights, and they do not know where to find supports other than drug reminders should they need supports from the community.

- 7. TB patients are more likely not considering their rights although they Medical Practice Act available.**

This situation, as found in this study, is indicative of low awareness of their rights as patients. They are more likely discussing their responsibility as patients based on their role as a person to prevent TB new infections. And this usually fear-based notion, will lead to negative consequences, most likely be stigma and discrimination. None of the IDI respondents were aware of their rights when they access TB services. The finding that show zero issues in accessing the services, is a result of the national TB program, where in order to control TB, all TB suspect people will have access to TB services, and this is supported with the health financing program run by both districts, North Jakarta and Sidoarjo, that enable the patient getting their diagnosis and treatment as soon as possible.

However, it has to be noted that among TB-HIV co-infection patients, issues around marginal community, including access to ID may compound their rights to accessing health services.

- 8. Health providers of TB services received very little/no human rights training.**

The situation is different with health providers of HIV services, from of TB services, where human rights training had been part of the training sets, basic or advanced, and the capacity is highly critical particularly because they are providing services to HIV key population. The study finds that sensitization about human rights is also needed for TB health providers.

- 9. Considering the urgency to increase awareness among different stakeholders who play important roles in TB program implementation, targeted advocacy and campaign is necessary for program improvements.**

In terms of communication strategy, where we need to target decision makers, the community and the patients as well as patients' family members, all available means of communication are necessary to be available. However, the priority seems to be placed in two strategies: advocacy for main stakeholders, and campaign for societies.

Conclusion and Recommendations

The Indonesian constitution has guaranteed the protection of citizens' rights in accordance with the principles of human rights and gender equality, including for people with TB. At least six legislation at constitutional level cover protection towards TB community: (1) UUD 2045 (the constitution), (2) Law No. 39/1999 about Human Rights, (3) Law No. 36/2009 about Health, (4) Law No. 1/1970 about Work Safety, (5) Law No. 40/2004 about National Social Security System – SJSN, (6) Law no 29/2004 on Medical Practice, and (7) Law No. 13/2003 about Workers/Manpower. These laws provide warrants and protection to people rights to health, health service, and social security. Taking it further, these laws imply the rights to live in healthy life that is related to proper living condition, access to health, and other regulation that prevents people to live in “harmful” areas including places that are susceptible to disaster (i.e. river banks, flooding, and slum areas).

Such regulations are available at district level. TB-related regulations available are (1) Minister of Health Decree No. 67/2016 about TB Control, (2) Minister of Health Decree No. 13/2013 about Guidelines on Comprehensive Management of TB-MDR control, (3) Director General of CDC Decree No. 2088/2015 on CDC Program Action 2015-2019, (4) Attachment of Minister of Health Decree No. 67/2016 about TB Control about the Guideline. Among those 4 regulations, only the latest issuance, the decree and its attachment, have clear support to TB communities, however there is no legislation that specifically regulates Gender equality in Indonesia, particularly regulations which address issues on women and girls, men and boys, transgender people and key affected populations in relation to HIV, TB, HIV/TB, or MDR-TB.

Until now, several laws and regulations governing matters related to gender are separated based on their respective issues (i.e Domestic Violence, Immigrants, marriage, etc.), and none of them has a say for TB, nor HIV. Legally, the Indonesian health system does not discriminate against people with TB. The Indonesian government expressly determines that all people in Indonesia have the right to access TB services for free, regardless of the background of particular population groups and irrespective of their gender. In practices, there is no gender-based discrimination in the provision of TB services. And, at both selected districts, those who do not have the subsidized health insurance nor local ID, are still able to access TB services because the national TB program has its back for them. Such condition may describe a gender-blind condition, where when looked further, more male or female disproportionately affected in getting services. The study was far from concluding any issues related to this, and especially with health providers at selected sites have both genders available.

However, the study acknowledged several regulations and policies, including local regulations that criminalize certain population groups that are vulnerable to HIV transmission, including sex workers, people who use drugs, LGBT people that potentially restrict their access to TB diagnostic and treatment. Therefore, a focus on gender is essential when designing TB programming and when analyzing laws, policies and practices.

Recommendations

Based on study results, there are several important recommendations to contribute to answer the ending of TB in Indonesia since Indonesia as one of the high burden country countries has

committed to implementing the UN HLM TB resolution in 2018. The recommendations are as follows:

1. The inter-sectoral policies and joint programme for TB control are available, such as the TB control program at the Indonesian National Police (POLRI) health facilities, TB control guideline at the workplace etc. However, this is not strong enough to take sectoral collaboration to more effective wider coverage of TB programming in Indonesia. Regulation is necessary for robust multi-sectoral involvement, including TB key and vulnerable populations, TB survivors, civil society, private sector innovators and the TB control program. This should be developed in a coordinated manner that necessitates the national planning and development coordinating body to lead the endeavor. This will include sub-national level planning and budgeting where the Ministry of Health provides technical support and mentoring during the process; and, advocating for parliament and the national planning agency related health and social development and infrastructure budgets both at national and sub-national levels. Moreover, the Government of Indonesia also needs to enhance and continue the implementation of UNHLM Country targets and accountability.
2. Understanding gender in the context of TB is nuanced. Advancing and strengthening gender responsive programming and facilitating an enabling legal and policy environment, including for women, girls and transgender persons, including in the National TB Strategic Plan should be a priority. To achieve that, the key is to have the strategy development team to get sensitization training on both gender equality and the interaction between gender and accessing services as well as enabling legal environment issues and opportunities. Multi-sectoral governance can serve as a channel as Indonesia is adopting Sustainable Development Plan, collaboration with Ministry of Women Empowerment and Ministry of Law and Human Rights would pave a way to a more sustainable TB response that is gender sensitive and completed with legal aspect review.
3. Capacity building in terms of gender sensitization for different stakeholders is one of the priorities as the awareness on gender-related issues, i.e. how gender, gender norms and traditional gender roles impedes universal access to TB services, is still lacking. Before the critical mass could begin with gender-related works for TB programming, they need to acquire understanding on gender-associated and related barriers and how gender hinders TB affected people accessing proper diagnosis and treatment. This is the gateway to TB programming improvements. As the study uses CRG tools as its basis, it is recommended that the recommendations are accepted and are operationalized as part of a national operational plan and ultimately in the National Strategic Plan.
4. As many of the decision makers are also not convinced of the importance of the relationship between gender and TB, advocacy and sensitization initiatives will be critical. And it will be very useful, if in the course of the capacity building the decision makers are involved in international movements/activities on gender, and at the same time are provided with guidance, tools and technical support to help them develop a more targeted or tailored programmatic development for specific key and vulnerable populations, including among men, women, boys, girls and trans populations. Training to assist identify evidence of gender-associated and related barriers and to develop gender equality indicators for various level of TB program will be important.

5. Capacity Building on diagnostics and treatment literacy and on rights literacy – including access to justice, at the grassroots level is critical for the health service providers, policy makers, patients undergoing TB treatment, TB survivors and members of populations vulnerable to TB in order to gain knowledge and confidence on TB prevention, diagnosis, treatment and care services. This includes the civil society, TB survivor community, TB-HIV support groups and health professionals; to be able to provide support to TB patients to complete the treatment successfully.
6. The government, private sector and research institutions need to continue to conduct research to find diagnostic and treatment options that are more innovative, new technology, inexpensive and accessible to the public. For this reason, funding commitments from both the government and international development partners are needed to support the implementation of these studies and operational research.
7. The government must ensure that the supply-side of diagnostic tools, prevention and treatment including MDR-TB drugs for all health services including the private sector is available and affordable. TB affected communities must also be empowered to monitor availability of TB drugs and diagnostics including issues of side effects, stigma and stockouts.
8. TB strategies that are more detailed in the way they include and engage vulnerable, marginalised and TB key populations will have potentially higher yield of effective prevention, case detections, treatment initiation and successful treatment completion. It is recommended to prepare a list of “TB key populations” (including PLHIV, PWUD, prisoners and detainees, migrants and indigenous people) prior to next strategy plan development, together with representatives from each of the groups lists, to understand more about what effective TB prevention, diagnosis, treatment, care and support means to each of those groups, and to prioritise populations with higher risks to TB. By 2020, beside lessons learned from the on-going TB program implementation, new approaches should be taken into consideration.
9. It is important to strengthen the integration and collaboration of TB/HIV by conducting a TB screening program for all risk populations or the general population reached in HIV programs and referred to TB testing for those suspected of TB. This approach is cost efficient and can be implemented by educating outreach workers in TB screening.
10. Findings of this study on TB at slum areas, where access to services were relatively reachable and affordable, leaves a recurring problem of TB-reinfections that leads to drug resistance if TB survivors would have to be back to the slum areas. In relation to enabling legal environment and human rights, promoting rights to housing, and right to hygiene can be a relevant answer. This notion is relatively new to Indonesia, but there is an on-going movement at the global level to support this. Thus, capacity on how to create the demand needs to take place. Prior to this, a group of TB program staff needs to collect credible information using on disaggregated data to show how people living in poor, high-density area settings affected by hygiene and housing conditions. In turn, National TB Program will have to collaborate with related sectors to advocate and work in rights to adequate housing and safe workplaces, that not only significantly reducing transmission, but also increase the level of people’s welfare. More legislation is needed to further development, including holistic TB workplace policies as recommended by the ILO, UNAIDS and WHO.

11. Given the findings about people living in slums in urban environments, it would also be prudent to undertake a more thorough analysis of CRG issues impacting people living in remote and isolated environments, including some of the more remote islands of Indonesia. It would also be valuable to understand more about the context of TB and universal access in other high-density living environments such as prisons and detention centers.
12. It is important to encourage the involvement of TB affected people to be involved in TB programs both in policy development, planning, implementation and evaluation. In addition, it is necessary to facilitate the establishment and strengthening of peer support system for the TB affected people from various parties including technical assistance and funding support. Furthermore, support is required for networks of people affected by TB to build independence and begin with empowerment through peer support groups.
13. The study also found several TB survivors who are never recorded as TB patients, due to migration or personal reference on health facility that are not having integrated information system. This condition leads to recommendations to improve reporting and recording system by including all facilities, public and private to the national management information system – irrespective of migration status and where they move within Indonesia. This, in turn, will enable people found not completing the treatment to get back to treatment, and the system would allow community to take roles as treatment observer to ensure every TB patient completes treatment. Further analysis of the experience of documented and undocumented migrants in other regions of Indonesia is recommended to understand how to overcome this challenge.
14. The study found considerable barriers for TB people and their families to get comprehensive knowledge on TB – whether it be prevention, diagnosis, treatment, care and support. What might constitute a violation of their rights to health is also not widely known and understood whether it be the right to privacy, rights to information, right to liberty, right to freedom from discrimination among others. Correct information provided in timely manner, particularly from peers, would, in part, address this lack of knowledge on cause, transmission and prevention, and especially those of in higher risk to TB. Hence, a communication strategy, including a know your rights component and a legal support component, ought to be scaled up in Indonesia.
15. Communication, coordination and engagement strategies reaching the grass roots communities and increasing CSO/CBO's/TB survivor networks skills and knowledge must be a priority focus for overcoming barriers to TB universal access.
16. Use of IEC materials for health workers (e.g., 10-minutes video or a longer refresher training) would be efficient ways to increase health personnel readiness to deal with TB and to understand the broader human rights and gender equality issues that are a challenge for many of the people who are affected by TB.
17. Closer TB and MCH program integration is urgently needed to increase capacity in diagnosing and referring pregnant women to TB care.
18. Strengthening public-private partnership and communication, often among clinicians will be significant in ensuring prevention as well as timely diagnoses, treatment, care and support.

19. It is further recommended, that a package of costed CRG interventions be developed based on these findings and recommendations. This package should be reflected in the National Strategic Plan and upcoming Global Fund funding requests or re-programming initiatives.

20.

Annexes

Annex 1: Summary Table of Indonesian 2018 Global TB Report

FIGURE 12. TB EPIDEMIOLOGICAL UPDATE 2018 (PART 1)

ESTIMATES OF TB BURDEN,^a 2017		
	NUMBER (THOUSANDS)	RATE (PER 100 000 POPULATION)
Mortality (excludes HIV+TB)	107 (100–114)	40 (38–43)
Mortality (HIV+TB only)	9.4 (5–15)	3.6 (1.9–5.8)
Incidence (includes HIV+TB)	842 (767–919)	319 (291–348)
Incidence (HIV+TB only)	36 (20–57)	14 (7.7–21)
Incidence (MDR/RR-TB) ^b	23 (16–31)	8.8 (6.2–12)

ESTIMATED TB INCIDENCE BY AGE AND SEX (THOUSANDS),^a 2017			
	0–14 YEARS	> 14 YEARS	TOTAL
Females	23 (23–23)	326 (308–345)	349 (329–370)
Males	26 (26–27)	466 (435–497)	492 (458–526)
Total	49 (48–50)	792 (723–862)	842 (767–919)

TB CASE NOTIFICATIONS, 2017	
Total cases notified	446 732
Total new and relapse	442 172
— % tested with rapid diagnostics at time of diagnosis	2%
— % with known HIV status	29%
— % pulmonary	90%
— % bacteriologically confirmed among pulmonary	54%

FIGURE 13. TB EPIDEMIOLOGICAL UPDATE 2018 (PART 2)

TB/HIV CARE IN NEW AND RELAPSE TB PATIENTS, 2017			
	NUMBER	(%)	
Patients with known HIV-status who are HIV-positive	7 729	6%	
— on antiretroviral therapy	2 244	29%	

DRUG-RESISTANT TB CARE, 2017			
	NEW CASES	PREVIOUSLY TREATED CASES	TOTAL NUMBER^c
Estimated MDR/RR-TB cases among notified pulmonary TB cases			12 000 (8 600–15 000)
Estimated % of TB cases with MDR/RR-TB	2.4% (1.8–3.3)	13% (9–18)	
% notified tested for rifampicin resistance	16%	223%	112 743
MDR/RR-TB cases tested for resistance to second-line drugs			1 813
Laboratory-confirmed cases		MDR/RR-TB: 5 070, XDR-TB: 51	
Patients started on treatment ^d		MDR/RR-TB: 3 042, XDR-TB: 50	

Annex 2: Supporting Data on Key Population Assessment

TABLE 3. PRIORITIZATION TOOL EXERCISE

Key Populations to Consider	Score 1	Score 2	Score 3	Score 4	Score 5	Risk/ Exposure & Barrier Scores Sub- Total (Sum of Scores 1-5) Max 5	Score 6	Combined Score to Facilitate Prioritization Discussion	
	At Risk of/ Exposed to Environment Risks (Over- crowded, poorly ventilated space, reside in zoonotic TB areas) 0 – None 0.5 – A little 1 – Substantial	At Risk of/ Exposed to Biology Risks (Reduced immunity, poor nutrition) 0 – None 0.5 – A little 1 – Substantial	At Risk of/ Exposed to Behavior Risks (In/exhaling from/into other’s mouth, sharing smoking equipment) 0 – None 0.5 – A little 1 – Substantial	Legal & Economic Barriers to Accessing Services (Criminalization, poverty) 0 – None 0.5 – A little 1 – Substantial	Human Rights & Gender Barriers to Accessing Services (Stigma, discrimination) 0 – None 0.5 – A little 1 – Substantial		Estimated (and/or official data, if available) Contribution to the Country’s TB Disease Burden (Active TB cases of all forms) 1 – Very Low (<1%) 2 – Low (1-3%) 3 – Medium (3-5%) 4 – High (5-10%) 5 – Very High (>10%)	Total Score (Sum of Scores 1-6) Max 10	Prioritization Discussion and Rationale for Prioritized Key Populations
People Living with HIV	0.5	1	0.5	0.5	0.5	3	3	6	PLHIV is the highest priority, and among PLHIV we also include People who use/inject drugs, sex workers, men who have sex with men and transgender people.
Urban Poor	1	0.5	1	0	0.5	3	3	6	As one of the national priorities, the people in high-density and poor areas (slum areas) at municipalities
Rural Poor	1	0.5	1	0	0.5	3	2	5	Slum areas exist at rural areas, particularly at the neighboring areas of the municipalities. , In regards to new infections, rural poor were seen as important as the urban poor. We included this in the high-density poor area, as MoH request an analysis between urban and rural areas

Key Populations to Consider	Score 1	Score 2	Score 3	Score 4	Score 5	Risk/ Exposure & Barrier Scores Sub- Total (Sum of Scores 1-5) Max 5	Score 6	Combined Score to Facilitate Prioritization Discussion	
	At Risk of / Exposure to Environment Risks (Over- crowded, poorly ventilated space, reside in zoonotic TB areas) 0 – None 0.5 – A little 1 – Substantial	At Risk of / Exposed to Biology Risks (Reduced immunity, poor nutrition) 0 – None 0.5 – A little 1 – Substantial	At Risk of / Exposed to Behavior Risks (In/exhaling from/into other’s mouth, sharing smoking equipment) 0 – None 0.5 – A little 1 – Substantial	Legal & Economic Barriers to Accessing Services (Criminalization, poverty) 0 – None 0.5 – A little 1 – Substantial	Human Rights & Gender Barriers to Accessing Services (Stigma, discrimination) 0 – None 0.5 – A little 1 – Substantial		Estimated (and/or official data, if available) Contribution to the Country’s TB Disease Burden (Active TB cases of all forms) 1 – Very Low (<1%) 2 – Low (1-3%) 3 – Medium (3-5%) 4 – High (5-10%) 5 – Very High (>10%)	Total Score (Sum of Scores 1-6) Max 10	Prioritization Discussion and Rationale for Prioritized Key Populations
Prisoners & Detainees	0.5	0.5	0	0.5	0.5	2	4	6	This TB KP is also one of the national priorities and part of the main program. We exclude this in the research due to budget constraints
People who Use/Inject Drugs	0.5	1	0.5	0.5	0.5	3	3	6	Included in PLHIV
Sex Workers	0.5	0.5	0.5	0.5	0.5	2.5	2	4.5	Included in PLHIV
Men who have sex with men	0.5	0.5	0.5	0.5	0.5	2.5	1	3.5	Included in PLHIV
Transgender people	0.5	1	0.5	0.5	0.5	3	2	5	Included in PLHIV
Miners	0.5	0	0.5	0	0	1	1	2	Not included
Mobile population	0.5	0	0.5	0	0	1	1	2	Not included, due to limited data available, especially for a follow up after diagnosed
People with Diabetes	0	1	0	0	0	1	3	4	Not included. We have sufficient data and researches on TB among people with Diabetes.
Children	0	1	0	0	0	1	1	2	Not included

Key Populations to Consider	Score 1	Score 2	Score 3	Score 4	Score 5	Risk/ Exposure & Barrier Scores Sub- Total (Sum of Scores 1-5) Max 5	Score 6	Combined Score to Facilitate Prioritization Discussion	
	At Risk of / Exposed to Environment Risks (Over- crowded, poorly ventilated space, reside in zoonotic TB areas) 0 – None 0.5 – A little 1 – Substantial	At Risk of / Exposed to Biology Risks (Reduced immunity, poor nutrition) 0 – None 0.5 – A little 1 – Substantial	At Risk of / Exposed to Behavior Risks (In/exhaling from/into other’s mouth, sharing smoking equipment) 0 – None 0.5 – A little 1 – Substantial	Legal & Economic Barriers to Accessing Services (Criminalization, poverty) 0 – None 0.5 – A little 1 – Substantial	Human Rights & Gender Barriers to Accessing Services (Stigma, discrimination) 0 – None 0.5 – A little 1 – Substantial		Estimated (and/or official data, if available) Contribution to the Country’s TB Disease Burden (Active TB cases of all forms) 1 – Very Low (<1%) 2 – Low (1-3%) 3 – Medium (3-5%) 4 – High (5-10%) 5 – Very High (>10%)	Total Score (Sum of Scores 1-6) Max 10	Prioritization Discussion and Rationale for Prioritized Key Populations
Elderly	0	1	0	0	0	1	1	2	Not included
Hospital Workers	0	0	1	0	0	1	1	2	Not included

Understanding and Defining Key Populations

TABLE 4. PRISONERS AND DETAINEE

TB Risks				TB Risk Drivers	TB Case Finding and Treatment Service Challenges
Environment	Biology	Behaviour	Limited Access to Service	Legal & Economic Human Rights and Gender	
Both, all prison or detaining center are over-capacity, underfunded, and understaff. A small room may be used for more than 20 prisoners.	Low in immune system, among other due to HIV, mental health, and addiction problems	Some inmates use drugs before incarcerated.	Each of the prison or detaining center has health workers as part of the organization structure. However, not all well-equipped with TB screening, diagnosis or treatment. Not all prison and DC has good collaboration with nearest PHC/ DOH staff Heavily reliant on donor funding	Stigma and discrimination among those recognized by other inmates as TB patient.	TB-HIV screening is mandatory. Although coordination with nearest health facilities is built, problems raised because there is no systematic funding to deliver reagent/testing or treatment from different health facilities.

Potential Responses
<ul style="list-style-type: none"> • Need to build stronger coordination with health workers and health facilities surrounding the prison/detaining center. • Need to ensure the national minimum standard of health services (SPM) includes services for prisoners and detainees. • Build a transit mechanism for people in TB treatment, including those who have to be mobilized from a prison to another.

TABLE 5. PEOPLE LIVING AT POOR-HIGH DENSITY NEIGHBOURHOOD

TB Risks				TB Risk Drivers	TB Case Finding and Treatment Service Challenges
Environment	Biology	Behaviour	Limited Access to Service	Legal & Economic Human Rights and Gender	
<p>Poor and un-hygiene environment.</p> <p>A house with more than one family unit (day and night)</p> <p>Relatively far even from the nearest PHC, for those who are very poor (not having sufficient transportation cost)</p>	<p>Malnourished.</p> <p>Exposures to many other communicable disease</p> <p>Humid, dusty and poor air circulation that cause vulnerable lung condition</p> <p>Permanent deteriorated physical fitness after TB infection</p>	<p>Lack of knowledge on TB among community</p> <p>High tobacco-smoking prevalence</p>	<p>Transportation cost</p> <p>Lack of knowledge on the services available.</p> <p>Not seeking health services when getting sick (delay to go to health facilities)</p>	<p>Highly stigmatized</p> <p>Although the national or sub-national insurance are available, getting the administrative process completed may be challenging</p>	<p>Late diagnosis (due to self-medication)</p> <p>Delay to treatment</p> <p>Drop out</p> <p>Default</p> <p>Lack of prevention measures among family members</p>

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Potential Responses
<ul style="list-style-type: none"> • Community-based active case finding – cadre roles in the society • Ex-patients as advocates and educators • Community strengthening program for TB program

TABLE 6. PEOPLE LIVING AT POOR-HIGH DENSITY NEIGHBORHOOD

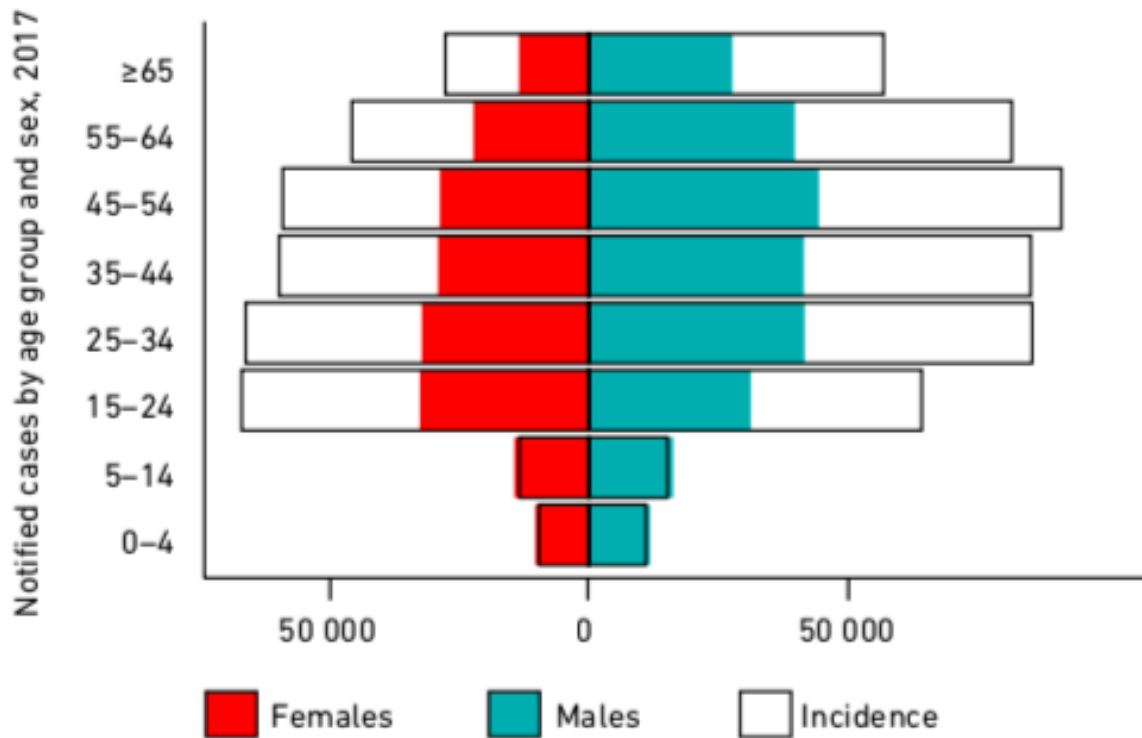
TB Risks				TB Risk Drivers	TB Case Finding and Treatment Service Challenges
Environment	Biology	Behaviour	Limited Access to Service	Legal & Economic Human Rights and Gender	
<p>Many of TB patients were of HIV key population or PLHIV who</p> <p>Poor and un-hygiene environment.</p> <p>Infected by the family members because of lack of information on TB prevention (including TPT)</p>	<p>Weakened immune system</p> <p>Using drugs or alcohol</p> <p>Have to work in the night</p>	<p>Lack of knowledge on TB among PLHIV and their family members</p>	<p>Transportation cost</p> <p>Not seeking health services when getting sick (delay to go to health facilities)</p> <p>Lack of services providing HIV related services</p>	<p>Highly stigmatized</p> <p>Although the national or sub-national insurance are available, getting the administrative process completed may be challenging</p>	<p>Late diagnosis (due to self-medication)</p> <p>Delay to treatment</p> <p>Complication</p> <p>Drop out</p> <p>Default</p> <p>Lack of prevention measures</p>

					among family members

Potential Responses
<ul style="list-style-type: none"> • Add more health facilities providing HIV-TB services • Intensify TB screening among PLHIV • Intensify TPT program • TB literacy for PLHIV as part of support group program

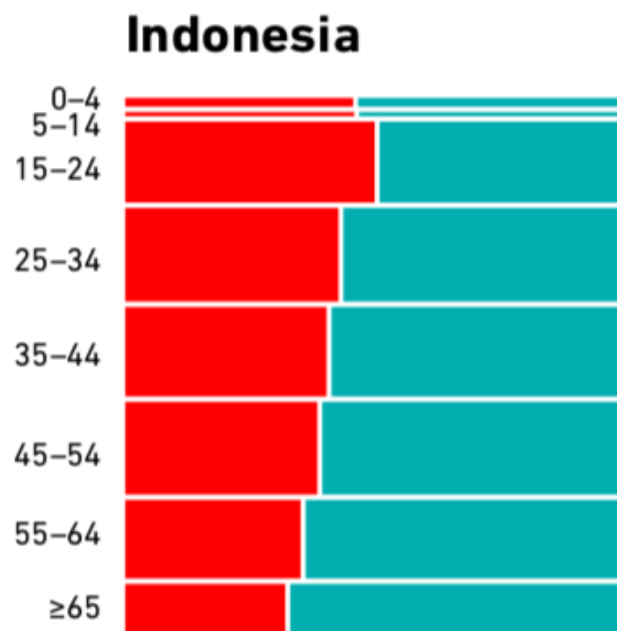
Annex 3: Supporting Data on Gender Analysis

FIGURE 14. ESTIMATES OF TB INCIDENCE (BLACK LINE) AND CASE NOTIFICATIONS DISAGGREGATED BY AGE AND SEX (FEMALE IN RED AND MALE IN GREEN). 2017, IN 30 HIGH TB BURDEN COUNTRIES.



Source: Global TB report.

FIGURE 15. ESTIMATED DISTRIBUTION OF TB MORTALITY IN HIV-NEGATIVE PEOPLE IN THE 30 HIGH TB BURDEN COUNTRIES GROUP AND SEX (FEMALE IN RED; MALE IN GREEN). 2017



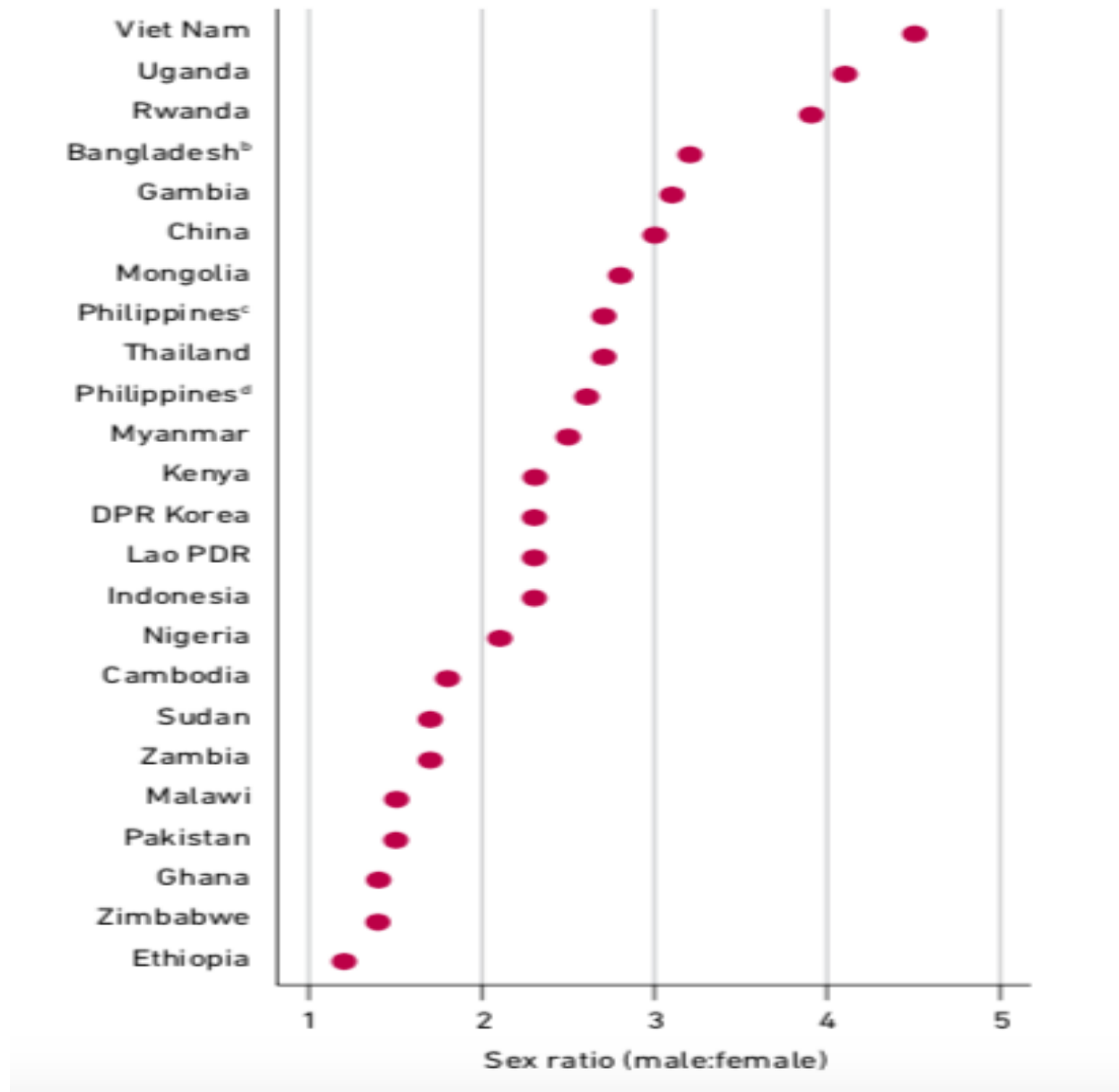
Source Global TB Report.

TABLE 7. ESTIMATED TB PREVALENCE PER 100,000 POPULATION AGED ≥ 15 BY SEX.

Sex	Estimated	
	Smear positive	Bacteriologically confirmed
Male	392.5	1,082.7
Female	131	460.6

Source: TB Prevalence Survey in Indonesia report, 2013-2014

FIGURE 16. THE MALE TO FEMALE RATIO OF BACTERIOLOGICALLY CONFIRMED ADULT TB CASES DETECTED IN PREVALENCE SURVEY IMPLEMENTED 2007-2017.



Source Global TB Report 2018

TABLE 8. LEVEL OF TB UNDERREPORTING (%) BY TYPE OF HEALTH CARE PROVIDER, TYPE OF TB CASE, AGE, AND STRATA.

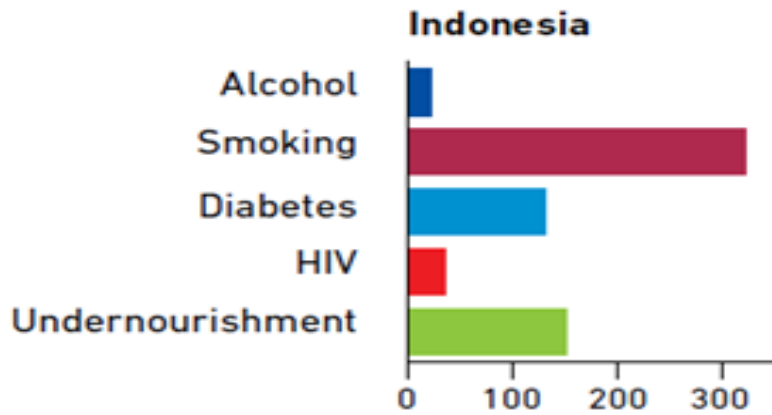
	MEAN PERCENTAGE (95% CONFIDENCE INTERVAL)
Total	41 (36–46)
By type of health provider	
Primary health care ("puskesmas")	15 (11–20)
Non-primary health care	71 (61–79)
Hospital	62 (52–72)
Other ^a	96 (92–98)
By TB case type	
Bacteriologically confirmed	21 (16–26)
Clinically diagnosed	55 (49–61)
By site of disease	
Pulmonary	38 (33–44)
Extra-pulmonary	58 (49–66)
By age	
<15 years	54 (44–64)
≥15 years	39 (34–44)
By sex	
Female	41 (36–47)
Male	41 (36–46)
By strata	
Sumatera	40 (24–59)
Bali/Java	42 (18–47)
Other	39 (28–51)

^a Clinics, general practitioners, laboratories.

Source: Inventory study in Indonesia, 2016-2017.

Annex 4: Supporting Data on Drivers of TB in Indonesia

FIGURE 17. ESTIMATED NUMBER OF TB CASES ATTRIBUTABLE TO FIVE RISK FACTORS IN INDONESIA, 2017.



Source: Lönnroth, K. et al. (2009) 'Drivers of tuberculosis epidemics: The role of risk factors and social determinants', *Social Science and Medicine*, 68(12), pp. 2240–2246. doi: 10.1016/j.socscimed.2009.03.041