

# Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations

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Stop **TB** Partnership

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# Acronyms

ACSM	Advocacy, Community and Social Mobilization
AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Therapy
BCG	Bacille Calmette-Guérin (vaccine)
СВМ	Community-based Monitoring
СВО	Community-based Organization
ССМ	Country Coordinating Mechanism
CDC	Centre for Disease Prevention and Control
CESCR	Committee on Economic, Social and Cultural Rights
СРТ	Co-trimoxazole Preventive Therapy
CSO	Civil Society Organization
DOTS	Directly Observed Treatment, Short-Course
НВС	High-burden Country
HBV	Hepatitis B Virus
нси	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
IDP	Internally Displaced Persons
ILO	International Labour Organization
ЮМ	International Migration Organization
IPT	Isoniazid Preventive Therapy
IUATLD	International Union Against Tuberculosis and Lung Disease
KNCV	Royal Netherlands Tuberculosis Association
LTBI	Latent Tuberculosis Infection
M&E	Monitoring and Evaluation
MDG	Millennium Development Goal
MDR-TB	Multidrug-resistant Tuberculosis
ММТ	Methadone Maintenance Treatment
МОН	Ministry of Health
NGO	Non-governmental Organization
NRL	National Reference Laboratory
NTP	National Tuberculosis Programme
OST	Opioid Substitution Therapy
PHC	Primary Health Care
PLHIV	People Living with HIV
PSE	Population Size Estimate

PWID	People Who Inject Drugs
PWTB	People With Tuberculosis
PWUD	People Who Use Drugs
RDS	Respondent Driven Sampling
SDG	Sustainable Development Goal
SOP	Standard Operating Procedure
SRS	Simple Random Sampling
STD	Sexually Transmitted Disease
тв	Tuberculosis
TLS	Time Location Sampling
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNIDO	United Nations Industrial Development Organization
UNODC	United Nations Office on Drugs and Crime
USAID	United States Agency for International Development
WHO	World Health Organization
XDR-TB	Extensively Drug-resistant Tuberculosis

# Glossary

Active TB Disease: An illness in which TB bacteria are multiplying and attacking different parts of the body. The symptoms of active TB disease include cough, weakness, weight loss, fever, no appetite, and sweating at night. A person with active TB disease may be infectious and spread TB to others. In this document, "people with TB" or "people ill with TB" refers to those who have active TB disease.

**Antibiotic**: A drug used to treat bacterial infections. Anti-TB drugs are also antibiotics. Antibiotics have no effect on viral infections.

**Antibiotic Resistance:** The ability of a microorganism to withstand the effects of antibiotics. Antibiotic resistance typically evolves when random mutation of the microorganism develops which makes it less susceptible to the effects of a particular drug.

Antibiotic Susceptibility Test: Also drug-susceptibility test (DST), this is a laboratory test to assess whether TB bacteria are sensitive or resistant to certain anti-TB drugs.

Antiretroviral Therapy (ART): The use of a particular class of drugs (antiretrovirals) to treat HIV infection.

**BCG:** The Bacillus Calmette–Guérin TB vaccine is named after the French scientists who developed it, Calmette and Guérin. BCG provides adolescents and adults, with little protection against TB, but it is often given to infants and small children in countries where TB is common as it can prevent some of the most severe forms of TB in children.

**Case Detection:** When a person's TB is diagnosed and reported within the national surveillance system. Although the term 'case' is used widely in public health to refer to an instance of disease, it should be used with sensitivity in health care settings to avoid dehumanizing people. A person is not a case but a fellow human being. Individuals seeking or receiving care for TB may find it demeaning if they overhear a health worker describing them as a 'case'.

**Contact:** A person who has spent time with a person with active TB.

**Close Contact:** A person who has had prolonged, frequent, or intense contact with a person with TB while he or she was infectious. This group includes persons who live together or spend a great deal of time together in close proximity. Close contacts, or household contacts, are more likely to become infected with M. tuberculosis than contacts who see the person with TB less often.

**Community Systems:** Community systems are the structures, mechanisms, processes, and actors through which communities act on the challenges and needs that they face. They are made up of different types of entities: community members, formal and informal community organizations and networks, and other civil society organizations. They are usually less formalized and less clearly defined. Entities that make up community systems have close links with communities and, therefore, better understand the issues facing those that are most affected and better suited to find smart solutions.

**Community Systems Strengthening:** Initiatives that contribute to the development and/or strengthening of community-based organizations in order to increase knowledge of and access to improved health service delivery. It usually includes capacity building of infrastructure and systems, partnership-building, and the development of sustainable financing solutions.

**Culture:** A test to see whether there are TB bacteria in your sputum/phlegm or other body fluids. This test can take 2 to 4 weeks for positive results (but up to 8 weeks for negative results) in most laboratories.

**Drug-resistant Tuberculosis (DR-TB):** Disease caused by a strain of TB bacteria that is resistant to the most commonly used anti-tuberculosis drugs.

**Extensively Drug-resistant Tuberculosis (XDR-TB):** Disease caused by a strain of the TB bacteria that is resistant to isoniazid and rifampicin (the two most commonly used anti-TB drugs) plus fluoroquinolone and at least one of the three injectable second-line drugs (amikacin, kanamycin, capreomycin).

**Extra-pulmonary TB:** TB disease in any part of the body other than the lungs (for example, the kidney, spine, brain, or lymph nodes).

**Gender-sensitive:** Gender-sensitive policies, programmes, or training modules recognize there are different gender actors (women, men, transgender) within a society, that they are constrained in different and often unequal ways and that consequently they may have differing and sometimes conflicting perceptions, needs, interests, and priorities.

**Gender–responsive:** A programme or tailored approach that is specific to different genders (women, men, transgender) due to particular challenges faced by that gender.

**Multidrug-resistant Tuberculosis (MDR-TB):** Disease caused by a strain of TB bacteria that is resistant to at least isoniazid and rifampicin (the two most commonly used anti-TB drugs).

Mycobacterium Tuberculosis: Bacteria that cause TB infection and TB disease.

**Nutritional Support:** It aims at ensuring adequate nutrition and includes assessment of the dietary intake, nutritional status, and food security of the individual or household, offering nutrition education and counselling on how to ensure a balanced diet, mitigate side-effects of treatment and infections and ensure access to clean water, and providing food supplements or micronutrient supplementation where necessary.

**Person-centred Approach to TB Care:** A person-centred approach considers the needs, perspectives and individual experiences of people affected by TB, while respecting their right to be informed and receive the best quality of care based on individual needs. It requires the establishment of mutual trust and partnership in the care recipient-provider relationship and creates opportunities for people to provide input into and participate in the planning and management of their own care. Person-centred approach improves treatment outcomes while respecting human dignity.

**People Affected by TB:** This term encompasses people ill with TB and their family members, dependents, communities and healthcare workers who may be involved in care-giving or are otherwise affected by the illness.

**Person Lost to Follow Up:** Someone who, generally because of poor quality health services or the lack of a person-centred approach, doesn't start or complete TB treatment. Previously people lost to follow up were referred to as defaulters. The term defaulters should be avoided as it unfairly puts all the blame on care recipients.

**Person to be Evaluated for TB:** In the past used as "TB suspect" which is sometimes used to define a person who presents with symptoms or signs suggestive of TB. The word "suspect" should not be used.

**People with TB (PWTB):** This term encompasses people who are ill with active TB. The term people (or person) with TB recognizes that a person with TB should not be defined solely by their condition, and may be preferable to the word 'patients' in certain contexts (e.g. non-medical and community settings).

**Preventive Therapy:** Medicines that prevent TB infection from progressing to active TB disease.

**Programme Integration:** This term refers to joining together different kinds of services or operational programmes in order to maximize outcomes, e.g. by organizing referrals from one service to another or

offering one-stop comprehensive and integrated services. In the context of TB care, integrated programmes may include HIV testing, counselling and treatment; sexual and reproductive health, primary care and maternal and child health.

**Smear Microscopy:** A test to see whether there are TB bacteria in sputum. To do this test, lab workers smear sputum on a glass slide, stain the slide with a special dye, and look for any TB bacteria on the slide. This test usually takes one day to produce results.

**Sputum:** Phlegm coughed up from deep inside the lungs. Sputum is examined for TB bacteria using smear microscopy, culture or molecular tests.

**Stigma:** Derived from the Greek meaning a mark or a stain. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within particular cultures or settings, certain attributes are seized upon and defined by others as discreditable or unworthy. When stigma is acted upon, the result is discrimination that may take the form of actions or omissions.

**TB Disease:** An illness in which TB bacteria are multiplying and attacking a part of the body, usually the lungs. The symptoms of active TB disease include weakness, weight loss, fever, no appetite and sweating at night. Other symptoms of TB disease depend on where in the body the bacteria are growing. If TB disease is in the lungs (pulmonary TB), the symptoms may include a bad cough, pain in the chest, and coughing up blood. A person with pulmonary TB disease may be infectious and spread TB bacteria to others.

**TB Infection:** Also called latent tuberculosis infection (LTBI), is a condition in which TB bacteria are alive but inactive in the body. People with latent TB infection have no symptoms, don't feel sick, can't spread TB bacteria to others, and usually have a positive test for infection – positive to a tuberculin skin test or a special test called IGRA test. In this document, people referred to as "infected with TB" are people having such latent TB infection.

**TB Prevention and Care**: The efforts of healthcare workers to provide TB services to the communities they serve. These terms should be preferred over "TB control" which may create the perception that TB experts are in full control of all aspects of prevention, treatment and care of people with TB. It is useful to examine the term 'control' critically so as to avoid neglecting community and care recipient resources and capacities.

# **Executive Summary**

There have been many successes in reducing TB incidence and mortality during the 15-year period (2000-2015) of the Millennium Development Goal (MDG). However, the current 1.5% annual decline in incidence<sup>1</sup> will require decades, rather than the 15 years as agreed in the new Sustainable Development Goal (SDG, 2016-2030),<sup>2</sup> to eliminate this largely curable disease by 2030. Today there are still 10.4 million people falling ill with TB every year (active TB) and 2 billion infected but have not fallen ill, otherwise known as people with latent TB infection (LTBI).<sup>3</sup> TB still kills 1.4 million people a year largely due to inadequate programmatic and service delivery issues, including inappropriate or inadequate drug regimes or difficulties in adhering to the 6-9 months treatment.<sup>4</sup> To meet the SDG goal to eliminate TB by 2030, TB services across the world need a new strategy.

The WHO END TB Strategy<sup>5</sup> provides a road map of indicators (mortality, incidence, catastrophic costs) from 2020 to 2035, including the 2030 SDG target of 90% reduction in mortality and 80% reduction in incidence. It also lays out key principles that all countries should respect. Two of the four principles that accompany the strategy are directly related to population sub-groups ("key populations" for the purpose of this document) facing higher risk of TB exposure and infection compared to the general population. First, TB responses should forge strong coalitions and working relationships with communities from key populations such as community-based organizations (CBOs) and non-governmental organizations (NGOs). And second, TB programmes must be sensitive to the fact that these key populations are often socially disadvantaged and their human rights frequently violated and that TB responses must respect and address their rights and ensure the same level and quality of services as that for the general population. Furthermore, current data about these key populations are limited and efforts to fill data gaps - including risk and exposure factors, estimated size of the population affected and TB prevalence - are needed as part of the END TB Strategy.

To help achieve the targets of the WHO End TB Strategy, the Stop TB Partnership developed the Global Plan to END TB<sup>6</sup> by first calling for a paradigm shift, including how TB services are organized, managed and funded, moving:

- From passive to active case finding including the use of methodologies to measure risk, exposure and prevalence with strong engagement of civil society including networks and organizations led by key populations facing higher risk of TB
- From vertical to integrated service delivery systems
- From small incremental to accelerated substantial financial investments

Second, the Global Plan to END TB specifies TB testing and treatment services must reach at least 90% of key populations as defined by countries across the world by 2020 through TB programmes that are human-rights-based, gender-responsive, multi-stakeholder and inclusive. Addressing TB issues key populations face is critical to the overall goal of ending the epidemic for the entire population. Key populations vary by country and include people with increased exposure to TB due to where they live or

<sup>&</sup>lt;sup>1</sup> WHO (2015) "Global Tuberculosis Report" (http://apps.who.int/iris/bitstream/10665/191102/1/9789241565059\_eng.pdf)

<sup>&</sup>lt;sup>2</sup> UN Sustainable Development Goals (<u>http://www.un.org/sustainabledevelopment/health/</u>)

<sup>&</sup>lt;sup>3</sup> Global Tuberculosis Report (2016) (<u>http://apps.who.int/iris/bitstream/10665/250441/1/9789241565394-eng.pdf</u>)

<sup>&</sup>lt;sup>4</sup> TB Facts "TB Treatment – Curing TB, Failure, Relapse & Recurrence" (<u>http://www.tbfacts.org/tb-treatment/</u>) (accessed 15 Aug 2016)

<sup>&</sup>lt;sup>5</sup> WHO (2014) "The End TB Strategy: Global Strategy and Targets for Tuberculosis Prevention, Care and Control After 2015" (<u>http://www.who.int/tb/strategy/End\_TB\_Strategy.pdf</u>)

<sup>&</sup>lt;sup>6</sup> StopTB Partnership (2015) "The Paradigm Shift: the Global Plan to End TB 2016-2020"

<sup>(</sup>http://www.stoptb.org/assets/documents/global/plan/GlobalPlanToEndTB\_TheParadigmShift\_2016-2020\_StopTBPartnership.pdf)

work, people with limited access to quality TB services, and people at greater risk due to biological or behavioural factors.

This document provides a framework for countries to accelerate TB responses among key populations. The framework describes key principles and a process that countries can utilize and adapt to design and implement their TB programmes for key populations. It has been primarily designed for governments and civil society service providers and other stakeholders to take actions against TB among key populations. Other relevant stakeholders include national health coordination bodies and development partners and other implementers that support country efforts to carry out TB services for key populations.

# Principles

Four key principles must be adhered to at all stages of TB responses among key populations from planning, implementation to monitoring and evaluation:

- 1. **Multi-stakeholder and Participatory** National and local TB programmes need to engage and coordinate closely with other public health programmes, social support programmes, public and private health care providers, non-governmental and civil society organizations, communities and other support associations from programme planning to service delivery to ensure the provision of high-quality, integrated, person-centred TB care and prevention for key populations across the health system. Civil society organizations involved must be treated as equal partners for them to contribute freely both their knowledge of and practical experience working with the community. Ensuring community is meaningfully engaged is critical to removing barriers key populations face in accessing services and minimizing loss to follow up by public TB services.
- 2. **Human Rights-based** The design and delivery of TB services for key populations must ensure key populations' rights to privacy, confidentiality, informed consent, freedom of movement, access to information are safeguarded and key populations are free from discrimination, involuntary treatment, isolation, detention and incarceration. National and local TB programmes must also proactively engage and empower key populations from programme design, data collection, service delivery to accountability.
- 3. **Gender-responsive** National and local TB programmes must recognise and pro-actively consider and respond to gender differences within each key population.
- 4. **Evidence-driven** National and local TB programmes must recognize data for key populations is scant and commit to collecting data to first guide the initial design of TB programmes for key populations and put in place system to collect data during program implementation for continuous programme improvement.

# Steps

Eight key steps are highlighted in this framework to help countries plan and roll out TB services to key populations:

- 1. **National multi-stakeholder TB Key Populations Committee** Convene a multi-stakeholder committee at national level, including civil society and advocate or community representatives of potential key populations, to discuss the following.
- 2. Determine which population sub-groups should be considered as key populations Identify and prioritize potential population sub-groups that would need additional attention if TB was to be eliminated in the country, based on estimated size of the potential population sub-groups, risks (environment, biology, behavior) and service access barriers (legal, economic, gender and human rights) they face. The prioritized population sub-groups are then designated as key

populations. See Section 3 "Understanding and Defining Key Populations" for examples of understanding a key population from risk perspective, Annexes A2.1-A2.5 for illustrative examples of key populations, and Section 4.1 "National-level Key Population Prioritization" for the prioritization tool.

- 3. Conduct rapid assessment to support key population programme development Use qualitative research to identify data gaps to ensure TB programmes would address the risks, risk drivers and service access barriers key populations are faced with. It involves three stages: (a) Gather key information to identify specific issues that need to be addressed in order for the TB services for key populations to be successful; (b) Prioritize potential responses; and (c) Design interventions for prioritized responses. See Section 6 "Rapid Assessment" for methodological details.
- 4. Fill key population programme and service planning data gaps Use probability-based sampling methods (Respondent Driven Sampling, Time Location Sampling) to quantify in a particular locale the size, risks and service access barriers of key populations, who are often hard-to-reach without official records of addresses or contact information. Ensure surveys used for sampling methods are designed to allow for the application of population size estimate techniques (Multiplier, Service Data, Unique Object). Then extrapolate local-level estimates to derive regional and national estimates. See Section 7 "Sampling Methods to Fill Data Gaps" for further methodological details.
- 5. Add prioritized key populations to the National TB Plan Integrate qualitative research and quantitative sampling survey results on prioritized key populations into the country's National TB Plan, specifying where key populations are located, what are their TB risks and corresponding risk drivers, what service access barriers key populations might encounter, what service package are needed to minimise access barriers, what targets should be set for TB programmes for key populations and are there still data gaps that need to be addressed. See Section 4.4 "National Strategic Plan" for a template of key population information that should be included in the National TB Plan.
- 6. Invest in human resources at local level Have a staff (TB key population specialist) within the local health bureau dedicated to coordinating and ensuring services by different local government departments (primary health clinics, TB dispensaries, social, law enforcement, women) and civil society organizations are integrated. This would require additional resources to fund the key population specialist and salaries and programme costs of civil society organisations. See Section 8 "Service Planning at City/District Level".
- 7. Invest in capacity building programme for civil society organizations Plan local-level person-centred services to fully reap the potential benefits of integrating services of government clinics and civil society organizations. The staff within the local health bureaus dedicated to TB key populations (TB key population specialist) should lead the capacity building process which involves three stages: (a) Project planning, (b) Project dry run, and (c) Project roll out. See Annex A7 "Local Key Populations Service Planning Process An Example" for details.
- 8. Integrate service cascades and community-based monitoring into the TB service monitoring and evaluation system at both national and local levels – Design a service cascade with indicators for each step of the cascade and community accountability system to facilitate early identification and correction of implementation and coordination bottlenecks between relevant government clinics, department and civil society organisations to maximise programme impact. See Section 9 "Tracking Performance" for details.

# 1. Introduction

This document is an action framework designed for countries to plan tuberculosis (TB) services for groups within their populations that are more vulnerable, underserved or at higher risk of infection and illness related to TB. These groups are referred to as key populations in the Stop TB Partnership Global Plan to END TB.<sup>7</sup> They are key because addressing TB issues they face is critical to the overall goal of ending the epidemic for the entire population. Key populations vary by country and include people with increased exposure to TB due to where they live or work, people with limited access to quality TB services, and people at greater risk due to biological or behavioural factors.

The Global Plan to END TB calls for a paradigm shift, including how TB services are organized, managed and funded, moving:

- From passive to active case finding with strong engagement of civil society including key population-led networks and organizations
- From vertical to integrated service delivery systems
- From small incremental to accelerated substantial financial investments

Of the three targets included in the Global Plan to END TB, the second is dedicated to key populations recognizing their importance in curbing the epidemic, namely TB testing and treatment services must reach at least 90% of key populations as defined by countries across the world by 2020. And the third target of a minimum of 90% treatment success includes all people diagnosed with TB, including key populations.

Figure 1: Stop TB Partnership Global Plan to END TB for 2016-2020

<sup>&</sup>lt;sup>7</sup> StopTB Partnership (2015) "The Paradigm Shift: the Global Plan to End TB 2016-2020" (http://www.stoptb.org/assets/documents/global/plan/GlobalPlanToEndTB\_TheParadigmShift\_2016-2020\_StopTBPartnership.pdf)

Targets	1.	TB services reach at least 90% of all people with TB (including latent) and place all of them in appropriate therapy – first-line, second-line and preventive therapy as required.
	2.	<b>TB</b> services reach at least 90% of key populations (most vulnerable, underserved, at-risk) with TB (including latent).
	3.	At least 90% of treatment success for all people diagnosed with TB through affordable treatment services, adherence to complete and correct treatment, and social support.
Changes Needed	1.	A change in mindset - From being satisfied with modest incremental gains to committed to ambitious yet realistic elimination.
	2.	A human-rights based and gender-based approach to TB - Non-discriminatory and mechanisms to seek redress of discrimination, right to know TB status, participatory decision making, privacy and confidentiality, gender equality.
	3.	<b>Changed and more inclusive policy</b> – National level political commitment to multi-stakeholder approach that includes civil society and relevant government ministries.
	4.	<b>Community and person-driven approach</b> – People living with or affected by TB must be involved in TB responses from programme planning, implementation, monitoring and evaluation.
	5.	Innovative TB programmes equipped to end TB – <b>Identification of key populations at high risk of TB</b> at national level, <b>programmatic mapping of key population communities at local level</b> , use of social media in service delivery.
	6.	Integrated health systems fit for purpose – TB services should be integrated with HIV/Aids and maternal and child health programmes and part of the primary health that provides universal coverage.
	7.	New, innovative and optimized approach to funding TB care – Frontloading investment during 2016-2020, performance-based financing and public-private partnership.
	8.	Investment in socioeconomic actions - Improved housing ventilation and poverty reduction.

The Stop TB Partnership also published a series of guides illustrating possible key and vulnerable populations a country may encounter.<sup>8</sup> These briefs highlight TB risks specific to these sub-populations and corresponding challenges in delivering services to them. They also offer countries an opportunity to identify key populations in their contexts and could help countries think about what TB services might be needed for their own key populations. Five of these populations (Mobile populations, Miners, Prisoners and Detainees, People who use Drugs and People living with HIV) will be highlighted throughout this document to illustrate how the action framework could be utilized by countries to plan TB services for key populations.

This framework complements the WHO screening guidelines<sup>9</sup> by providing more process details such as filling gaps in basic programme data needed to design TB programmes and services for key populations and having key populations actively and meaningfully participate from programme and service planning, implementation to monitoring at both national and local levels. As key population work for TB is still at its early stage many concepts and tools for key populations included in this framework are borrowed from the HIV community,<sup>10</sup> which started key population work over 20 years ago. This framework is intended to be a living document for the TB community to update continuously as it accumulates more data, experience and lessons learned from implementing its own key population work. The past 20 years of HIV work on key populations also informed us, despite the lack of data, we cannot afford putting off

<sup>&</sup>lt;sup>8</sup> Mobile Populations (Migrants/Refugees/Internally Displaced People) -

http://www.stoptb.org/assets/documents/resources/publications/acsm/KP\_Mobile\_Spreads.pdf

Miners - http://www.stoptb.org/assets/documents/resources/publications/acsm/KP\_Miners\_Spreads.pdf

Prisoners/Detainees - http://www.stoptb.org/assets/documents/resources/publications/acsm/KP\_Prisoners\_Spreads.pdf People Who Use Drugs -

http://www.stoptb.org/assets/documents/resources/publications/acsm/KP\_PeopleUseDrugs\_Spreads.pdf People Living with HIV - http://www.stoptb.org/assets/documents/resources/publications/acsm/KPBrief\_PLHIV\_ENG\_WEB.pdf Health Care Workers -

http://www.stoptb.org/assets/documents/resources/publications/acsm/KPBrief\_HealthCareWorker\_ENG\_WEB.pdf Children Under 5 - http://www.stoptb.org/assets/documents/resources/publications/acsm/KP\_Children\_Spreads.pdf Urban Poor - http://www.stoptb.org/assets/documents/resources/publications/acsm/KP\_Urban\_Spreads.pdf Rural Poor - http://www.stoptb.org/assets/documents/resources/publications/acsm/KP\_Rural\_Spreads.pdf

<sup>&</sup>lt;sup>9</sup> WHO (2015) "Systematic Screening for Active Tuberculosis: An Operational Guide" (http://www.who.int/tb/tbscreening/en/)

<sup>&</sup>lt;sup>10</sup> Reid, Michael J. A.; Goosby, Eric (2017) "Lessons Learned from the HIV Care Cascade Can Help End TB", The International Journal of Tuberculosis and Lung Disease, Volume 21, Number 3, 1 March 2017, pp. 245-246(2)

programming for key populations until all the data needed has been collected and published. Programming and drawing lessons from data must go hand in hand.

# 1.1 Background

Despite successes in reducing TB incidence and mortality during the 15-year period (2000-2015) of the Millennium Development Goal (MDG), the current pace of 1.5% annual decline in incidence<sup>11</sup> means if we continue at this rate it will take decades, not the 15 years as agreed in the new Sustainable Development Goal (SDG, 2016-2030),<sup>12</sup> to eliminate this largely curable disease by 2030.

Today there are still 10.4 million people falling ill with TB every year (active TB), as compared to the 2 billion infected but have not fallen ill and they are referred to as people with latent TB infection (LTBI).<sup>13</sup> TB kills 1.4 million people largely due to inadequate programmatic and service delivery issues, including inappropriate or inadequate drug regimes or difficulties in adhering to the 6-9 months treatment.<sup>14</sup> Other factors impacting the effectiveness of our response to TB are antiquated treatments and regimens, a lack of roll out of new diagnostics tools, and a large proportion of people with active TB disease (4.3 million) missed by health systems across the world. Untreated active TB is detrimental to the physical and financial well being of the people with the disease and to their families. On a larger scale, untreated active TB poses serious public health threats to the rest of the general population as TB transmission is air-borne with a high multiplier where a person with active TB can infect 10 or more others in one year if not on treatment and appropriate precautions are not taken.<sup>15</sup>

Current efforts to combat TB are further challenged by the rise of drug-resistant TB. Although still comprising a relatively small proportion of all people with active TB, drug-resistant TB is more difficult and expensive to diagnose, treat and provide care and support. The longer treatment (often 1-2 years)<sup>16</sup> and more side effects of the treatment contribute to high treatment disruptions resulting in lower treatment success rates than non-resistant TB (<50% vs. >80% among those diagnosed) and leading to continued and amplified drug resistance and mortality. With the global rise of resistance to antibiotics in general, drug-resistant TB presents a real threat to achieving the Sustainable Development Goal (SDG) of elimination by 2030 and may even reverse the gains achieved in the past 15 years (MDG) if we do not change how we currently respond to the epidemic.

Many of the 4.3 million people with active TB currently missed by public health systems every year are likely to be disproportionally concentrated among individuals who are at higher risks of latent TB infection (and risk of latent TB becoming active TB) than the general population<sup>17</sup> due to their current physical conditions, living and working environments and their legal and social standing within society - those with compromised immune systems (e.g., people living with HIV, people with diabetes, poor people with inadequate nutrition), subject to poor air quality in their physical environments (e.g., mines, prisons,<sup>18</sup> health care facilities, refugee camps, urban slums), criminalized (e.g., people who use drugs, migrants, urban slum dwellers) and socially marginalized with little access to public health services (e.g., women, girls, urban slum dwellers, rural poor, refugees, migrants, miners, people who use drugs, people living with HIV). Criminalization and social stigma attached to both TB and socially marginalized

<sup>&</sup>lt;sup>11</sup> WHO (2015) "Global Tuberculosis Report" (<u>http://apps.who.int/iris/bitstream/10665/191102/1/9789241565059\_eng.pdf</u>)

<sup>&</sup>lt;sup>12</sup> UN Sustainable Development Goals (<u>http://www.un.org/sustainabledevelopment/health/</u>)

<sup>&</sup>lt;sup>13</sup> Global Tuberculosis Report (2016) (<u>http://apps.who.int/iris/bitstream/10665/250441/1/9789241565394-eng.pdf</u>)

<sup>&</sup>lt;sup>14</sup> TB Facts "TB Treatment – Curing TB, Failure, Relapse & Recurrence" (<u>http://www.tbfacts.org/tb-treatment/</u>) (accessed 15 Aug 2016)

 <sup>&</sup>lt;sup>15</sup> WHO (2017) "Tuberculosis Fact Sheet" (<u>http://www.who.int/mediacentre/factsheets/fs104/en/</u>) (accessed 1 Apr 2017)
 <sup>16</sup> TB Facts "Treatment of Drug Resistant TB – Shorter and Conventional Regimens" (<u>http://www.tbfacts.org/treatment-of-drug-resistant-tb/</u>) (accessed 17 Feb 2017)

 <sup>&</sup>lt;sup>17</sup> Giorgia Sulis, Alberto Roggi, Alberto Matteelli, and Mario C. Raviglione (2014) "Tuberculosis: Epidemiology and Control" Mediterranean Journal of Hematology and Infectious Disease 6(1): e2014070, DOI: 10.4084/MJHID.2014.070
 <sup>18</sup> Kelemework Adane, Mark Spigt, Semaw Ferede, Tsehaye Asmelash, Markos Abebe, and Geert-Jan Dinant (2016) "Half of Pulmonary Tuberculosis Cases Were Left Undiagnosed in Prisons of the Tigray Region of Ethiopia: Implications for Tuberculosis Control" PLoS One. 11(2): e0149453. Published online 2016 Feb 25. doi: 10.1371/journal.pone.0149453

population groups further deter these individuals from accessing public health services even when such service is provided for free.

Criminalized and socially marginalized (often due to stigmatization and discrimination) groups present a real challenge to current TB services across the world. The figure below illustrates how just providing the same service (equality, everybody gets one box) without addressing the differences in circumstances (inequity, different heights) to overcome systemic barriers (the fence) limits the chance of success of the overall objective that everyone sees the game (above the fence). Hence more boxes (additional efforts to overcome barriers) are needed to support those not tall enough to see the game above the fence.



### Figure 2: From Equality to Equity

Source: Cultural Organization (<u>http://culturalorganizing.org/the-problem-with-that-equity-vs-equality-graphic/</u>), accessed 7 Apr 2017.

TB services often assume all individuals with TB are no different from the general population in that they can recognize TB symptoms and present themselves on their own to the largely passive health services (TB dispensaries and hospitals, maternal and child health clinics). This ignores the social, financial, logistical, legal and other human-rights barriers that prevent these individuals from accessing TB services. These systemic barriers, along with inadequate systematic outreach to screen for latent TB and put those screened positive on preventive treatment, have contributed to the 4.3 million people with active TB missed by public health services every year. Even when they manage to access TB services, their financial and social disadvantages make it very difficult for them to adhere to the long treatment of active TB which often disrupts gainful work, forcing unfairly, these groups to choose between livelihood of themselves and/or their families and being treated for TB. Hence these individuals need specific health services interventions as well as financial and psychosocial support and protection in order to help people prevent the progression of latent TB to active TB and to get cured of TB if they have active TB.

To meet the SDG goal of elimination of TB by 2030, TB services across the world need a new strategy. The WHO END TB Strategy<sup>19</sup> and the Stop TB Partnership Global Plan to END TB (described above) outline how to meet these objectives. The END TB Strategy provides a road map of indicators (mortality, incidence, catastrophic costs) from 2020 to 2035, including the 2030 SDG target of 90% reduction in mortality and 80% reduction in incidence. It also lays out four key principles all countries should respect (see table below for details).

Two of the four principles are of particular relevance to TB key populations. First, TB responses should forge strong coalitions and working relationships with communities from key populations such as key population community-based organizations (CBOs) and non-governmental organizations (NGOs) serving key populations. And second, TB programmes must be sensitive to the fact that key populations are often socially disadvantaged and their human rights often violated and that TB responses must respect and address the rights of key populations and ensure the same level and quality of services as that for the general population.

<sup>&</sup>lt;sup>19</sup> WHO (2014) "The End TB Strategy: Global Strategy and Targets for Tuberculosis Prevention, Care and Control After 2015" (<u>http://www.who.int/tb/strategy/End\_TB\_Strategy.pdf</u>)

### Figure 3: WHO END TB Strategy

Vision Goal	A world free of TB – zero deaths, disease and suffering due to TB End the global TB epidemic						
Indicators	2020	2020 2025 2030 (SDG) 2035					
Reduction in number of TB deaths compared with 2015 (%)	35%	75%	90%	95%			
Reduction in TB incidence rate compared with 2015 (%)	20% (<85 per 100,000)	50% (<55 per 100,000)	80% (<20 per 100,000)	90% (<10 per 100,000)			
TB-affected families facing catastrophic costs due to TB (%)	Zero	Zero	Zero	Zero			
Principles	<ol> <li>Strong coalition w</li> <li>Protection and pro</li> </ol>	Strong coalition with civil society organizations and communities Protection and promotion of human rights, ethics and equity					
Pillars		Compo	onents				
1. Integrated, person-centrered care and prevention	of contacts and hig B. <b>Treatment of all pe</b> C. Collaborative TB/HI	<ul> <li>A. Early diagnosis of TB including universal drug-susceptibility testing, and systematic screening of contacts and high-risk groups</li> <li>B. Treatment of all people with TB including drug-resistant TB, and treatment support</li> <li>C. Collaborative TB/HIV activities, and management of co-morbidities</li> </ul>					
2. Bold policies and supportive systems	<ul> <li>A. Political commitment with adequate resources for TB care and prevention</li> <li>Engagement of communities, civil society organizations, and public and private care providers</li> <li>C. Universal health coverage policy, and regulatory frameworks for case notification, vital registration, quality and rational use of medicines, and infection control</li> <li>D. Social protection, poverty alleviation and actions on other determinants of TB</li> </ul>						
3. Intensified research and innovation	<ul><li>A. Discovery, development and rapid uptake of new tools, interventions and strategies</li><li>B. Research to optimize implementation and impact, and promote innovations</li></ul>						

# 1.2 Framework Objectives

This document is a framework for countries (both government TB services and civil society) to identify specific key populations, understand their vulnerabilities to TB and enable them to develop specific interventions to ensure key populations are reached with appropriate services. The framework has the following six primary objectives:

First, to introduce principles critical to the success of TB programmes for key populations, namely multistakeholder, participatory, human rights-based, gender-responsive and evidence-driven.

Second, to introduce an approach for countries to understand and define their own key populations based on TB risks they face, what factors that drive their TB risks, barriers they experience in accessing TB services and challenges TB services in delivering TB services to them - using examples of five possible key populations to illustrate.

Third, to highlight a sample multi-stakeholder process of programme and service planning at national level to prioritize, design and scale up TB programmes for key populations.

Fourth, to illustrate, using five possible key populations, data is currently limited and present methods to conduct rapid assessment and collect actionable and representative data to fill the data gaps needed for programme and service planning for TB key populations at both local and national levels.

Fifth, to highlight the importance of local-level service planning to strengthen public services integration and collaboration between TB services and civil society organizations to maximize programme effectiveness and service quality.

Sixth, to introduce a service cascade and community-based monitoring as programme performance monitoring tools that are particularly useful for key populations.

The chart below provides an example of the cascade of services for all forms of TB for the general population of India in 2013 (National Tuberculosis Control Program, error bars representing 95% confidence intervals).<sup>20</sup> For further discussion on service cascade for key populations, please see Section 9: Tracking Performance.



Figure 4: India National Tuberculosis Programme Cascade of Care 2013

Source: B. Subbaraman, R. Nathavitharana, S. Satyanarayana, M. Pai, B. Thomas, V. Chadha, K. Rade, S. Swaminathan, K. Mayer (2016). "The Tuberculosis Cascade of Care in India's Public Sector: A Systematic Review and Meta-analysis", PLOS Medicine, October 25, 2016 (http://dx.doi.org/10.1371/journal.pmed.1002149)

# 1.3 Target Audience

This framework has been primarily designed for governments and civil society service providers and other stakeholders to take actions against TB among key populations. Other relevant stakeholders include national health coordination bodies and development partners and other implementers that support country efforts to carry out TB services for key populations. These stakeholders at both national and local levels are discussed below.

At the national level, the Ministries of Health (MoH) are critical and must take the lead role in providing stewardship in coordinating the development and the official endorsement of the national strategy for TB key populations. MoH need to ensure that services for key populations are integrated between different

<sup>&</sup>lt;sup>20</sup> B. Subbaraman, R. Nathavitharana, S. Satyanarayana, M. Pai, B. Thomas, V. Chadha, K. Rade, S. Swaminathan, K. Mayer (2016). "The Tuberculosis Cascade of Care in India's Public Sector: A Systematic Review and Meta-analysis", PLOS Medicine, October 25, 2016 (<u>http://dx.doi.org/10.1371/journal.pmed.1002149</u>)

government departments and civil society organizations and the strategy development process is participatory that also involves a broad range of relevant stakeholders outside MoH. From the government, other ministries and councils such as social welfare, justice, law enforcement, drug control, immigration, labour, development, women/children and education are the most relevant. For civil society, national TB and other coalitions such as people living with HIV (PLHIV), TB NGOs, national TB key population coalitions and networks, national civil society organizations delivering TB and/or non-TB services to key populations or advocating services for TB key populations. Inputs from other relevant national coordination bodies such as Global Fund Country Coordinating Mechanisms (CCM), national health coordinating committees, national business coalitions and national professional bodies are also needed. Development partners such as multi-lateral and bi-lateral organizations, which can also provide financial and technical assistance, with expertise in key populations of the country should also be part of the strategy development process.

At the local/district level, district health departments, following the national strategy, must take the lead role in providing stewardship to local TB programmes and services for key populations. During the programme planning phase, they need to ensure local TB key population programmes are coordinated among local government departments (health, social welfare, justice, prisons, police, immigration, labour, development, women/children, education) and with civil society (PWTB support groups, TB NGOs, local key population coalitions, local civil society organizations delivering TB and/or non-TB services to key populations or advocating services for them, local businesses).

### **1.4 Framework Structure**

The diagram shows how the rest of the action framework is organized.



# Figure 5: TB Key Population Action Framework Structure

#### 1.5 Working Definitions for Five TB Key Populations

The Global Plan to END TB identified sub-populations that are more prone to TB either due to more environmental (over-crowdedness, poor ventilation), biological (immunologically suppressed, poor nutrition), or behavioural risks (direct air borne transmission or indirectly through behaviour that increases the risk of non-TB diseases that suppresses immunity), or barriers in accessing public services (systematically excluded from access often due to criminalization, stigma and discrimination) they face. Many of these key populations overlap (e.g., a person who uses drugs in detention who is also living with HIV, miners who migrated from another country, women trafficked from another country) have multiple risks making delivering TB and other health services to them very challenging.

- Migrants, Refugees, Internally Displaced People, Nomadic Populations, Miners, Prisoners, Detainees
- People Who Use Drugs, People with Alcohol Dependency, Smokers, Sex Workers
- Lesbian, Gay, Bi-sexual, Transgender People
- Indigenous Populations, Homeless, People with Mental or Physical Disabilities, Urban Poor, Rural Poor
- People Living with HIV, People with Silicosis, People with Diabetes, Children, Elderly
- Hospital Workers, Prison Workers, Refugee Camp Workers, Community Health/Outreach Workers
- Hospital Visitors, Prison Visitors, Peri-prison Communities, Peri-mining Communities, Sex Worker Clients, Families of People Who Use Drugs
- People at risk of zoonotic TB<sup>21</sup>

The above is not an exhaustive list but a starting point for a country to go through the full list to identify which sub-groups within its population may be more prone to TB and assess how some apparently non-TB related issues might impact the country's TB response among its key populations (more details in Section 4: Prioritizing and Planning TB Programmes for Key Populations). Although each of these populations is important, this framework presents five TB specific key populations (Mobile populations, Miners, Prisoners and Detainees, People who use Drugs and People living with HIV) for illustrative purpose (see Section 3: Understanding and Defining Key Populations for an approach countries can use to define their key populations). For the purpose of this document, the working definitions for these five populations are:

#### **Mobile Populations**

Mobile Populations as a TB key population include migrants, refugees and internally displaced persons who have moved across an international border or within the national border away from their habitual place of residence who are often faced with malnutrition, overcrowded living conditions and have limited access to health and social services at different phases of migration: at origin, during transit, at destination and upon return.<sup>22</sup>

<sup>&</sup>lt;sup>21</sup> People living in areas where Mycobacterium bovis causes TB in bovines and other domestic and wild species and in which sociocultural practices favor the transmission of M. bovis either by direct contact with infected animals or by indirect contact via contaminated food products (e.g. milk, fresh cheeses, contaminated meat). Cattle-herders, dairy workers, farmers, veterinarians, slaughter house workers and those who consume unpasteurized milk and untreated animal products are at higher risk of contracting zoonotic TB.

Muller B, Dürr S, Alonso S., et al. (2013) "Zoonotic Mycobacterium Bovis-induced Tuberculosis in Humans." Emerging Infectious Diseases 2013;19:899–908. doi:10.3201/eid1906.120543.

Cosivi O, Grange JM, Daborn CJ, et al. (1998) "Zoonotic Tuberculosis Due to Mycobacterium Bovis in Developing Countries." Emerging Infectious Diseases 1998;4:59–70.

Olea-Popelka, F. J., Muwonge, A., Perera, A., Dean, A. S., Mumford, E., Erlacher-Vindel, E., Forcella, S., Silk, B. J., Ditiu, L., El Idrissi, A., Raviglione, M., Cosivi, O., LoBue, P., Fujiwara, P. I. (2016). "Zoonotic Tuberculosis in Human Beings Caused by Mycobacterium Vovis - A Call for Action". The Lancet Infectious Diseases. doi: 10.1016/S1473-3099(16)30139-6

WHO (2007) "Tuberculosis Care and Control in Refugees and Displaced Populations: An Inter-agency Manual" (http://apps.who.int/iris/bitstream/10665/43661/1/9789241595421\_eng.pdf)

### Miners

Miners as a TB key population include individuals involved in either industrial or artisanal mining and quarrying with limited access to health and social services, and exposed to silica dust or confined to poorly ventilated environments.<sup>23</sup>

## **Prisoners and Detainees**

Prisoners as a TB key population include individuals in any places of detention (prisons for convicted individuals as well as detention centres for prosecuted individuals waiting for trials or illegal immigrants), which are overcrowded, poorly ventilated or lacking in the provision of medical care and adequate nutrition.<sup>24</sup>

### People who Use Drugs (PWUD)

PWUD as a TB key population include people who inject drugs (excluding alcohol) and those do not inject but share drugs or drug equipment with others, inhale and exhale smoke directly from and into another person's mouth (shot-gunning), and live or take drugs with others in cramped conditions with poor ventilation.<sup>25</sup>

(Examples of sharing drug equipment include smoking marijuana from the same water pipe or smoking crack cocaine from the same glass pipe.)

#### People Living with HIV (PLHIV)

PLHIV as a TB key population include individuals who have been diagnosed as having been infected with the human immunodeficiency virus (HIV), regardless of whether the infection has progressed to acquired immune deficiency syndrome (AIDS) or being on antiretroviral treatment (ART) or not. PLHIV also have increased risk of extra-pulmonary TB which is difficult to diagnose.<sup>26</sup>

<sup>&</sup>lt;sup>23</sup> WHO (2017) "Tuberculosis Among Miners, Families and Communities in Myanmar"

<sup>(</sup>http://www.searo.who.int/myanmar/areas/tb\_amongcommunities/en/), accessed on 17 Jan 2017.

Global Fund (2016) "Grant to Fight TB in Southern Africa's Mining Sector" (<u>http://www.theglobalfund.org/en/news/2016-02-05\_Grant\_to\_Fight\_TB\_in\_Southern\_Africa\_s\_Mining\_Sector/</u>), accessed on 17 Jan 2017

<sup>&</sup>lt;sup>24</sup> WHO (2017): "Tuberculosis in Prisons" (<u>http://www.who.int/tb/areas-of-work/population-groups/prisons-facts/en/</u>), accessed 17 Jan 2017

WHO (2014): "Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations"

<sup>&</sup>lt;sup>25</sup> Haileyesus Getahun, Annabel Baddeley and Mario Raviglione (2013) "Managing Tuberculosis in People Who Use and Inject Illicit Drugs" Bulletin of the World Health Organization. 91:154-156 (http://www.who.int/bulletin/volumes/91/2/13-117267/en/)

Robert G. Deiss, Timothy C. Rodwell, and Richard S. Garfein (2009) "Tuberculosis and Illicit Drug Use: Review and Update" Clinical Infectious Diseases 48 (1): 72-82.

<sup>&</sup>lt;sup>26</sup> WHO (2017) "TB and HIV" (http://www.who.int/tb/areas-of-work/tb-hiv/en/), accessed 17 Jan 2017.

# 2. Overarching Principles

This section highlights key principles critical to the success of delivering TB services to key populations – multi-stakeholder participatory, human rights-based, gender-responsive and evidence-driven. All TB stakeholders need to understand, promote and protect human rights in planning and implementing programmes and services for key populations. Key populations are often socially marginalized and criminalized. TB services must be free of stigma and discrimination and have measures in place to minimize legal barriers key populations face in accessing TB and related health services. TB services also need to be responsive of the needs of different genders.

# 2.1 Multi-stakeholder and Participatory

The fourth principle of the WHO END TB Strategy (adaptation of strategy) calls for national TB programmes to strengthen their services through a person-centred approach.<sup>27</sup> In particular, national TB programmes need to engage and coordinate closely with other public health programmes, social support programmes, public and private health care providers, nongovernmental and civil society organizations, communities and other support associations in order to help ensure provision of high-quality, integrated, person-centred TB care and prevention across the health system.

The fact that many key populations are often socially marginalized and stigmatized makes it more difficult for traditional TB services to reach them. Traditional TB services' passive case finding approach usually depends on individuals presenting themselves when they have active TB, while self-presentation is likely to be insufficient for detecting enough cases in order to reduce the epidemic.<sup>28</sup> And key populations, faced with double stigmatization (being socially marginalized and the potential of having TB) are less likely than the general population to present themselves to TB services or present themselves at advanced staged when they are often quite sick. To combat this, TB services need to mobilize and work with key population communities at both national and local levels to pro-actively screen, prevent (both latent infection and progression from latent to active TB) and treat TB among key populations.

At the national level, national TB programmes should consult and ensure key populations are meaningfully engaged<sup>29</sup> in survey planning and design, data collection and data use including programme design and planning processes, such as identifying key populations, quantifying key population size, and identifying rights-based and gender responsive TB services key populations need. National TB programmes also need to ensure there are national endorsements usually in the form of TB National Strategic Plans to acknowledge service access barriers key populations are faced with and to recognize key populations' current and potential contributions requiring all local TB services work with local civil society (key population communities and/or NGOs serving key populations) to integrate their services with the public TB services. Civil society organizations involved must be treated as equal partners for them to contribute freely both their knowledge of and practical experience working with the community. Ensuring community is meaningfully engaged is critical to removing barriers key populations face in accessing services and minimizing loss to follow up by public TB services.<sup>30</sup>

<sup>27</sup> WHO (2015) "The END TB Strategy", p.7-8

<sup>&</sup>lt;sup>28</sup> A. Shapiro, R. Chakravorty, T. Akande, K. Lonnroth, J. E. Golub. (2013). "A Systematic Review of the Number Needed to Screen to Detect a Case of Active Tuberculosis in Different Risk Groups."

<sup>(</sup>http://www.who.int/tb/Review3NNS\_case\_active\_TB\_riskgroups.pdf)

<sup>&</sup>lt;sup>29</sup> Stop TB Partnership (2014) "Meaningful Participation of TB Communities in National Planning"

<sup>(</sup>http://www.stoptb.org/assets/documents/global/fund/MEANINGFUL%20PARTICIPATION%20OF%20TB%20COMMUNITIES%2 0IN%20NATIONAL%20PLANNING.pdf)

Global Fund (2016) "Achieving Inclusiveness of Country Coordinating Mechanism"

<sup>(</sup>https://www.theglobalfund.org/media/1269/publication\_keypopulations\_casestudy\_en.pdf)

<sup>&</sup>lt;sup>30</sup> A key outcome of the local-level service planning is collaboration standard operating procedures (SOP). An SOP is usually a simple (2-3 pages) flow chart that schematically describes the collaboration that aims at removing service gaps between different service providers (health, social to criminal justice). An integral part of the flow chart are community-based organizations (CBOs) from the key populations or non-government organizations (NGOs) serving these key populations, which complement the public services by first outreaching key populations that government health services usually find hard to reach, then building these key populations' confidence in government services. Such confidence is built by initial counseling and information provision, then

Local TB services should also consult CBOs and/or NGOs serving key populations to conduct surveys and estimate the population sizes of TB key populations. Information from CBOs and NGOs and surveys conducted among key populations should assess whether and how key populations access government and non-government services or what deters them from doing so (see Sections 4 and 8, respectively, for more discussion on TB key population programme and service planning at both national and local/district levels).

# 2.2 Human Rights-based

Human rights violations and the failure to fulfill human rights obligations increase individuals' vulnerability to contracting TB and reduce access to diagnostic, prevention and treatment services.<sup>31</sup> People affected by TB usually suffer a double burden: the impact of the disease as well as the consequential loss of other rights.<sup>32</sup> For key populations, due to additional stigmatization, discussed in Section 2.1, the burden is in fact triple.

A rights-based approach to TB is founded on respect for the dignity and autonomy of people affected by TB. It articulates and protects individual freedoms and entitlements, and is built on governments' obligations to respect, protect and fulfill the right to health. The approach focuses on the underlying determinants of TB through the lens of social, economic and cultural rights.

A human rights-based approach to TB also has components related specifically to the collection and use of data on TB key populations. Most importantly, the rights to privacy and confidentiality of all members of key populations must be explicitly acknowledged and protected during the collection and use of data. This is required under human rights law and necessary to ensure effective and sustainable interventions. In addition, countries must involve key populations in the design, implementation and evaluation of data collection and use efforts. In particular, the UN Committee on Economic, Social and Cultural Rights has established that, pursuant to the international right to health, countries must:<sup>33</sup>

- Adopt and implement a national public health strategy and plan of action on the basis of epidemiological evidence with particular attention to vulnerable or marginalized groups (CESCR, General Comment No. 14, para. 43(f));
- Ensure the participation of members of key populations in the design, implementation, evaluation and eventual use of all data collected, in line with States' obligations under the right to health (CESCR, General Comment No. 14, paras. 11, 17, 43(f), 54); and
- Use and improve epidemiological surveillance and data collection on a disaggregated basis (CESCR, General Comment No. 14, para. 16).

followed by accompanying key populations to various government testing and treatment services to minimize loss to follow up. See Section 8: Service Planning at City/District Level for further details.

 <sup>&</sup>lt;sup>31</sup> Global Fund to Fights AIDS, Tuberculosis and Malaria, Global Fund Information Note: TB and Human Rights, 2011.
 <sup>32</sup> FXB Center for Health and Human Rights and Open Society Foundations (2013) "Health and Human Rights Resource Guide."
 Fifth Edition (https://cdn2.sph.harvard.edu/wp-content/uploads/sites/25/2014/03/HHRRG-master.pdf)

<sup>&</sup>lt;sup>33</sup> CESCR (2000) Committee on Economic, Social and Cultural Rights 22<sup>nd</sup> Session (http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmIBEDzFEovLCuW1AVC1NkPsgUedPIF1vfPMJ2c7ey6PA z2qaojTzDJmC0y%2b9t%2bsAtGDNzdEqA6SuP2r0w%2f6sVBGTpvTSCbiOr4XVFTqhQY65auTFbQRPWNDxL)

The figure below lists the freedoms and protections, entitlements and obligations found in international and regional treaties and national constitutions.

Individual freedoms and protections:	Individual entitlements:	Government obligations:
<ul> <li>Right to non-discrimination</li> <li>Right to privacy and confidentiality, including testing and participation in TB data collection and use of data</li> <li>Right to informed consent, including testing and participation in TB data collection and use of data</li> <li>Right to body integrity</li> <li>Right to liberty and security of the person</li> <li>Freedom from torture or inhuman or degrading treatment or punishment</li> <li>Freedom of movement</li> </ul>	<ul> <li>Right to life</li> <li>Right to health, including access to health services and essential drugs</li> <li>Right to participation</li> <li>Right to information</li> <li>Right to enjoy the benefits of scientific progress and its applications</li> <li>Right to social and economic determinants of health (food, housing, sanitation, water)</li> <li>Right to education</li> </ul>	<ul> <li>Respect individual freedoms and protections (privacy, confidentiality, informed consent)</li> <li>Fulfill individual entitlements</li> <li>Protect against violations by non-state actors, including health care providers and drug manufacturers</li> <li>Ensure adequate, equitable and sustainable financing for health</li> </ul>

Figure 6: Individual Freedoms, Entitlements and Government Obligations

### Human Rights and Unequal Access to TB Care and Treatment

It is often especially difficult for some key populations to mobilize and demand realization of their rights.<sup>34</sup> For example, migrants face challenges accessing health care in host countries and, in some settings, may face deportation if diagnosed with TB. Miners with TB have the threat of layoffs based on their health status and they face challenges accessing continuous TB treatment and care. Prisoners often experience increased risks of contracting TB due to poor prison conditions and many lack access to good quality services while in detention. Upon release from prison, former prisoners face complications seeking health care and adhering to treatment, as well as stigma and discrimination in their communities. In many countries criminalization of PWUD contribute to long delays in diagnosis and lack of case management, leading to treatment disruptions. PLHIV often have access to community support, but the lack of integration of TB and HIV services continues to be a major challenge in the areas of service delivery, human resources and supply of medicines and products.<sup>35</sup> More details about the challenges facing key populations and the potential rights-based solutions can be found in Section 3.

### Criminalization of TB Status: Involuntary Treatment, Isolation, Detention and Incarceration

People, affected by TB, can be subjected to arbitrary and harmful measures such as involuntary treatment, detention, isolation and incarceration.<sup>36</sup>

According to WHO: "Involuntary isolation, except in narrowly defined circumstances (see below for exceptional circumstances and specific conditions that must be met), is unethical and infringes an individual's rights to liberty of movement, freedom of association, and to be free from arbitrary detention. It is unethical to isolate persons with TB if the person is not contagious or if isolation holds no clear public health benefit to the community.<sup>37</sup>

<sup>&</sup>lt;sup>34</sup> B. Citro, E. Lyon, M. Mankad, K. R.Pandey, C. Gianella (2016) "Editorial: Developing a Human Rights-Based Approach to Tuberculosis" Health and Human Rights Journal, June 21, 2016, Volume 18 Number 1.

<sup>&</sup>lt;sup>35</sup> H. Legido-Quigley, C.M. Montgomery, P. Khan, R. Atun, A. Fakoya, H. Getahun, A.D. Gran. (2013) "Integrating Tuberculosis and HIV Services in Low- and Middle-income Countries: A Systematic Review." Tropical Medicine and International Health, volume 18(2): 199–211.

<sup>&</sup>lt;sup>36</sup> FXB Center for Health and Human Rights and Open Society Foundations (2013). "Health and Human Rights Resource Guide." Fifth Edition.

<sup>&</sup>lt;sup>37</sup> WHO (2017) "Ethics Guidance for the Implementation of the End TB Strategy". Ch. 15 (http://apps.who.int/iris/bitstream/10665/254820/1/9789241512114-eng.pdf?ua=1)

WHO further specifies exceptional circumstances when involuntary isolation can be considered as the last resort for an individual who is:

- Known to be contagious, refuses effective treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful; *OR*
- Known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home, and refuses care at medical facilities; *OR*
- Highly likely to be contagious (based on laboratory evidence) but refuses to undergo assessment of his/her infectious status, while every effort is made to work with the person with TB to establish a treatment plan that meets his needs.

And ALL of the following nine conditions must be met in order to justify any involuntary isolation:

- 1. Isolation is necessary to prevent the spread of TB; AND
- 2. Evidence that isolation is likely to be effective in this case; AND
- 3. Person with TB refuses to remain in isolation despite being adequately informed of the risks, the meaning of being isolated and the reasons for isolation; *AND*
- 4. A person with TB's refusal puts others at risk; AND
- 5. All less restrictive measures have been attempted prior to forcing isolation; AND
- 6. All other rights and freedoms (such as basic civil liberties) besides that of movement are protected; *AND*
- 7. Due process and all relevant appeal mechanisms are in place; AND
- 8. Person with TB has, at least, basic needs met; AND
- 9. The isolation time given is the minimum necessary to achieve its goals.

In some of the Former Soviet Union countries there are laws prescribing involuntary anti-TB treatment in case an individual with smear-positive results refuses to be treated voluntarily. Recent litigation cases in Kenya<sup>38</sup> challenging imprisonment of PWTB and a literature search by Mburu et al.<sup>39</sup> on the application of public health laws to enforce treatment adherence highlight the need for human rights-based legislation and policies for involuntary isolation. These include strengthening health systems to eliminate use of prisons as isolation spaces, decentralizing TB treatment to communities, enhancing treatment education through involvement of key populations, revising the public health laws, and addressing socioeconomic and structural determinants associated with TB incidence and loss to follow-up."

# **Other Examples of Human Rights Violations**

The table below shows some other examples of human rights violations that TB key populations might face.<sup>40</sup>

<sup>&</sup>lt;sup>38</sup> A. Maleche and N. Were. (2016) "Petition 329: A Legal Challenge to the Involuntary Confinement of TB Patients in Kenyan Prisons." Health and Human Rights Journal, Volume 18 Number 1.

<sup>&</sup>lt;sup>39</sup> G. Mburu, E. Restoy, E. Kibuchi, P. Holland, A. D. Harries. (2016) "Detention of People Lost to Follow-Up on TB Treatment in Kenya: The Need for Human Rights-Based Alternatives." Health and Human Rights Journal, 18(1):43-54

<sup>&</sup>lt;sup>40</sup> Stop TB Partnership (2017) "Legal Environment Assessment for Tuberculosis: An Operational Guide" (forthcoming)

# Figure 7: Examples of Human Rights Violations

Rights	Examples of Violations
Right to life	<ul> <li>Imprisoned or otherwise institutionalized individuals face a disproportionate risk of TB infection, disease and death</li> <li>Health workers face prolonged exposure to TB, risk MDR and XDR TB and death</li> </ul>
	<ul> <li>People who use drugs, prisoners, other marginalized communities may be denied life-saving TB treatment and face death</li> </ul>
Right to the highest	Persons with TB are denied access to quality TB treatment and care in prison
attainable standard of	Persons with MDR-TB are denied tailored therapies of second-line drugs
physical and mental health	<ul> <li>Government's failing to utilize donor resources to construct isolation wards</li> <li>People with TB who belong to additionally marginalized groups are discriminated against in TB</li> </ul>
nearm	care- given subpar treatment or denied care
Right to enjoy the	Persons with TB in resource-constrained settings may have limited access to high-quality
benefits of scientific	diagnostic services and first- and second-line medicines for treatment
progress and its	Poor communities are tested with faulty antiquated tests and consequently over-diagnosed and
applications	over-treated.
Right to non-	<ul> <li>Restrictive intellectual property regimes limit access to quality, affordable anti-TB medicines</li> <li>Persons with TB are refused medical treatment or given a lower standard of care</li> </ul>
discrimination and	<ul> <li>Persons with TB are denied and fired from jobs based on their TB status or TB history</li> </ul>
equality	
Right to privacy	Information about a person's TB status is disclosed through provider breach of confidentiality,
	flawed contact investigations, of poor data protections in surveillance systems
	An individual's migrant, HIV, drug use, or other status is disclosed in TB diagnostic setting
Right to be free from	Institutional settings are overcrowded or poorly ventilated, making it more likely for individuals to
torture or cruel,	contract TB. • Prisoners are not screened or tested for TB and cannot access medical treatment and care for a
inhuman or degrading treatment or	TB diagnosis.
punishment	Other medicines, such as substitution treatment, are not provided to people with TB who also
punionnent	use drugs in institutional settings • People with TB who are detained are often kept in conditions that may lack access to basic
	medical services
	Placing individuals who are arbitrarily arrested in such conditions could constitute cruel, inhuman or degrading treatment
Right to informed	People with TB are involuntarily tested for HIV
consent	<ul> <li>Unapproved medication regimens are used to treat people with TB without informing them</li> <li>People with TB are involuntarily summoned for treatment</li> </ul>
Right to freedom of	• Person with TB under quarantine or isolation or in detention are unable to freely move or reside in
movement	a country, or to leave and return <ul> <li>People exercising freedom of movement for work are denied TB services because they lack</li> </ul>
	identity documents <ul> <li>In some settings, people with TB may only receive free treatment in their home districts, but not</li> </ul>
	where they live
Right to information	People who are illiterate may have less knowledge of TB and its signs and symptoms
-	Health care workers fail to adequately explain to persons with TB why adherence to TB medicine     is important
Right to freedom from	Persons diagnosed with TB, who have been declared to be noncompliant with TB treatment, are
arbitrary arrest and	arrested
detention	<ul> <li>Persons arrested for noncompliance with TB treatment are not provided with treatment while in detention or detained in environments that are non-medical settings (prisons, holding cells, etc.)</li> </ul>
Right to a fair trial/due process	<ul> <li>Individuals with TB are detained without adequate justification that it is the least restrictive alternative, strictly necessary or a measure of last resort</li> </ul>
Right to participation	People with TB and those who had TB have limited opportunity to have a say in designing
- ·	programmes that aim to support them
	Communities of people with TB are not seen as partners in the fight against TB; peer-to-peer
Disht to associate from	approaches are not common in TB care programmes
Right to access of an	<ul> <li>People with TB, especially those from most marginalized communities, may not be able to afford legal aid to seek remedy for their violated rights</li> </ul>
adequate, effective, and	

### Human Rights-based TB Programming and Interventions

The human rights-based approach to TB programming can be broken down into the following elements, each with respective benefits:

Element	Benefit
Privacy, confidentiality and informed consent	Safeguarding the privacy, confidentiality and informed consent of people with TB.
Participation	Meaningful engagement of the key populations and other stakeholders increases commitment, ownership and agency, and also contributes to the development and strengthening of the local community systems.
Accountability	Emphasis on the rights and well as the responsibilities of all involved, including the persons affected by TB, fosters transparency. This includes creating and sustaining the mechanisms for ensuring the implementation of rights, monitoring and protection against rights violations.
Non-discrimination	Ensuring equal access and conditions to all and providing additional support to those in disadvantaged situation reduces the vulnerability of key populations.
Empowerment	Strengthening of key populations and the other stakeholders' knowledge, skills, attitudes and practices builds their autonomy and capacity to protect own rights and interests in a self-determined and responsible way.
Linkage to rights	Promoting realization of human rights by linking to international and regional legal frameworks that recognize and protect individual freedoms and entitlements and outline the government's obligations ensures equal access to health for all. Also eliminating financial and physical barriers to treatment and care.
Sustainability	Fostering the political will, local ownership and partnerships helps achieve long-lasting results and profound changes in reducing and eliminating disparities.

Figure 8: Human rights-based Approach to TB Programming

Based on chapter 3, p. 358 of FXB Center for Health and Human Rights, Human Rights Resource Guide 5<sup>th</sup> Edition (<u>https://cdn2.sph.harvard.edu/wp-content/uploads/sites/25/2014/03/HHRRG-master.pdf</u>) and Open Society Foundations and the Stop TB Partnership Communities' Human Rights and Gender article (<u>http://www.stoptb.org/communities/</u>)

The human rights-based TB interventions include, but are not limited to: <sup>41</sup>

- Training for key populations to increase awareness about TB and human rights
- Other capacity building activities for key populations in the area of TB and human rights
- Documentation of human rights violations
- Development of community-based monitoring of human rights in TB
- Routine negotiation, mitigation or formal complaints to challenge actions or inaction of the authorities, state or non-state providers
- Strategic litigation to bring about changes in policy and legal frameworks
- Developing strategic partnerships with attorneys, legal clinics, human rights NGOs and academia
- Training lawyers on TB and human rights
- Mass media campaigns

<sup>&</sup>lt;sup>41</sup> UNDP (2014) "Know Your Rights, Use Your Laws. Handbook for Legal Empowerment of People who Live with or Are at Risk of HIV, Their Close Ones, and Service Providers." (<u>http://www.eurasia.undp.org/content/rbec/en/home/library/hiv\_aids/know-your-rights--use-your-laws.html</u>)

#### 2.3 Gender-responsive

While men in low- and middle-income countries in general have higher TB prevalence than women,<sup>42</sup> TB was one of the top three causes of death among the women of reproductive age.<sup>43</sup> In some settings women experience greater barriers in accessing TB services than men.<sup>44</sup> In addition, TB among women may be more difficult to screen and diagnose.<sup>45</sup> Hence a gender-responsive approach to TB means paying attention to the challenges and needs of men, women and transgender. For example, working men are not able to access TB services during office hours, women may have challenges putting their children in day-care for a few hours in order to attend a DOTS clinic or transgendered persons being stigmatized by clinic staff. Some other examples of men and women specific risks are in the figure below.

Men	Women
<ul> <li>More social contacts/more exposure.</li> <li>High TB risk occupations and living conditions.</li> <li>Limited or delayed health seeking behaviour due to cultural specifics or work obligations (current health system is not pro-active enough to reaching out to men).</li> <li>Smoking and alcohol consumption.</li> <li>Primary income earner, pressure to return to work.</li> </ul>	<ul> <li>Lower educational level, less likely to recognize TB symptoms.</li> <li>Indoor food preparation, using biomass fuel, as a risk due to indoor air pollution.</li> <li>Intra-household de-prioritization of women's health care.</li> <li>Greater financial barriers to start treatment due to a lack of income.</li> </ul>

### Figure 9: Examples of Gender-specific TB Risks

An assessment tool is available to assist countries to assess their HIV and TB epidemic context and response from a gender perspective, helping them to make their responses gender sensitive and reduce the dual burden of HIV and TB.<sup>46</sup>

### 2.4 Evidence-driven

### The Evidence for Addressing Key Populations

"Evidence-driven" refers to an approach derived from or informed by objective research, body of facts or information, integrated with the values of the affected populations. Ninety-five percent of the 10 million people who develop active TB disease yearly are in developing countries. Poverty and HIV co-infection fuel active TB while crowded and poorly ventilated living spaces and work places contribute to an increased susceptibility to TB.<sup>47</sup> Without scaled-up evidence-based programmes for those most marginalized and vulnerable, it will neither be possible to meet the United Nations Sustainable Development Goals (SDG) nor the goals set out in the Stop TB Partnership Strategy 2016- 2020.<sup>48</sup>

(http://c1280432.cdn.cloudfiles.rackspacecloud.com/Women\_Tuberculosis.pdf)

<sup>46</sup> Stop TB Partnership & UNAIDS (2016) "Gender Assessment Tool for National HIV and TB Responses"

<sup>48</sup> Global Fund Advocates Network (2016) "Key Populations and the Global Fund: Delivering Key Results"

<sup>&</sup>lt;sup>42</sup> Horton KC, MacPherson P, Houben RMGJ, White RG, Corbett EL (2016) "Sex Differences in Tuberculosis Burden and Notifications in Low- and Middle-Income Countries: A Systematic Review and Meta-analysis", PLoS Med 13(9): e1002119. doi:10.1371/journal.pmed.1002119

<sup>&</sup>lt;sup>43</sup> WHO (2015) "TB in Women" (http://www.who.int/tb/publications/tb\_women\_factsheet\_251013.pdf)

<sup>&</sup>lt;sup>44</sup> Wei-Teng Yang, Celine R. Gounder, Tokunbo Akande, et al. (2014) "Barriers and Delays in Tuberculosis Diagnosis and Treatment Services: Does Gender Matter?" Tuberculosis Research and Treatment, vol. 2014, Article ID 461935. doi:10.1155/2014/461935

<sup>&</sup>lt;sup>45</sup> ACTION (2010) "Women and Tuberculosis: Taking a Look at a Neglected Issue"

<sup>(</sup>http://www.stoptb.org/assets/documents/resources/publications/acsm/Gender\_Assessment\_Tool\_TB\_HIV\_UNAIDS\_FINAL\_2016 %20ENG.pdf)

<sup>&</sup>lt;sup>47</sup> The Global Fund (2014) "Key Populations Action Plan 2014-2017"

<sup>(</sup>https://www.theglobalfund.org/media/1270/publication\_keypopulations\_actionplan\_en.pdf)

<sup>(</sup>http://www.globalfundadvocatesnetwork.org/wp-content/uploads/2016/07/GFAN-Key-Populations-the-Global-Fund-full-report-JUN2016.pdf)

Social, biological and economic determinants, which differ among countries and regions, may be better than traditional TB control programme indicators like the success of DOTS in understanding the dynamics of TB incidence.<sup>49</sup> Similarly, there is emerging evidence of social protection – addressing income disparities and social vulnerability – and livelihood strengthening interventions in support of treatment adherence yield better treatment outcomes.<sup>50,51</sup> Key population and PWTB organizations and communities are best positioned to help address these determinants that prevail among key populations, using community-based and peer-led education and services.<sup>52</sup> Scaling up of these approaches is recommended by the WHO, Stop TB Partnership and UN agencies.

# **Collecting Better Data from Existing and Other Data Sources** ("going beyond the health sector for data")

There is an obvious lack of surveillance and effective monitoring of TB prevalence and behavioural risks in key populations (e.g., using drugs in crowded or poorly ventilated space), which is a major hindrance to TB response. Intervention-based research and routine data collection using robust sampling methods is essential in measuring progress. Data from the general populations should be disaggregated by gender, age and key population groups and data from specific key populations should be disaggregated by gender and age, while ensuring personal safety and confidentiality of key populations throughout the process from data collection, analysis to reporting.

Data disaggregation allows for a more granular understanding of the data collected, increased engagement of sub-populations (gender, age groups and key populations) in TB response, identification of access and services gaps and the development of people-centred solutions. The first step for countries to start collecting key population-specific data is defining and prioritizing the key populations most affected by TB. The next step is to develop the most important indicators needed to understand their level of risk and needs. Definitions of key populations and measurement indicators should to be harmonized for inter- and cross-country comparison.

When key population data are not available from surveillance, TB national strategic plans and investment cases, it is advisable to go beyond the health sector. More information regarding data limitations of the above key populations is in Section 5: Limited Data Available.

<sup>&</sup>lt;sup>49</sup> Dye C, Lönnroth K, Jaramillo E, Williams BG, Raviglione M (2009) "Trends in Tuberculosis Incidence and their Determinants in 134 Countries." Bulletin World Health Organization 87(9):683-91.

<sup>&</sup>lt;sup>50</sup> The Stop TB Partnership (2015) "The Paradigm Shift - the Global Plan to End TB, 2016-2020"

<sup>&</sup>lt;sup>51</sup> Hargreaves JR, Boccia D, Evans CA. (2011) "The Social Determinants of Tuberculosis: From Evidence to Action." American Journal of Public Health 101(4): 654–662

<sup>&</sup>lt;sup>52</sup> Global Forum on MSM and HIV (2013) "Community Systems Strengthening and Key Populations: A Policy Discussion Paper" (<u>http://msmgf.org/wp-content/uploads/2015/09/CSS\_and\_Key\_Populations\_3oct2013.pdf</u>)

# 3. Understanding and Defining Key Populations

This section shows how each of the five illustrative TB key populations could be understood from their perspectives. Countries can then use similar approach to define their own key populations.

The first step of this approach is to understand situations facing these key populations - what TB risks key populations face, factors that drive these risks, and challenges in providing services to a key population. Then some potential responses to address these challenges are presented for countries to consider.

Contents included in each of the five possible key populations discussed below are based on experiences across the world. Every country's circumstance and context is different.

Hence, countries are encouraged to engage key populations to first think about these issues systematically (risks, risk drivers, service challenges, template available in Annex A1) and see TB from the perspectives of key populations (see Annexes A2.1-A2.5 for illustrative examples) before designing responses for key populations (template available in Annex A3). This information would also inform the design of the rapid assessment (see Section 6) and the questionnaire for the survey used in the sampling method to estimate population size, disease burden, risks and service access barriers (Section 7).

### 3.1 Mobile Populations<sup>53</sup>

TB Risks			<b>TB Risk Drivers</b>		
Environment (Over-crowded, poor ventilation)	<b>Biology</b> (Reduced immunity)	<b>Behaviour</b> (Prone to transmission)	Limited Access to Services (Health, social and economic)	Legal & Economic (criminalization, poverty) Human Rights & Gender (stigma, discrimination)	TB Case Finding and Treatment Service Challenges
Living spaces of migrants can be over-crowded. Working conditions can also be substandard with overcrowding and poor ventilation.	Health profile of a migrant depends on the characteristics of the migration process. For example, the immune status especially of the refugees and forced migrants can be weakened due to stress and malnutrition.	nil	Lack of legal status in transit and at destination. Language barriers. Lack of knowledge of the local health services and entitlements to such. Out-of-pocket payments for health services.	<ul> <li>Cultural beliefs.</li> <li>Fear related to stigma.</li> <li>Poverty, or small amounts to spend on health in proportion to limited incomes.</li> <li>Police harassment, fear or deportation can impact health-seeking behaviour.</li> </ul>	<ul> <li>Legal status at destination.</li> <li>Discriminatory policies.</li> <li>Insecure working arrangements.</li> <li>Availability of health services.</li> <li>Continuity of care.</li> <li>Attitudes of health care workers.</li> <li>Language and cultural barriers in health care settings.</li> <li>Poverty and stigma.</li> </ul>

#### **Potential Responses**

- Mobile health services.
- Health passports to ensure continuity: at origin, during transit, at destination, upon return.
- Advocacy and increased awareness about rights.
- Measuring and analysing TB burden among migrants.
- Using conditional cash transfers and financial incentives for health-seeking behaviour.
- Screening migrants (focus on those at higher risk of TB) as preparation for resettlement and immigration while safeguarding rights of migrants that TB status should not be used as basis for migration or settlement decisions.
- Providing a comprehensive range of TB-related services, including physical examination, radiological investigation, the tuberculin skin test, sputum smear and culture, drug susceptibility testing (DST) and directly observed treatment-short-course (DOTS), in line with partner government protocols.
- Offering linguistically and culturally appropriate services.
- Cross-jurisdictional referral/information transfer systems should be included.

<sup>53</sup> IOM, presentation "TB Determinants and Findings" <u>http://health.iom.int/determinants-and-findings</u> (accessed 15 Aug 2016) Stop TB Partnership (2016), "Key Populations Brief - Migrants"

IOM (2016) "Migration Health Annual Review 2014" (https://publications.iom.int/system/files/mhd\_ar\_2014.pdf) IOM (2017) "Migration Health Annual Review 2015" (https://publications.iom.int/system/files/mhd\_ar\_2015.pdf)

### 3.2 Miners<sup>54</sup>

TB Risks			TB Risk Drivers	TB Case Finding	
Environment (Over-crowded, poor ventilation)	<b>Biology</b> (Reduced immunity)	<b>Behaviour</b> (Prone to transmission)	Limited Access to Services (Health, social and economic)	Legal & Economic (criminalization, poverty) Human Rights & Gender (stigma, discrimination)	and Treatment Service Challenges
Occupational (silica) dust exposure, overcrowding, poor or lack of ventilation in living and working spaces (house built without ventilation). Lack of access to effective respiratory protection.	Silicosis, asbestos related disease, black lung disease, and Pneumoconiosis. HIV, plus the atypical TB manifestations in PLHIV can be difficult to diagnose.	Failure to use respiratory protection. Delayed health seeking due to fear of dismissal.	Lack of (continuity of) care in and near mining sites. Lack of (continuity of) care during migration and in remote or rural areas of permanent residence. Poor cross border referrals without full medical records.	<ul> <li>Cross-border migrant miners without legal residency of receiving countries often have trouble accessing public services, including health, in host countries.</li> <li>Low income (driven by business profits) limits access to often-private medical services.</li> <li>Barriers to compensation during sickness.</li> </ul>	<ul> <li>Unavailability of TB services at or near mining sites.</li> <li>Treatment and follow-up interruption related to migration.</li> <li>Challenges are exacerbated in artisanal and small-scale miners.</li> </ul>

#### **Potential Responses**

Community-based case finding and treatment adherence.

• Ensure legislative protections of the rights to work.

• Support and ensure legislative protections and adherence to occupational health and safety standards (control and monitoring of dust, gases, radiation in particular).

• Cross-border referrals (both medical and community) to ensure miners returning to their countries of origin are given proper medical records prior to departure (e.g., health passports) to facilitate continuum of care of TB and other health conditions to be provided by both medical professionals (TB treatment) and civil society (community treatment adherence and psychosocial support).

• Regional and national-level campaigns to work with mining companies to improve workplace safety and living conditions to prevent TB and other lung diseases among miners (e.g., controls and monitoring of the exposures to dusts, gases, radiation and other impurities in both the mines and accommodation; miners work clothes or uniforms not to be taken to where miners stay to avoid exposure).

· Policy research to study how to remove current practices of barring ex-TB miners from returning to work in the mines.

<sup>&</sup>lt;sup>54</sup> Stop TB Partnership (2016), "Key Populations Brief - Miners"

### 3.3 Prisoners and Detainees<sup>55</sup>

TB Risks				TB Risk Drivers	
Environment (Over-crowded, poor ventilation)	Biology (Reduced immunity)	Behaviour (Prone to transmission)	Limited Access to Services (Health, social and economic)	Legal & Economic (criminalization, poverty) Human Rights & Gender (stigma, discrimination)	TB Case Finding and Treatment Service Challenges
Most prison and detention facilities are over capacity. Many held in supposedly short-term detention centres for years without any access to health services.	Many prisoners and detainees are HIV key populations (people who use drugs, sex workers) with many already infected with HIV before incarceration.	Prisoners who use drugs by Inhaling and exhaling directly into each other's mouths have increased TB risk.	Most prisons and detention centres are under-staffed and don't even have basic health care providers on-site, let alone TB screening and treatment.	<ul> <li>Harsh criminal and immigration laws incarcerating non- violent crimes (drug users, sex workers, homosexuals, bisexuals, transgender), asylum seekers and illegal immigrants.</li> <li>Male prison culture insensitive to female inmates limiting access to women's health services (ex-sex workers in particular).</li> <li>Prison abusive and hierarchical culture among inmates limits access even when health service is available.</li> </ul>	<ul> <li>Lack systematic HIV and TB screening upon entry and annual mass screening for all inmates.</li> <li>Lack isolation facilities for inmates showing symptoms of TB.</li> <li>Lack TB preventive treatment for inmates with HIV.</li> <li>Lack treatment for inmates diagnosed with TB and TB/HIV.</li> <li>Lack harm reduction services such as Methadone Maintenance Treatment for inmates who are drug users lowering TB treatment adherence.</li> <li>Lack gender-sensitive services to address specific physical and mental health needs of women, sexual abuse victims in particular.</li> <li>Lack treatment adherence support for TB, HIV and Methadone Maintenance Treatment.</li> <li>Lack discharge or inter-facility transfer planning that integrates HIV/TB/harm reduction public services (health, social) and community (psychosocial) in places where the released inmate will reside to ensure treatment adherence.</li> <li>Societal stigma against ex-prisoners making post-prison re-integration into society difficult (getting employed or accepted by family), increasing risk of drug use and sex work and TB treatment disruption.</li> </ul>

### **Potential Responses**

- National/district committees of government (health, justice, narcotics, social) and community (prisoners/detainees, exprisoners/detainees, families, NGOs) stakeholders to advocate for more resources for prison/detention centre health infrastructure (isolation, laboratory) and human resources (on-site health staff or referrals to health facilities near prisons).
- National/district committees of government (health, justice, prison/detention centre management, narcotics, social) and community (prisoners/detainees, ex-prisoners/detainees, families, NGOs) stakeholders to coordinate to deliver integrated services both in prison/detention centres and after release/transfer.

 Train ex-prisoners peers and NGOs working with prisoners/detainees or ex-prisoners/detainees to work with public health and social authorities to raise health awareness (HIV, TB, Methadone Maintenance Treatment, needles and syringes exchange) and provide psychosocial and treatment adherence support.

UNODC (2008) "Handbook for Prison Managers and Policymakers on Women and Imprisonment" (https://www.unodc.org/documents/justice-and-prison-reform/women-and-imprisonment.pdf)

<sup>•</sup> Train peer prisoners to raise health awareness (HIV, TB, Methadone Maintenance Treatment, needles and syringes exchange) and support treatment adherence in prison/detention centre.

<sup>&</sup>lt;sup>55</sup> Stop TB Partnership (2016) "Key Populations Brief - Prisoners"

WHO (2014) "Prison and Health" Chapter 8: Tuberculosis (<u>http://www.euro.who.int/\_\_data/assets/pdf\_file/0005/249188/Prisons-and-Health.pdf</u>)

UNODC (2006) "HIV/AIDS Prevention, Care, Treatment and Support in Prison Settings: A Framework for Effective National Response" (https://www.unodc.org/pdf/HIV-AIDS\_prisons\_July06.pdf)

TBCTA and ICRC (2009) "Guidelines for Control of Tuberculosis in Prisons" (http://pdf.usaid.gov/pdf\_docs/PNADP462.pdf)

# 3.4 People Who Use Drugs<sup>56</sup>

TB Risks				TB Risk Drivers	
Environment (Over-crowded, poor ventilation)	<b>Biology</b> (Reduced immunity)	Behaviour (Prone to transmission)	Limited Access to Services (Health, social and economic)	Legal & Economic (criminalization, poverty) Human Rights & Gender (stigma, discrimination)	TB Case Finding and Treatment Service Challenges
If drug use takes place in hidden and small space with poor ventilation, risks of TB would be higher.	Many people who use drugs are infected with HIV due to sharing injecting equipment or engaging in un- protected sex, making them more prone to latent TB infections or latent TB becoming active TB. Long term injecting drug use may lead to wasting and other illnesses, which in turn depress the immune system and make people more susceptible to TB.	Inhaling and exhaling directly into each other's mouths increases TB risk.	Drug users are reluctant to access public services, including health.	<ul> <li>Criminalization drives drug use underground confining drug users to over-crowded space with poor ventilation.</li> <li>Criminalization limits drug users' trust in public services even when they need and would like to use services including health.</li> <li>Harassment by police and stigmatization by health care providers deter drug users from accessing services even when services are available.</li> <li>Many people who inject drugs sell sex (often un-protected and sexually abused by both clients and pimps) to pay for drugs.</li> <li>Drug use could exhaust not just the user's own resources but that of the family's to the point of abandonment by family.</li> <li>Social isolation leads to more drug use.</li> </ul>	<ul> <li>Drug use makes it harder for the user to recognize TB symptoms, keeping medical appointments or adhering to treatment.</li> <li>Police raids during public health outreach or at treatment service points such as Methadone Maintenance Treatment increase relapse, leading to HIV and TB treatment disruption.</li> <li>Lack of integration of harm reduction (Methadone Maintenance Therapy, needles and syringes exchange), HIV and TB services leads to TB and HIV treatment disruptions, increasing risk of drug resistance.</li> <li>Social stigma against ex-drug users limits re-integration into society, becoming very prone to relapse particularly when failing to get a job or gain social support from family.</li> </ul>

#### **Potential Responses**

- National/district committees of government (health, justice, narcotics, social) and community (people who use drugs, people who stopped using drugs, families, NGOs) stakeholders to advocate for a people-centred response that integrates HIV, TB and harm reduction services.
- National/district committees of government (health, justice, narcotics, social) and community (drug users, former drug users, families, NGOs) stakeholders to coordinate to deliver a people-centred response that integrates HIV, TB and harm reduction services.
- Train peer drug users or ex-drug users to raise health awareness (HIV, TB, Methadone Maintenance Therapy, needles and syringes exchange) and support treatment adherence among drug users.
- Train ex-drug user peers and NGOs working with drug users on how to work with public health and social services to help drug users navigate through the public system.

Drugs" (http://apps.who.int/iris/bitstream/10665/204484/1/9789241510226\_eng.pdf?ua=1) UNODC (2012) "Female Injecting Drug Users and Female Sex Partners of Men Who Inject Drugs: Assessing Care Needs and

(https://www.hri.global/files/2016/11/14/GSHR2016\_14nov.pdf)

(http://www.tbcare1.org/publications/toolbox/tools/access/Compendium\_of\_Tools.pdf)

<sup>&</sup>lt;sup>56</sup> Stop TB Partnership (2016) "Key Populations Brief - People Who Use Drugs"

Haileyesus Getahun a, Annabel Baddeley a & Mario Raviglione (2013) "Managing Tuberculosis in People Who Use and Inject Illicit Drugs" Bulletin of the World Health Organization 2013; 91:154-156 (<u>http://www.who.int/bulletin/volumes/91/2/13-117267/en/</u>) WHO (2013) "Developing Tuberculosis Services for People Who Use Drugs: Training Manual" (<u>http://www.euro.who.int/\_data/assets/pdf\_file/0019/234352/EHNR-manual-Eng.pdf</u>)

WHO (2016) "Integrating Collaborative TB and HIV Services Within a Comprehensive Package of Care for People Who Inject

Developing Responsive Services" (http://www.aidsdatahub.org/sites/default/files/documents/FIDU\_report\_2012.pdf) Harm Reduction International (2016) "The Global State of Harm Reduction 2016"

Mitchell, E. M.H., Pray, R., Ngamvithayapong-Yana, J. Ryan, T., Lemaine, I., Lonnroth, K., Reeves, R., Turusbekova, N. Verduin, R., Stikkers, B., Voskens, J., Massaut, S., Suarez, P. (2014) "Compendium of Tools and Strategies to Achieve Universal Access to TB Care for Vulnerable and At-Risk Groups"
### 3.5 People Living With HIV<sup>57</sup>

	TB Risk	(S		TB Risk Drivers	
Environment (Over-crowded, poor ventilation)	<b>Biology</b> (Reduced immunity)	<b>Behaviour</b> (Prone to transmission)	Limited Access to Services (Health, social and economic)	Legal & Economic (criminalization, poverty) Human Rights & Gender (stigma, discrimination)	TB Case Finding and Treatment Service Challenges
HIV treatment facilities might have poor TB infection control such as poor ventilation. Those PLHIV who live or work in over-crowded settings (the poor, prisoners, detainees, drug users in particular) have elevated risks of TB.	People infected with HIV but not on ART have lower levels of immunity against diseases making them more prone to latent TB infection or latent TB becoming active.	PLHIV often have limited knowledge of TB transmission and prevention.	PLHIV not accessing TB services due to stigma associated with TB. Children living with HIV more likely to be orphaned or vulnerable due to loss of their parents to HIV.	<ul> <li>Lack of or inadequate anti-stigma policies and anti-discrimination laws in countries where stigma and discrimination against PLHIV are widespread deter PLHIV accessing health services, including TB.</li> <li>PLHIV who are poor or have trouble getting a job due to societal discrimination are more likely to be living in sub-standard over-crowded housing with poor ventilation and less knowledgeable about TB treatment, transmission and prevention.</li> <li>Female PLHIV are faced with additional economic and stigma barriers in accessing health services and many are not aware of the impact of TB on their sexual and reproductive rights.</li> </ul>	<ul> <li>Inadequate TB screening for people newly diagnosed with HIV.</li> <li>Existing public TB services are not integrated with HIV services (both government and NGOs).</li> <li>Limited PLHIV's knowledge of TB treatment, transmission and prevention.</li> <li>Many PLHIV with latent TB are not on TB preventive treatment.</li> </ul>

#### **Potential Responses**

- Integrate HIV and TB services in government primary care facilities such as antenatal clinics, including mobile clinics.
- Develop standard operating procedures for referrals between HIV and TB services in places or situations where TB and HIV services cannot be physically integrated.
- Train PLHIV NGOs on TB treatment, transmission and prevention to look for signs of TB among their PLHIV clients, refer and support those with TB symptoms (coughing for two weeks or more) to HIV/TB clinics and support those diagnosed with active TB to adhere to treatment and those with latent TB to adhere to preventive TB treatment.
- Involve NGOs (PLHIV, individuals who recovered from TB) to train staff of public health and social services on gender-sensitivity and stigma-free service provision.
- Provide information to women PLHIV on TB impact on sexual and reproductive health issues.

<sup>&</sup>lt;sup>57</sup> Stop TB Partnership (2016) "Key Populations Brief - PLHIV"

WHO (2012) "WHO Policy on Collaborative TB/HIV Activities: Guidelines for National Programmes and Other Stakeholders" (http://apps.who.int/iris/bitstream/10665/44789/1/9789241503006\_eng.pdf?ua=1&ua=1)

International HIV/Aids Alliance (2013) "Community-based TB and HIV Integration: A Good Practice Guide" (http://www.aidsalliance.org/assets/000/000/719/90636-Good-practice-guide-Community-based-TB-and-HIVintegration\_original.pdf?1406297871)

International HIV/Aids Alliance (2013) "Community-based TB and HIV Integration: Workbook"

<sup>(</sup>http://www.aidsalliance.org/assets/000/000/721/90636-Workbook-for-the-Good-Pratice-Guide-Community-based-TB-and-HIVintegration\_original.pdf?1406297911)

# 4. Prioritizing and Planning TB Programmes for Key Populations

The programme planning stage for key populations involve four key components – prioritization, population size estimates, disease burden and risks at local level, population size estimates and risks at national level, and the inclusion of key populations in the National Strategic Plan.



#### Figure 10: Prioritization and Programme Planning Process

#### 4.1 National-level Key Population Prioritization

The first step of national planning for key populations is to systematically consider all possible key populations and prioritize them according to their contribution to TB cases, TB risks and service access barriers they face.

This should take place through a multi-stakeholder government and non-government platform such as national health coordination committee, Global Fund Country Coordinating Mechanism (CCM) or, in the absence of these, Ministries of Health should take the lead to initiate a national TB Key Population Working Group composed on of disease/programme experts (TB, HIV, harm reduction) and community experts (PWTB support groups, TB NGOs, key population representatives, CSOs serving key populations).

Below is a simple template for the working group to score all potential key populations in their countries using available data or best proxy information when such information is not available. Proxy data could be administrative data from another government ministry not directly dealing with the key population being considered, national data from another country of comparable epidemic, social, economic and political context.

For each potential key population, the working group is asked to score the following six areas:

- Estimated contribution of all TB burden (active TB cases of all forms) by that key population (1-Very Low <1%, 2-Low 1-3%, 3-Medium 3-5%, 4-High 5-10%, 5-Very High >10%)
- Whether the key population is faced with any environmental risks such as being in over-crowded or poorly ventilated space (0-No, 1-Yes)
- Whether the key population is faced with any biological risks such as reduced immunity or poor nutrition (0-No, 1-Yes)
- Whether the key population is faced with any behavioural risks such as inhaling from or exhaling into one another's mouth or sharing smoking equipment (0-No, 1-Yes)
- Whether the key population is faced with any legal and economic barriers to accessing services such as criminalization and poverty (0-No, 1-Yes)
- Whether the key population is faced with any human rights and gender-related barriers to accessing services such as stigma and discrimination (0-No, 1-Yes)

Then the simple sum of the above six scores becomes the combined score for the key population (maximum 10). After going through all the key populations listed (or others not listed but added by the working group), the working group would then have a qualitative discussion if the key populations with the highest combined scores should be prioritized. If not, the working group should further discuss and provide rationale why a certain key population with a high combined score is not prioritized or vice versa.

This prioritization tool is designed to make the prioritization process more accessible to the community, key populations in particular, who can inform the other non-key population working group members, based on their own experience (from accessing services to staying on treatment) or consultation with their own community networks prior to attending the working group's prioritization exercise. Their consultations with the key populations would look at whether a key population is actually faced with any of the environmental, biological and behavioural risks, and legal, economic, human rights and gender-related barriers to accessing services.

If a country determines a specific population group that belongs to more than one key populations (e.g., PWUD in prison), just add this specific group to the bottom of the table.

After key populations have been systematically scored and prioritized (with rationale), the working group should follow the WHO screening guidelines to conduct further analysis on the prioritized key populations to check their potential case finding yields, risks and costs of different screening algorithms.<sup>58</sup> Further discussion will need to address any capacity and resource gaps of the country's health system to reach these prioritized key populations.

<sup>&</sup>lt;sup>58</sup> WHO (2015) "Systematic Screening for Active Tuberculosis: An Operational Guide"

<sup>(</sup>http://apps.who.int/iris/bitstream/10665/181164/1/9789241549172\_eng.pdf?ua=1&ua=1)

WHO (2017) "Ethics Guidance for the Implementation of the End TB Strategy, Ch. 16 on Screening (http://apps.who.int/iris/bitstream/10665/254820/1/9789241512114-eng.pdf).

A corresponding online tool "ScreenTB" (https://wpro.shinyapps.io/screen\_tb/) is available to help countries assess the pros and cons of different screening algorithms for a prioritized key population in terms of number of individuals needed to screen and cost per case detected and estimate number of cases of true positive, false negative (cases missed) and false positive (particularly in situations where TB is highly stigmatized). WHO added the tool is meant to serve only as an aid in the process of prioritizing risk groups for screening and choosing screening algorithms. It should not be used for detailed planning, or for projection of future impact on TB epidemiology. Countries should refer to "Systematic Screening for Active Tuberculosis: An Operational Guide" and "Ethics Guidance for the Implementation of the End TB Strategy" for other elements of the planning and implementation process.

# Figure 11: Prioritizing Key Populations at National Level (also included in Annex A4)

	Score 1	Score 2	Score 3	Score 4	Score 5	Score 6	Facilitat	ned Score to e Prioritization scussion
	Estimated Contribution to the Country's TB Disease Burden	Faced with Environm ent Risks	Faced with Biology Risks	Faced with Behaviour Risks	Legal & Economic Barriers to Accessing Services	Human Rights & Gender Barriers to Accessing Services	Total Score	Prioritization
Key Populations to Consider	(Active TB cases of all forms) <b>1 – Very Low</b> (<1%) <b>2 – Low</b> (1-3%)	(Over- crowded, poorly ventilated space, reside in zoonotic TB areas)	(Reduced immunity, poor nutrition)	(In/exhaling from/into other's mouth, sharing smoking equipment)	(Criminalization, poverty)	(Stigma, discrimination)	(Sum of Scores 1-6, Max 10)	Discussion and Rationale for Prioritized Key Populations
	<b>3 – Medium</b> (3-5%) <b>4 – High</b> (5-10%) <b>5 – Very High</b> (>10%)	0 - No 1 - Yes	0 - No 1 - Yes	0 - No 1 - Yes	0 - No 1 - Yes	0 - No 1 - Yes		
People Living with HIV								
People with Silicosis								
Miners							1	
		1			1			
Migrants		1		1	1	1		
Refugees								
Internally Displaced People								
Nomadic Populations								
Prisoners & Detainees								
People who Use Drugs								
People with Alcohol								
Dependency								
Smokers								
Sex Workers								
Lesbian, Gay, Bisexual & Transgender								
Indigenous Populations								
Homeless								
People with Mental or Physical Disabilities								
Urban Poor								
Rural Poor								
People with Diabetes								
Children			ļ					
Elderly								
Heenitel Werker-			<u> </u>					
Hospital Workers Prison Workers								
Refugee Camp Workers		<u> </u>						ļ
Community Health/								
Outreach Workers Hospital Visitors								
Prison Visitors								
Peri-prison								
Communities								
Peri-mining Communities								
Sex Worker Clients							l	
People Who Use Drugs Family Members								
Miners Family Members								
People at risk of zoonotic TB								

### 4.2 Local-level Population Size Estimates, Disease Burden and Risks

When assessing and presenting population size estimations, disease burden, risks and service access barriers, it is useful to provide information about how these data were obtained. For instance, for population size estimation, were they derived through best guesses from NGOs and stakeholders or was some specific methodology used (see Section 7)? For disease burden and risks, were these data obtained using probability or non-probability based sampling method? If a survey was conducted and population size estimations and/or TB burden and/or risks were collected for only a few cities in a country, then these need to be extrapolated to a national level. This can be done by the local TB health authority convening a local-level multi-stakeholder consultation that involves key population community representatives. The agreed estimates would then be submitted to the national TB programmes to come up with final national figures for these key populations.

# 4.3 National-level Population Size Estimates, Disease Burden and Risks

To derive national figures of the sizes of the prioritized key populations, national TB programmes can use all local figures submitted by the local TB authorities. Local figures can be used to classify estimates by localities into several tiers of size of populations and weight the figures submitted by the local TB authorities according these tiers (see Section 7 below for further details).

Again, the national working group which prioritized key populations should now be convened again to discuss and fine-tune these national figures. Once agreed, these national figures should be included in the country's National Strategic Plan.

#### 4.4 National Strategic Plan

Once the size estimates and corresponding risks and service access barriers of key populations have been identified, the next step is for the national working group to discuss the following to provide more details for each of the prioritized key populations to be included in the country's National Strategic Plan:

- Where these key populations are?
  - Focus on which geographical broad area such as provinces (digital broad area such social media application) where most of these individuals are likely to be found
- What are their TB risk drivers?
  - Legal and economic (criminalization, poverty)
  - Human rights and gender (stigma, discrimination)
- What are their TB service access barriers?
  - TB, HIV, harm reduction (Methadone Maintenance Treatment, needles and syringes exchange), STD, HCV, HBV, social security protection against catastrophic costs
- Define service package for the prioritized key populations to address TB service access barriers?
  - $\circ$  TB, HIV, harm reduction (Methadone Maintenance Treatment, needles and syringes
    - exchange), STD, HCV, HBV, social security protection against catastrophic costs
  - TB-HIV joint-planning is of particular importance, given TB being the leading cause of death among PLHIV<sup>59</sup>
- Preliminary national targets for each prioritized key population?
  - Identify if there are any targets for the selected key population in the National TB Strategic Plan (and/or TB or TB/HIV grants of the Global Fund)
- Any data gaps on size of each key population prioritized?

Below is a tool to summarize the above discussion to facilitate inclusion of these prioritized key populations in the National Strategic Plan.

<sup>&</sup>lt;sup>59</sup> WHO (2012) "WHO Policy on Collaborative TB/HIV Activities: Guidelines for National Programmes and Other Stakeholders" (<u>http://apps.who.int/iris/bitstream/10665/44789/1/9789241503006\_eng.pdf?ua=1&ua=1</u>)

# Figure 12: Programme Planning at National Level (also included in Annex A5)

Key Populations <u>Prioritized</u>	Estimated Size of prioritized key populations (age and sex disaggregated) in the country	Where are they concentrated (geographically, digitally)?	What are their <u>key</u> <u>TB risks</u> and related <u>drivers</u> ?	What are their TB case finding and treatment <u>services</u> <u>challenges</u> ?	What <u>TB service</u> package (and integration with other health, harm reduction, social, community, immigration, labour, police) is needed?	Preliminary national targets	Service and Data gaps that need to be addressed?

# 5. Limited Data Available

This section uses the same five key populations discussed earlier to illustrate the scarcity of TB data and identify critical data gaps that are needed for planning TB responses among them. Although not covered in this section, other key populations covered by Stop TB Partnership's key population briefs such as children under five,<sup>60</sup> urban and rural poor are also likely to have similar data limitation issues.

A literature search<sup>61</sup> of last five years of published studies shows data measuring TB prevalence and size estimation and associated behavioural risks and service access barriers (legal, economic, human rights and gender such as stigma and discrimination) for the five key populations are in general unavailable. For data that are available, data collection methods and guality are not often described well enough to determine external validity (i.e., whether it represents the population sampled). For each of the five illustrative TB key populations we provide background on the data available at the global level among the 48 countries identified by WHO as TB high burden countries.62

<sup>&</sup>lt;sup>60</sup> WHO (2013) "Roadmap for Childhood Tuberculosis: Towards Zero Deaths"

<sup>(</sup>http://apps.who.int/iris/bitstream/10665/89506/1/9789241506137\_eng.pdf?ua=1&ua=1)

Based on PubMed online searches in Mar 2017 for publications within the past five years using key words "Tuberculosis" and "Mobile Populations", "Migrants", "Refugees", "Internally Displaced", "Miners", "Prisoners", "Detainees", "People who Use Drugs", "Drug Users", "People Living with HIV". Some studies published earlier than five years but cited by studies published in the last five years are also included.

WHO (2015) "Use of High Burden Country Lists for TB by WHO in the Post-2015 Era"

<sup>(</sup>http://www.who.int/tb/publications/global\_report/high\_tb\_burdencountrylists2016-2020summary.pdf?ua=1)

#### 5.1 Mobile Populations

According to the World Bank (2015) there are 234 million migrants in the world, while the International Organization for Migration (IOM) estimates over 1 billion migrants<sup>63</sup> including 244 million international and 740 million internal migrants. In addition to the recorded migrants, IOM estimates 55 million unrecorded or irregular migrants. UNICEF estimated there were 31 million migrant children and 10 million of them were refugees.<sup>64</sup>

There are 259 migrants with TB per 100,000 examinations and 382 refugees with TB per 100,000 examinations in 2014.65

In 2014 as a core component of migrants' health assessments, the majority of IOM-examined migrants underwent TB screening prior to their departure. These assessments are conducted in medium and high TB burden countries. The TB detection rate was 297 per 100,000 exams - 382 cases per 100,000 among refugees and 259 per 100,000 among immigrants. The difference is attributed to poorer health and nutritional status, living and socioeconomic conditions of refugees.<sup>66</sup> There were 953 total active TB cases were referred for treatment in 2014, of which 736 (77%) were laboratory confirmed and 217 (23%) were referred based on clinical diagnosis.<sup>67</sup> In 2014 IOM's data on TB detection among immigrants (per 100,000 tests) per region was: 416 (Asia), 102 (Africa), 21 (Europe), 0 (Middle East) and among refugees: 734 (Asia), 239 (Africa), 160 (Europe), 5 (Middle East).

The data about the burden of TB among irregular and internal migrants and internally displaced persons is largely absent. Screening of irregular migrants for TB is challenging, it is a political and international process. One such possibility for TB screening is upon irregular migrants' deportation from a host country. For instance IOM Zimbabwe, implementing a TB REACH project, screens irregular migrants deported from South Africa. As of December 2015, 46,002 people have been screened, of whom 3,673 were reported to have presumptive TB. Of the 3,673 cases of presumptive TB, 2,584 were tested and 258 were positive TB cases.<sup>68</sup> A similar IOM project in Cambodia established TB prevalence among irregular migrants deported from Thailand as 1.150/100.000 (Feb 2012 until Jan 2013).69

TB and MDR-TB in migrant populations are usually higher than in autochthonous population in countries with low TB incidence. For example, migrant TB cases accounted for 17.4% (n = 92,039) of all TB cases reported in the EU/EEA in 2007–2013, continuously increasing from 13.6% in 2007 to 21.8% in 2013.70 The table below contains information, based on UNICEF migration profiles (2013)<sup>71</sup> among the 48 countries, identified by WHO as TB high burden countries.

<sup>69</sup> WHO (2013) "TB in Cambodia and Active Case Finding among Irregular Migrants"

<sup>63</sup> IOM (2015) "Global Migration Trends – Factsheet"

<sup>(</sup>https://publications.iom.int/system/files/global\_migration\_trends\_2015\_factsheet.pdf) <sup>64</sup> UNICEF (2017) "Child Migration and Displacement" (http://data.unicef.org/topic/child-migration-and-displacement/migration/) accessed 1 May 2017

IOM (2014) "Migration Health Annual Review 2014" (http://publications.iom.int/system/files/mhd\_ar\_2014.pdf) 66 Ibid.

<sup>67</sup> Ibid.

<sup>&</sup>lt;sup>68</sup> IOM (2015) "Zimbabwe Annual Report 2015" (<u>https://www.iom.int/sites/default/files/country/docs/zimbabwe/IOM-Zimbabwe-AR-</u> 25Aug2016.pdf)

<sup>(</sup>http://www.searo.who.int/thailand/news/tb0105.pdf?ua=1) <sup>70</sup> Ködmön C, Zucs P, van der Werf MJ. (2016) "Migration-related Tuberculosis: Epidemiology and Characteristics of Tuberculosis Cases Originating Outside the European Union and European Economic Area, 2007 to 2013." Europe Surveillance 21(12):pii=30164. DOI: http://dx.doi.org/10.2807/1560-7917.ES.2016.21.12.30164

<sup>&</sup>lt;sup>71</sup> UNICEF "Migration Profiles" (<u>https://esa.un.org/MigGMGProfiles/indicators/indicators.htm</u>) accessed 1-5 Sep 2016

				Migrant	S				
				UNICEF migra	tion profiles 2	013 accessed	between 1-5	Sept 2016	
WHO				5) st	ant 013	ant 013	a بر	5 7	5 0 7
2016 Top				tal ne 10-1	nigra of 2(	nigra of 2( )	tiona ( as c	latio the fend	llatio m thu if enu
ТВ	TΒ	MDR-TB	TB/HIV	Estimated total net migration (2010-15)	international migrant stock by sex as of 2013 (male)	international migrant stock by sex as of 2013 (female)	Total international migrant stock as of 2013	Refugee population coming into the country (as of end 2012)	Refugee population outgoing from the country (as of end 2012)
Burden		Σ	F	mat atio	hati by s (r	nati by s (fe	al in rant	ugee Intry 2	ugee tgoir nntry
				Esti nigr	nter ock	nter ock	Tot mig	Refu co cou	Refu out cou
Countries									
Angola Azerbaijan	Y	Y Y	Y	66,000 0	42,176 153,703	45,260 170,140	87,436 323,843	20,740	5,805
Bangladesh	Y	Y Y		-2041000	1,209,928	186,586	1,396,514	230,674	6,575
Belarus		Y		-2041000	497,102	588,294	1,085,396	230,074	
Botswana		<b>-</b>	Y	20000	80,058	66,398	146,456		
Brazil	Y		Ŷ	-190,000	323,720	275,958	599,678		
Cambodia	Ŷ		· · ·	-175,000	40,560	35,006	75,566		12,666
Cameroon			Y	-50,000	162,411	129,381	291,792	92,094	6,676
Central African Re	Y		Y	10,000	74,028	60,209	134,237	10,662	157,968
Chad			Ŷ	-120,000	228,342	210,774	439,116	372,834	32,220
China	Y	Y	Y	-1,500,000	440,482	408,029	848,511	300,897	177,373
Congo	Y		Y	-45,000	229,671	201,799	431,470	97,828	
DPR Korea	Y	Y		0	23,233	23,580	46,813		
DR Congo	Y	Y	Y	-75,000	216,219	230,705	446,924	60,104	378,981
Ethiopia	Y	Y	Y	-60,000	386,678	331,563	718,241	372,692	49,379
Ghana			Y	-100,000	195,345	163,484	358,829	13,855	17,371
Guinea-Bissau			Y	-10,000	9,168	8,856	18,024	7,700	
India	Y	Y	Y	-2,294,000	2,736,253	2,602,233	5,338,486	184,472	10,328
Indonesia	Y	Y	Y	-700,000	183,002	112,431	295,433		9,368
Kazakhstan		Y		0	1,715,290	1,760,943	3,476,233		
Kenya	Y	Y	Y	-50,000	469,764	485,688	955,452	557,308	
Kyrgystan		Y		-175,000	102,802	124,158	226,960		
Lesotho	Y		Y	-20,000	1,998	1,097	3,095		
Liberia	Y		Y	-20,000	119,724	105,760	225,484	65,560	5,156
Malawi			Y	0	98,279	108,299	206,578		
Moldova		Y		-103,000	183,959	207,549	391,508		
Mozambique	Y	Y	Y	-25,000	134,302	84,509	218,811		
Myanmar	Y	Y	Y	-100	54,902	48,215	103,117		406,333
Namibia	Y		Y	-3,000	27,047	24,401	51,448		
Nigeria	Y	Y	Y	-300,000	663,035	570,557	1,233,592		
Pakistan	Y	Y	1	-1,634,000	2,307,164	1,773,602	4,080,766	1,637,740	34,695
Papua New Guine	Y	Y	Y	0	16,132	9,309	25,441	9,368	
Peru		Y		-300,000	53,432	51,487	104,919		
Philippines	Y	Y		-700,000	110,421	102,729	213,150		
Russia	Y	Y		1,100,000	5,423,915	5,624,149	11,048,064		93,140
Sierra Leone	Y			-21,000	51,829	44,539	96,368		
Somalia		Y		-150,000	13,328	11,265	24,593		1,000,425
South Africa	Y	Y	Y	-100,000	1,391,918	1,007,320	2,399,238	42,593	
Swaziland			Y	-6,000	13,903	11,621	25,524		
Tajikistan		Y		-100,000	118,811	156,924	275,735		
Tanzania	Y		Y	-150,000	156,059	156,719	312,778	98,673	
Thailand	Y	Y	Y	100,000	1,877,391	1,844,344	3,721,735	83,317	
Uganda			Y	-150,000	261,770	269,631	531,401	182,568	
Ukraine		Y		-40,000	2,366,197	2,785,181	5,151,378		20,059
Uzbekistan		Y		-200,000	587,271	679,007	1,266,278		
Viet Nam	Y	Y		-200,000	39,636	28,654	68,290		333,301
Zambia	Y		Y	-40,000	49,965	48,942	98,907	20,834	
Zimbabwe	Y	Y	Y	400,000	205,817	155,175	360,992		12,155
Countries with data (48 max)	30	30	30	48	48	48	48	21	20
Total					25,848,140	24,132,460	49,980,600	4,462,513	2,769,974

5.2 Miners

There are an estimated 7 million people worldwide in industrial mining (formal sector) and about 100 million artisanal miners (informal sector) in 80 countries.<sup>72</sup> TB burden among miners is not available except for South Africa and a handful of other countries.

Information about the number of formal sector miners is not available with an exception of a few countries<sup>73</sup>:

- o In South Africa (according to the Chief Inspector of Mines, 2013 data) there were 1,165 TB cases per 100,000 miners. Total number of mine workers: 423,032 (screened for TB 308,403 (73%); HIV co-infection 81%. In South Africa roughly 230,000 men migrate each year from other countries for mining jobs.74
- o Miners in sub-Saharan Africa have greater incidence of TB than do any other working populations in the world (reported at 3,000–7,000 per 100,000 miners per year in some areas).<sup>75</sup>
- o A recent study on copper miners in Zambia found 9.5% prevalence of active TB.<sup>76</sup>

Estimations of the number of artisanal miners vary from 100 million (World Bank) to 13 million engaged in small-scale mining and 80–100 million people's livelihood affected by it, according to ILO.<sup>77</sup>

- o Estimated 30% of people involved in all activities associated with artisanal mining are women.<sup>78</sup> In Guinea, women comprise 75% of those involved in the sector while in Madagascar, Mali and Zimbabwe 50%.79
- o An estimated one million children are involved in artisanal and small-scale mining worldwide.<sup>80</sup>

A recent study on mining and TB for 44 countries in southern Africa estimated even a modest 10% increase in mining production would lead to a 33% rise in TB incidence in the overall population, not just among the miners, an increase of 760,000 TB cases from 2.3 million to 3.1 million.<sup>81</sup>

o With the means available today, even funded and well-functioning DOTS programmes in mines are not able to stop the spread of TB among miners, which inevitably spill over to the communities and have a population-wide impact on public health.<sup>82</sup>

The table below shows only a handful of the 48 countries identified by WHO as TB high burden countries that have some information on TB among miners. These data are from various sources including the

<sup>&</sup>lt;sup>72</sup> World Bank (2013) "Brief on Artisanal and Small-Scale Mining"

<sup>(</sup>http://www.worldbank.org/en/topic/extractiveindustries/brief/artisanal-and-small-scale-mining)

TB in Mining Section (TIMS) is implementing a Global Fund regional grants for mineworkers in ten countries in Southern Africa. which implementation data will provide TB data of miners in these countries

<sup>(</sup>https://www.timssa.co.za/Whoweare/AboutTIMS.aspx).

WordPress EpiAnalysis (2011) "The Production of Consumption: Addressing the Impact of Mining on Tuberculosis" (https://epianalysis.wordpress.com/2011/07/25/miningandtb/) <sup>75</sup> South Africa: Ministry of Health (2007). "Tuberculosis Strategic Plan for South Africa, 2007–2011"

<sup>&</sup>lt;sup>76</sup> Kingsley Ngosa and Rajen N. Naidoo (2016) "The risk of Pulmonary Tuberculosis in Underground Copper Miners in Zambia Exposed to Respirable Silica: A Crosssectional Study", BMC Public Health (2016) 16:855

<sup>&</sup>lt;sup>7</sup> R. Eisler (2003) "Health Risks Of Gold Miners: A Synoptic Review." Environmental Geochemistry and Health 25: 325–345

<sup>&</sup>lt;sup>78</sup> Hilson, G. (2002) "Small-Scale Mining and Its Socioeconomic Impact in Developing Countries." Natural Resources Forum vol. 26, no. 1, pp. 3-13.

<sup>&</sup>lt;sup>79</sup> World Bank (2002) "Global Report on Artisanal & Small-Scale Mining" (http://www.ddiglobal.org/login/resources/g00723.pdf) <sup>80</sup> ILO (2005) "A Load too Heavy: Child Labour in Mining and Quarrying."

<sup>(</sup>http://www.ilo.org/ipec/Campaignandadvocacy/wdacl/2005/lang--en/index.htm) accessed 5 Sep 2016

<sup>&</sup>lt;sup>81</sup> Stuckler D, Basu S, McKee M, Lurie M (2011). "Mining and Risk of Tuberculosis in Sub-Saharan Africa." American Journal of Public Health 101(3):524-30.

<sup>&</sup>lt;sup>82</sup> WordPress EpiAnalysis (2011) "The Production of Consumption: Addressing the Impact of Mining on Tuberculosis" (https://epianalysis.wordpress.com/2011/07/25/miningandtb/)

World Bank,<sup>83</sup> UNIDO,<sup>84</sup> ITS Global<sup>85</sup> and other reports by or sources from national governments or chambers of commerce.<sup>86</sup>

http://pubs.iied.org/pdfs/G00723.pdf

<sup>&</sup>lt;sup>83</sup> World Bank (2002) "Global Report on Artisanal & Small-Scale Mining" (http://www.ddiglobal.org/login/resources/g00723.pdf) World Bank (2009) "Mining Together : Large-Scale Mining Meets Artisanal Mining, A Guide for Action" (https://openknowledge.worldbank.org/handle/10986/12458)

<sup>&</sup>lt;sup>84</sup> UNIDO (2010) "World Statistics on Mining and Utilities"

<sup>(</sup>http://www.unido.org//fileadmin/user\_media/Publications/Research\_and\_statistics/Branch\_publications/Research\_and\_Policy/File s/Reports/Statistical\_Reports/UNIDO\_Mining\_Utilities-2010.pdf)

<sup>&</sup>lt;sup>85</sup> ITS Global (2011) "The Economic Contribution of Indonesia's Forest-Based Industries"

<sup>(</sup>http://www.itsglobal.net/sites/default/files/itsglobal/ITS\_Indoforest\_Economic\_Report.pdf)

Accessed the following 5 Sep 2016:

http://ghanachamberofmines.org/media/publications/2015\_Mining\_in\_Ghana\_What\_future\_can\_we\_expect.pdf http://investimentos.mdic.gov.br/public/arquivo/arq1314392332.pdf

http://www.colby.edu/academics\_cs/courses/GE127/upload/Eisler2003.pdf http://myanmar.unfpa.org/sites/asiapacific/files/pub-pdf/2B\_Occupation\_and\_Industry\_EN.pdf

http://siteresources.worldbank.org/INTOGMC/Resources/336099-1156955107170/miningsourceeconomicgrowthrussian.pdf http://stat.tj/ru/img/7b6f49435ed5ae6ec685562d6e28583a\_1426678999.pdf

http://wiego.org/sites/wiego.org/files/publications/files/Asian-Devt-Bank-informal-sector-informal-employment-bangladesh.pdf http://www.cso.gov.bw/images/formal\_employ2015.pdf

http://www.gks.ru/free\_doc/doc\_2015/rus15\_eng.pdf

http://www.ibm.nic.in/writereaddata/files/03282016115329IMIG%202013-14.pdf

http://www.minem.gob.pe/\_detalle.php?idSector=1&idTitular=3640&idMenu=sub151&idCateg=816

http://www.nigerianstat.gov.ng/library

http://www.statssa.gov.za/publications/P0211/P02111stQuarter2016.pdf

http://www.ubos.org/onlinefiles/uploads/ubos/pdf%20documents/2010%20COBE%20Report.pdf

http://www.ulandssekretariatet.dk/sites/default/files/uploads/public/PDF/LMP/Imp\_cambodia\_2014\_final\_version\_revised.pdf https://psa.gov.ph/content/2013-annual-survey-philippine-business-and-industry-mining-and-quarrying-all-establishments

https://psip.malawi.gov.mw/reports/docs/Economic\_Report\_2014.pdf

				ſ	Miners							
				ŀ		es (accessed onli	ine on 05 sept 2	2016)				
WHO 2016									٩	er	ms	in a f
Тор ТВ		۴	≧		Number of miners in the formal sector	of which female miners	Estimated number of artisanal miners	(min - max)	of which female miners	incidence PTB (per 100,000)	incidence all forms (per 100,000)	(estimated) prevalence of TB in minders as a % of overall populaton
Burden	<b>T</b> B	MDR-TB	TB/HIV	Year	ber o form	hich fei miners	lated isana	- uic	hich fei miners	ence PTB 100,000)	ince a	stima lence ers a II po
Countries		-	-		umh the	of w	i stim farti	<u>د</u>	ofw	1 1	ncide (pe	e reval nind
	V	V	V	2009	<u> </u>		100.000	F00.000		.Ξ	.5	
Angola Azerbaijan	Y	Y Y	Y	2009			100.000	500.000				2
Bangladesh	Y	Ŷ		2005	103.000	13.900						
Belarus		Ŷ		2005	105.000	15.500						
Botswana		•	Y		12.733	1.661						2,5
Brazil	Y		Ŷ	2010	855.480	1.001	650.000					2,5
Cambodia	Ŷ			2004	15.200	6.800						
Cameroon			Y									
Central African Rep	Y		Y				60.000	120.000				
Chad			Y									
China	Y	Y	Y				3.000.000	15.000.000				
Congo	Y		Y									
DPR Korea	Y	Y										
DR Congo	Y	Υ	Y				800.000	1.500.000				
Ethiopia	Y	Y	Y				50.000	150.000				
Ghana			Y	2014	104.000		150.000	250.000	87.000			
Guinea-Bissau			Y				80.000	150.000				
India	Y	Y	Y	2014	512.270		500.000					
Indonesia	Y	Y	Y	2010	1.188.000		109.000		10.900			
Kazakhstan		Y		2003	15.950							
Kenya	Y	Y	Y	2007	5.249							
Kyrgystan		Y		2004	2.010							
Lesotho	Y		Y							3,085/100,0	000/year	S
Liberia	Y		Y				25.000	75.000				
Malawi			Y	2014	11.951		40.000		4.000			
Moldova	.,	Y		2006	2.683			60.000	40.000			
Mozambique	Y	Y	Y				12.000	60.000	18.000			
Myanmar	Y	Y	Y	2014	164.881	28.950	0.000	10.000				1,7
Namibia	Y		Y	2012	4 350 705	520 500	8.000	10.000				
Nigeria	Y	Y	Y	2012	1.358.795	529.590						
Pakistan	Y	Y	Y						12 000			
Papua New Guinea	Y	Y	Ŷ	2015	195.879		20.000		12.000			
Peru Philippines	Y	Y Y		2015 2013	35.940		30.000					
Russia	Y	Y		2013	1.068.000		1.034.000					
Sierra Leone	Y	T		2014	1.008.000		300.000	650.000				
Somalia	'	Y		$\vdash$			500.000	0.000				
South Africa	Y	Ŷ	Y	2016	473.000	60.750	8.000	25.000			7000	
Swaziland			Ŷ	2010	12.000	30.750	0.000					
Tajikistan		Y	•		12.000							
Tanzania	Y		Y		15.000		400.000	1.500.000	137.500			
Thailand	Ŷ	Y	Ŷ									
Uganda			Ŷ	2010	3.192	742						
Ukraine		Y		2007	52.690							
Uzbekistan		Y										
Viet Nam	Y	Y										
Zambia	Y		Y				25.000	50.000	9.000	288		
Zimbabwe	Y	Y	Y				200.000	400.000	153.000			
Countries with data	-		-									
(48 max)	30	30	30		22	7	21	15		2	1	3
					6.207.903	642.393		20.440.000	431.400			

# Figure 14: Current Data Available for Miners in 48 TB High Burden Countries

#### **5.3 Prisoners and Detainees**

According to the International Centre of Prison Studies, there are about 10 million prisoners and detainees on any day but could be anywhere 3-6 times this figure on an annual basis.<sup>87</sup> TB data among prisoners and detainees are rare with few countries systematically collecting such information. The latest effort to estimate the global total number of TB cases among prisoners and detainees was based on 25 countries and it found there are about 300,000 TB cases among prisoners and detainees around the world annually.<sup>88</sup> However the data available from these 25 countries are often a few years old.

At the country level, there are currently four sources of information on prisons, prisoners, drug use in prisons and TB prevalence. Apart from the size of prisoner population, most countries do not capture TB information in prisons, with the exception of Europe and Central Asia.

- World Prison Brief<sup>89</sup> This covers over 200 countries and territories worldwide with basic data on population size, percent male, female, and foreign born and prison occupancy capacity.
- The UNODC<sup>90</sup> website provides information on drug use in prison (ever and last 12 months) and drug use prevalence by drug class (any, cannabis, heroin, cocaine, ATS, ecstasy) of 50 countries.
- The UNAIDS's AidsInfo website<sup>91</sup> provides information on HIV prevalence among prisoners and detainees in over 50 countries.
- European CDC's TB Monitoring and Surveillance Reports<sup>92</sup> track TB cases and notification rates among prisoners and the proportion of prisoners among all TB cases in over 20 countries.

An article published in a special edition of Lancet in July 2016<sup>93</sup> provided information on the prevalence of TB and HIV-TB co-infection in 25 countries.

The table below shows data available for the 48 countries identified by WHO in 2016 as TB High Burden Countries. It is clear that apart from the population size of prisoners and detainees, TB data are scarce and often not up-to-date (last two columns of data from European CDC and Lancet). This is exacerbated because TB among prisoners is not a reporting requirement in UNODC's and WHO's annual reporting for countries.

<sup>&</sup>lt;sup>87</sup> International Centre for Prison Studies (2016) "World Prison Population List – 11<sup>th</sup> edition"

<sup>(</sup>http://www.prisonstudies.org/sites/default/files/resources/downloads/world\_prison\_population\_list\_11th\_edition\_0.pdf) <sup>88</sup> Kate Dolan, Andrea L Wirtz, Babak Moazen, Martial Ndeff o-mbah, Alison Galvani, Stuart A Kinner, Ryan Courtney, Martin McKee, Joseph J Amon, Lisa Maher, Margaret Hellard, Chris Beyrer, Fredrick L Altice (2016). "Global Burden of HIV, Viral Hepatitis, and Tuberculosis in Prisoners and Detainees", Lancet 14 July 2016 "HIV and Related Infections in Prisoners Series" <sup>89</sup> International Centre for Prison Studies (2016) "World Prison Population List – 11<sup>th</sup> edition"

<sup>90</sup> UNODC (2016) https://data.unodc.org/ (accessed 26 Aug 2016)

<sup>&</sup>lt;sup>91</sup> UNAIDS (2016) <u>http://aidsinfo.unaids.org/</u> (accessed 26 Aug 2016)

<sup>&</sup>lt;sup>92</sup> European Centre for Disease Prevention and Control (2016) "TB Surveillance and Monitoring Report 2016 - Table 19" (https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/ecdc-tuberculosis-surveillance-monitoring-Europe-2016.pdf)

<sup>2016.</sup>pdf) <sup>93</sup> Kate Dolan, Andrea L Wirtz, Babak Moazen, Martial Ndeff o-mbah, Alison Galvani, Stuart A Kinner, Ryan Courtney, Martin McKee, Joseph J Amon, Lisa Maher, Margaret Hellard, Chris Beyrer, Fredrick L Altice (2016). "Global Burden of HIV, Viral Hepatitis, and Tuberculosis in Prisoners and Detainees (Appendices A8 and A9)" Lancet 14 July 2016 "HIV and Related Infections in Prisoners Series"

				Wor	ld Prisoners	Brief (ac	cessed or	nline on 2	6 Aug 2010	5)		d UNAIDS (ad n 26-28 Aug		& Monit	CDC (TB Sur oring 2016 Table 19)		Lancet (July 2 on TB and HIV Table A8	in Prisons,
Countries	TB/HIV	Pop	% Pre-trial Detainees	% Female	% Junveniles/ Minor/Young	% Foreign	Number of Facilities	Capacity	Drug Use in Prison in Last 12 Months (UNDOC)	HIV Prevalence (UNAIDS)	HIV Prevalence (UNODC)	Number of New TB Cases (all forms) Notified	Rate of New TB Cases (all forms) Notified (per 100,000)	Prison % of all TB cases in country	Prevalence of Active TB (per 100,000)	HIV-TB Co-infection %		
Angola	Y	Y	Y	24,165	47.1%	2.7%			40	110.8%								
Azerbaijan	+	Y		22,526	16.9%	2.8%	0.3%	2.5%	53	81.4%			2.90%	321	1,801	5.5%		
Bangladesh Belarus	Y	Y Y		69,719 29,000	73.8% 19.0%	3.4% 6.8%	0.4%	0.1%	68 34	201.0% 96.8%				99	341	2.2%	600	
Botswana		-	Y	3,960	24.5%	2.4%	6.6%	3.1%	23	96.8%				39	541	2.2%		
Brazil	Y		Y	622,202	36.3%	6.0%	0.0%	0.4%	1,424	157.2%							917	0.3%
Cambodia	Y		·····	18,308	69.1%	7.8%	3.4%	4.6%	28	206.1%			3%					0.57
Cameroon	1		Y	26,702	59.9%	2.5%	3.3%	2.4%	78	157.1%			7.80%				3,197	
Central African Rep	Y		Y	764	70.2%	8.2%			5			1.8%						
Chad			Y	4,831	63.4%	2.8%	3.3%	1.3%	45	232.3%								
China	Y	Y	Y	1,649,804		6.5%	0.8%	0.4%										
Congo	Y		Y	1,240	60.0%	3.7%	4.4%		12									
DPR Korea	Y	Y																
DR Congo	Y	Y	Y	20,550	73.0%	3.0%			120			3.9%	8.3%				4 400	2.00
Ethiopia Ghana	Y	Y	Y Y	111,050	14.0%	2.8%	0.9%	6.4%	126 43	143.3%		2.3%	10.20/				1,482	3.6%
Guinea-Bissau			Y	14,150 92	18.5%	4.3%	0.9%	0.4%	43	143.3%		2.3%	19.2%					
India	Y	Y	Y	418,536	67.6%	4.3%	0.0%	1.5%	1,387	102.2%								
Indonesia	Y	Ŷ	Ŷ	180,347	33.1%	5.5%	3.2%	0.6%	428	149.2%	37.8%	3.0%	29.8%					
Kazakhstan	<u> </u>	Ŷ		39,179	14.5%	7.7%	0.3%	4.5%	93	68.9%		3.9%	3.7%	1,056	1,971	5.6%		
Kenya	Y	Y	Y	57,000	40.4%	5.3%	0.5%	0.7%	108	202.4%			8.2%					
Kyrgystan	-	Y		10,030	23.4%	3.9%	0.3%	4.9%	24	56.8%	15.0%		15.0%	125	1,609	1.8%		
Lesotho	Y		Y	2,073	19.5%	3.6%	2.4%	0.9%	12	70.6%								
Liberia	Y		Y	2,203	83.0%	3.2%	2.7%	2.0%	15	137.5%								
Malawi			Y	12,129	16.1%	1.1%	7.7%	0.2%	30	173.7%							2,900	
Moldova		Y	Y	7,881	19.3%	6.2%	0.4%	1.3%	17	91.1%	2.7%	24.0%	3.4%	142	1,858	3.2%		
Mozambique Myanmar	Y	Y Y	Y	15,976 60,000	32.9% 10.8%	3.9% 16.3%	0.0%	0.9%	184 142	195.1% 144.3%	30.0%	24.0%	17.5%					
Namibia	Y		Y	3,560	6.6%	2.4%	1.0%	5.5%	142	96.4%	50.0%							
Nigeria	Ŷ	Y	Ŷ	63,142	71.7%	1.7%	1.7%	0.3%	240	125.9%			2.4%				1,800	8.9%
Pakistan	Y	Ŷ	· · ·	80,169	69.1%	2.1%	1.7%	1.2%	88	171.6%			2.0%				2,200	
Papua New Guinea	Y	Y	Y	4,864	37.8%	5.0%	3.9%	0.4%	18	116.8%								
Peru		Y		77,298	50.6%	5.9%	0.0%	2.4%	67	234.3%		0.5%						
Philippines	Y	Y		142,168	63.6%	8.9%	0.4%	0.4%	1,137	316.0%								
Russia	Y	Y		650,633	18.1%	8.1%	0.2%	3.9%	975	82.2%	12.4%			11,627	1,704	11.0%	14,900	
Sierra Leone	Y			3,488	54.3%	3.3%	0.0%	1.3%	19	195.4%								
Somalia South Africa	Y	Y Y	Y	159,563	27.1%	2.6%	0.3%	6.3%	236	132.7%							8,800	5.1%
South Africa Swaziland	Υ Υ	r	Y Y	3,610	27.1%	2.6%	0.3%	6.0%	236	132.7%		34.9%	34.9%				8,800	5.1%
Tajikistan	+	Y		9.317	15.0%	1.6%	1.0%	4.9%	22	61.5%		54.570	54.570	112	1,120	2.0%	4,500	
Tanzania	Y	· · ·	Y	34,404	50.0%	3.4%	3.9%	3.7%	126	115.7%		6.7%	6.7%		_,		.,_50	
Thailand	Y	Y	Ŷ	321,347	17.5%	13.7%		4.2%	144	144.8%					1		1,300	
Uganda	1		Y	45,092	55.0%	4.5%	0.0%	0.4%	247	273.0%			11.0%		1		654	
Ukraine		Y		61,816	26.9%	4.5%	0.7%	1.7%	148	63.0%		1	13.6%	1,710	1,347	4.7%	4,100	
Uzbekistan		Y		43,900	10.0%				58	80.0%								
Viet Nam	Y	Y		136,245	17.6%	12.1%		0.2%	53									
Zambia	Y		Y	18,560	23.2%	1.0%	2.5%	2.1%	88	229.1%		27.4%	27.4%	ļļ.			12,000	1.6%
Zimbabwe	Y	Y	Y	18,857	17.1%	1.8%	0.5%	2.0%	46	110.9%		28.0%						
Countries with data																		

# Figure 15: Current Data Available for Prisoners and Detainees in 48 TB High Burden Countries

#### 5.4 People Who Use Drugs

According to UNODC there are about 250 million people who use drugs in the world.<sup>94</sup> The majority are occasional users but 29 million have drug use disorders and 12 million inject drugs. Among those injecting, 1.6 million have HIV and 6 million infected with Hepatitis C. And 200,000 died due to overdose. Of the 250 million PWUD, the majority are cannabis users (183 million), which is then followed by amphetamines (36 million), ecstasy (19 million), cocaine (18 million) and opiates (17 million).

Casual cannabis smokers consuming on their own or with others in well-ventilated or open space are probably faced with minimal risk of TB. But those engaged in injecting of any drugs or sharing equipment and inhaling and exhaling directly into each other's mouths are faced with elevated TB risks.<sup>95</sup>

Despite the known TB mortality risks experienced by PWUD infected with HIV, no TB data for PWUD. Even among those injecting (People who Inject Drugs, PWID), data on TB prevalence is very scarce.

At the country level, there are two sources of information on PWUD by drug class (amphetamines, cocaine, ecstasy, opiates), PWID and HIV prevalence:

- The UNODC website<sup>96</sup> covers the number of PWID, HIV/HCV/HBV prevalence among PWID, drugrelated deaths and number of users of different classes of drugs in over 200 countries/territories.
- The UNAIDS AidsInfo<sup>97</sup> provides information HIV prevalence among PWID in 83 countries.

A recent study in Tanzania found a TB prevalence of 4% among PWID who are on Methadone Maintenance Treatment.<sup>98</sup> This is 23 times of the 0.2% prevalence among the general population.

The table below shows data available for the 48 countries identified by WHO in 2016 as TB High Burden Countries. There are no data on TB prevalence available for PWUD. TB among PWUD (or PWID) is currently not a reporting requirement in UNODC's and WHO's annual reporting requirements for countries. When available, data are related to PWID's HIV prevalence. No data are available for PWUD who do not inject drugs or those who both inject and do not inject drugs. Also lacking are data about factors that put PWUD at higher risk of TB such as drug use patterns (combination of drug taking behaviour between injecting and non-injecting) and drug-taking behaviour (e.g., equipment sharing, inhaling and exhaling into each other's mouth) and space (level of air ventilation). These types of information are critical for designing prevention and health services for PWUD.

 <sup>&</sup>lt;sup>94</sup> UNODC (2016) "World Drug Report 2016" (<u>http://www.unodc.org/doc/wdr2016/WORLD\_DRUG\_REPORT\_2016\_web.pdf</u>)
 <sup>95</sup> Haileyesus Getahun a, Annabel Baddeley a & Mario Raviglione (2013) "Managing Tuberculosis in People Who Use and Inject Illicit Drugs" Bulletin of the World Health Organization 2013; 91:154-156 (<u>http://www.who.int/bulletin/volumes/91/2/13-117267/en/</u>)
 <sup>96</sup> UNDOC (2016) <u>https://data.unodc.org/</u> (accessed 2 Aug 2016)

<sup>&</sup>lt;sup>97</sup> UNAIDS (2016) http://www.aidsinfoonline.org/devinfo/libraries/aspx/Home.aspx (accessed 27 Aug 2016)

<sup>&</sup>lt;sup>98</sup> Gupta A, Mbwambo J, Mteza I, Shenoi S, Lambdin B, Nyandindi C, Doula BI, Mfaume S, Bruce RD (2014) "Active Case Finding for Tuberculosis Among People Who Inject Drugs on Methadone Treatment in Dar es Salaam, Tanzania." International Journal of Tuberculosis and Lung Diseases, 18(7):793-8. doi: 10.5588/ijtld.13.0208.

				Peopl	e who l	Jse Dru	ıgs												
						UNDO	C and UNA	IDS AIDSinfo	o (accessed	online on	27-28 Aug 2	016)			UNODC Estin		l on World Ba online 27 Aug		on Data
WHO 2016 TB High Burden Countries	TB	MDR-TB	TB/HIV	% of Aged 15-64 who are PWIDs (UNDOC)	Number of Aged 15-64 PWIDs (UNODC)	% of PWIDs HIV+ (UNDOC)	% of PWIDs HIV+ (UNAIDS)	Number of PWIDs HIV+ (UNODC)	Number of PWIDs HIV+ (UNAIDS)	Drug-Related Deaths (UNDOC)	% of Aged 15-65 who Use Amphetamines (UNODC)	% of Aged 15-65 who Use Cocaine (UNDOC)	% of Aged 15-65 who Use Ecstasy (UNDOC)	% of Aged 15-65 who Use Opiates (UNODC)	2015 Aged 15-64 (World Bank)	Number Aged 15-65 who Use Amphetamines	Number Aged 15-65 who Use Cocaine	Number Aged 15-65 who Use Ecstasy	Number Aged 15-65 who Use Onitate
Angola	Y	Y	Y							AND AND AND AND ADDRESS					12,520,017				
Azerbaijan		Y		1.08%	71,283	9.5%	9.5%	6,772	6,772	31				1.50%	6,992,920				104,89
Bangladesh	Y	Y Y		0.20%	24,240 76,281	5.3% 14.2%	1.1%	1,285 10,832	267 19,147	271	0.35%	0.06%	0.31%	0.37%	105,580,087 6,654,426	23.290	3,993	20,629	390,64 39,26
Belarus Botswana			Y	1.1170	70,201	14.2%	25.1%	10,652	19,147	2/1	0.55%	0.00%	0.51%	0.59%	1,457,127	25,290	5,995	20,029	59,20
Brazil	Y		Y	0.23%	227,253	5.0%	5.9%	11,294	13,408	200		0.70%	0.20%		143,680,172		1,005,761	287,360	
Cambodia	Ŷ			0.01%	1,300	24.8%	24.8%	322	322	200	0.60%	0.7070	0.14%	0.03%	10,013,439	60,081	1,005,701	14,019	3,00
Cameroon			Y												12,669,290				1
Central African Rep	Y		Y											0.05%	2,797,661				1,39
Chad			Y											0.22%	6,994,721				15,38
China	Y	Y	Y	0.19%	1,930,000	8.4%	5.9%	162,313	113,870					0.19%	1,003,968,793				1,907,54
Congo	Y		Y											0.13%	2,481,507				3,22
DPR Korea	Y	Y													17,430,908				
DR Congo	Y	Y	Y			13.3%	11.3%							0.13%	39,439,399				51,27
Ethiopia	Y	Y	Y Y			0.7%								0 1 49/	54,740,332				22.17
Ghana Guinea-Bissau			Y			0.7%				**** **** **** ****				0.14%	15,839,827 1,033,535				22,17
India	Y	Y	Y	0.20%	177,000	7.1%	9.9%	12,638	17,523						859,993,590				
Indonesia	Y	Y	Y	0.07%	105,784	39.7%	28.8%	41,996	30,466	447	0.18%	0.01%	0.19%	0.11%	172,912,592	311,243	17.291	328.534	190,20
Kazakhstan		Y		0.95%	110,940	7.9%	8.2%	8,764	9,097	323				0.89%	11,675,065		<u> </u>		103,90
Kenya	Y	Y	Y	0.52%	49,167	18.3%		8,998		1,571		0.30%	0.25%	0.22%	25,460,518		76,382	63,651	56,01
Kyrgystan		Y		0.75%	25,000	12.4%		3,100		170	Ì			0.74%	3,834,611				28,37
Lesotho	Y		Y												1,276,424				ļ
Liberia	Y		Y				3.9%							0.17%	2,462,608				4,18
Malawi			Y	1.23%	24.562	8.5%	8.5%	2 (02	2 (02	27	0.03%	0.04%	0.10%	0.420/	8,848,909	792	1.050	2.644	246
Moldova Mozambique	Y	Y Y	Y	0.01%	31,562 1,910	8.5%	8.5%	2,683	2,683	27	0.03%	0.04%	0.10%	0.12%	2,641,041 14,366,015	/92	1,056	2,641	3,16
Myanmar	Y	Y	Y	0.01%	83,000	23.1%	23.1%	19,206	19,173	22	0.22%			0.80%	36,159,453	79,551			289,27
Namibia	Ŷ	<u> </u>	Y	0.2370	03,000	23.1/0	23.170	13,200	13,173		0.22/0			0.0076	1,470,005	15,551			205,27
Nigeria	Y	Y	Y	0.02%	18,801	4.2%	3.4%	790	639		1.40%	0.70%		0.70%	97,066,480	1,358,931	679,465		679,46
Pakistan	Y	Y		0.40%	430,000	37.8%	27.2%	162,540	116,960		0.12%	0.01%		1.00%	114,295,357	137,154	11,430		1,142,95
Papua New Guinea	Y	Y	Y								1				4,560,020				
Peru		Y				13.0%				42	0.20%	0.70%	0.04%	0.18%	20,482,451	40,965	143,377	8,193	36,86
Philippines	Y			0.35%	14,456	46.1%	29.0%	6,664	4,192		2.13%	0.03%	0.18%	0.04%	63,915,738	1,361,405	19,175	115,048	25,56
Russia	Y	Y		2.29%	2,351,235	24.6%		577,228		8,189	0.39%	0.23%	0.68%	1.40%	100,698,078	392,723	231,606	684,747	
Sierra Leone	Y	Y		0.04%	1,500								0.16%	0.17%	3,547,159 5,444,348			8,711	6,03
Somalia South Africa	Y	Y Y	Y	0.21%	67,000	14.0%		9,380			1.02%	1.02%	0.16%	0.41%	5,444,348	368,442	368,442	8,711 111,977	148,09
Swaziland	<u> </u>	<u> </u>	Y	0.21/0	07,000	14.0/0		0,000			1.02/0	1.02 /0	0.31/0	0.41%	760,113	500,442	500,442	111,377	148,09
Tajikistan		Y		0.45%	23,100	13.5%	13.5%	3,119	3,119	47				0.54%	5,271,996				28,46
Tanzania	Y		Y	0.12%	30,000	36.0%	15.5%	10,800	4,650						27,590,383			******	
Thailand	Y	Y	Y	0.08%	40,300	19.0%	19.0%	7,665	7,657		1.40%	0.05%	0.30%	0.20%	48,806,616	683,293	24,403	146,420	97,61
Uganda			Y								ļ			0.05%	19,289,981				9,64
Ukraine		Y		1.05%	332,500	19.7%	21.9%	65,503	72,818	3,311	0.72%	0.52%	0.93%	1.05%	31,533,063	227,038	163,972	293,257	331,09
Uzbekistan		Y	ļ	0.47%	80,000	7.3%	5.6%	5,840	4,480	547				0.78%	20,915,060				163,13
Viet Nam	Y	Y		0.43%	271,506	10.3%	9.3%	27,965	25,250	2,184	0.22%		0.22%	0.53%	64,348,378	141,566		141,566	341,04
Zambia Zimbabuua	Y	~	Y Y								0.10%		0.30%	0.37%	8,296,609	8,297		24,890	30,69
imbabwe Countries with data	Y	Y												0.04%	8,649,405				3,46
(48 max) Total	30	30	30	26	26	27		24		15	15	13	15	33	<b>48</b> 3,266,987,987	15	13	15	33

# Figure 16: Current Data Available for People Who Use Drugs in 48 TB High Burden Countries

5.5 People Living with HIV

According to UNAIDS, there are 37 million PLHIV around the world,<sup>99</sup> and 1.2 million of them are co-infected with TB annually accounting for 11% of all TB cases.<sup>100</sup> PLHIV are 20 to 22 times more likely than the general population to develop active TB, which accounted for 35% of deaths among PLHIV in 2015.<sup>101</sup>

At the country level, there are two sources of information on PLHIV population size and TB burden:

- UNAIDS AidsInfo<sup>102</sup> provides PLHIV numbers (often with breakdowns of HIV key populations injecting drug users, sex workers, men who have sex with men, transgender) for over 100 countries/territories
- WHO Global Tuberculosis Report<sup>103</sup> provides information on TB case notifications. PWTB tested for HIV, HIV and TB co-infection, HIV treatment (ART) and TB preventive treatment (CPT, IPT) in over 200 countries/territories

The table below shows data available for the 48 countries identified by WHO in 2016 as TB High Burden Countries. PLHIV size and TB burden data are readily available, but needs alignment between UNAIDS and WHO to ensure countries' reporting through their annual data reporting requirements support service cascade from active case finding to treatment outcome.

<sup>102</sup> UNAIDS (2016) http://www.aidsinfoonline.org/devinfo/libraries/aspx/Home.aspx (accessed 28 Aug 2016)

<sup>103</sup> WHO (2015) "Global Tuberculosis Report 2015", Table 4.8

<sup>&</sup>lt;sup>99</sup> UNAIDS (2016) "Global AIDS Update 2016" (<u>http://www.unaids.org/sites/default/files/media\_asset/global-AIDS-update-</u> 2016 en.pdf)

<sup>&</sup>lt;sup>100</sup> WHO (2016) "Global Tuberculosis Report 2016" (<u>http://apps.who.int/iris/bitstream/10665/250441/1/9789241565394-</u> eng.pdf?ua=1) <sup>101</sup> WHO (2017) "Tuberculosis Fact Sheet" (<u>http://www.who.int/mediacentre/factsheets/fs104/en/)</u> (accessed 10 Mar 2017)

<sup>(</sup>http://apps.who.int/iris/bitstream/10665/191102/1/9789241565059\_eng.pdf)

				People	Living w	ith HIV								
				UNAIDS (AID	Sinfo databa	se accessed o	nline on 28	Aug 2016)		WHO Glob	al TB Report	2015 (Table	4.8)	
WHO 2016 TB High Burden Countries	B	MDR-TB	TB/HIV	Number of PLHIV in 2014 (estimate)	PLHIV Screened for TB in 2014 or Last Year with Data	HIV-TB Incidents in 2014 (estimate)	% of PLHIV with TB on Both TB and HIV Treatments (estimate)	Number of PLHIV on TB Preventive Therapy in 2014	Total TB (all forms) Patients Notified in 2014	TB Patients with Known HIV Status among all Notified in 2014	TB Patients Diagnosed HIV+ among all Notified in 2014	PLHIV-TB Patients on CPT (Pneumonia Preventive Treatment) among all Notified in 2014	PLHIV-TB Patients on ART among all Notified in 2014	PLHIV on IPT (TB Preventive Treatment) in 2014
Angola	Y	Y	Y	315,394	246	23,000	5%	1,100	55,206	27,699	2,827	2,827	101	
Azerbaijan	v	Y	ļ	10,659	1,661	130	78%	296 0	7,539	7,004	148	45	101	286
Bangladesh Belarus	Y	Y Y		9,636 2,635	726 8,928	570 310	8% 62%	539	196,797 4,274	1,110 4,274	45 271	45 271	45 191	C 539
Botswana	$\left  - \right $	1	Y	348,928	8,928	4,500	57%	738	4,274 6,019	4,274 5,496	3,280	3,132	2,546	539
Brazil	Y		Y	826,698	37,540	16,000	60%	674	81,512	56,981	9,578	5,132	2,340	
Cambodia	Y		<u> </u>	74,104	3,504	1,800	52%	901	43,738	35,635	953	938	938	901
Cameroon			Y	619,216	57,682	20,000	30%	1,373	26,517	23,006	8,565	7,679	5,955	
Central African Rep	Y		Y	118,776	184	7,600	15%	0	10,186	5,201	1,781			
Chad			Y	165,590	960	6,000	12%		12,305	6,636	1,291		721	1
China	Y	Y	Y	501,000	423,254	13,000	28%	0	826,155	343,515	5,309		3,675	
Congo	Y		Y	74,000	2,838	5,500	2%	0	10,194	1,313	386	104	94	
DPR Korea	Y	Y	ļ			310	1%	0	110,290					
DR Congo	Y	Y	Y	374,097	33,743	34,000	14%	0	116,894	53,285	7,206	5,671	4,799	
Ethiopia	Y	Y	Y	793,700	341,534	19,000	18%	10,385	119,592	89,320	8,670		3,396	10,385
Ghana			Y	274,562	49,343	11,000	10%	0	15,276	11,830	2,858	1,910	1,104	
Guinea-Bissau	<u> </u>		Y	41,000	11,420	2,900	5%	448	2,288	1,510	561	282	149	448
India	Y Y	Y Y	Y Y	2,118,060	1,114,394	110,000	36%	0	1,683,915	1,034,712	44,171	41,066	39,800	
Indonesia Kazakhstan	ř	Y Y	ř	692,777 23,134	22,190 12,446	63,000 590	1% 80%	805	324,539 15,718	15,074 15,435	2,355 625	963 487	624 472	805
Kenya	Y	Y	Y	1,517,670	426,102	40,000	65%	005	89,294	84,423	30,002	29,375	26,142	005
Kyrgystan	<u> </u>	Y	<u> </u>	8,098	2,147	180	62%	95	7,423	04,425	221	118	112	95
Lesotho	Y		Y	308,068	21,408	12,000	41%	16,403	9,856	9,145	6,600	6,600	4,866	
Liberia	Y		Y	30,205	161	2,100	5%	0	2,726	2,801	402	214	112	
Malawi	1		Y	976,281	515,554	19,000	43%	135,013	17,723	16,445	8,844	7,995	8,162	135,013
Moldova		Y	1	17,985	4,025	500	28%	0						
Mozambique	Y	Y	Y	1,505,910	563,377	85,000	28%	94,252	58,270	55,943	29,337	27,504	23,801	94,252
Myanmar	Y	Y	Y	224,795	54,178	19,000	12%	2,997	141,957	56,133	6,412	4,666	2,319	2,997
Namibia	Y		Y	210,847	93,845	5,600	60%	15,795	9,882	9,088	3,994	3,940	3,360	
Nigeria	Y	Y	Y	3,500,000	335,357	100,000	12%	26,383	91,354	84,161	16,066	14,569	11,997	26,383
Pakistan	Y	Y	L	102,042	2,917	6,400	1%	0	316,577	10,715	90	90	90	
Papua New Guinea	Y	Y Y	Y	40,110	2,812	3,500	14%	325	28,567	7,218	781	246 578	484 913	1 1 2 2
Peru	Y	Y Y		66,195	2,698	2,500	37%	1,126	31,461	23,280	1,385	20	53	1,126
Philippines Russia	Y Y	Y Y		42,453 522,611	5,995 235,753	2,500 5,500	2%	226 10,451	267,436 136,168	53,354 67,425	108 5,251	20	53	
Sierra Leone	Y			51,065	10,473	2,300	39%	1,339	12,721	11,048	1,305	816	887	1,339
Somalia	÷	Y		30,206	674	2,300	5%	226	13,130	7,714	248	166	111	226
South Africa	Y	Ŷ	Y	6,984,580	1,148,477	270,000	53%	551,787	318,193	295,136	179,756	155,017	141,755	
Swaziland	1		Y	218,550	110,370	5,900	53%	1,188	5,616	5,430	3,972	3,904	3,123	1,188
Tajikistan		Y		16,185	3,367	230	56%	280	6,260	5,656	161	156	128	280
Tanzania	Y		Υ	1,385,780	525,713	62,000	27%	23,124						
Thailand	Y	Y	Y	438,101	41,131	15,000	31%	127	71,618	50,670	6,831	4,359	4,691	
Uganda	4		Y	1,461,740	729,268	28,000	57%	121	46,171	43,883	19,612	19,211	15,877	
Ukraine	ļ	Y	ļ	218,972	1,184	8,100	53%	16,263	40,302	39,057	7,640	3,350	4,273	16,263
Uzbekistan		Y	ļ	32,704	780	830	43%	2,438	22,804	22,347	780	615	354	2,438
Viet Nam	Y	Y		255,113	90,592	7,000	40%	5,663	102,087	74,092	3,875	2,936	2,827	
Zambia Zimbabwo	Y Y	v	Y	1,211,880	11,961	38,000	46%	850	42,716	39,763	24,198	21,929	17,611	20 420
Zimbabwe	ŗ	Y	Y	1,425,760	133,997	25,000	66%	30,420	32,016	28,508	19,290	18,200	16,522	30,420
Countries with data (48 max)		30	30	47	47	<b>48</b>	47	<b>47</b>	<b>46</b>	44	45	38	41	21
Total				30,187,872	7,197,079	1,107,550	35%	954,151	5,591,282	2,842,471	478,041	391,949	355,180	877,171

# Figure 17: Current Data Available for People Living with HIV in 48 TB High Burden Countries

# 6. Rapid Assessment

A rapid assessment is a useful way of filling some data gaps and deciding on how to properly sample a key population. A rapid assessment is typically used in situations where data are needed quickly, where time or cost constraints rule out the use of other more conventional research techniques, and where organizations require current, relevant data to develop, implement, monitor or evaluate health programmes. It involves focusing on the characteristics of the health problem (TB related exposure and risk), the population groups affected, key settings and contexts, and social environment. It can also help you decide on which sampling methods to use if you decide to undertake a probability based survey (see Section 7 below). It can also identify existing resources and opportunities for more data collection and for planning, developing and implementing interventions and programmes.

Rapid assessments commonly use qualitative data collection methods. Qualitative research is usually non-statistical, non-representative and exploratory and commonly measures perceptions, beliefs, opinions, and behaviours of populations using in-depth interviews, group discussions, mapping or observation.<sup>104</sup> Below is an overview of steps and methods for conducting a rapid assessment. As it is impossible to cover all aspects of conducting a rapid assessment in this document, resources are provided as well.<sup>105</sup>

# 6.1 Identifying Data Gaps

Data gaps can be identified as you complete the Key Population TB Risks, Risk Drivers and Service Challenges Template (Annex A1) and National Key Populations Prioritization Template (Annex A4). These templates will help you to identify what types of data are still needed to understand and prioritize your efforts in combating TB in your country.

#### **Target population**

It is important to be certain about which target population(s) to investigate. You may identify that more than one group needs to be researched. Focusing on more than one population will require more resources and time. Furthermore, the selected target population to investigate may be a subgroup within a population such as in the example above, rural miners (a sub group within the group of all miners). Or maybe you are interested in a certain age group or sex. Focusing on a particular subgroup within a

Public Health-Seattle and King County, Seattle (2008) "RARE Project: Rapid Assessment, Response and Evaluation: Final Report and Recommendations." (<u>http://www.kingcounty.gov/health/services/health/communicable/hiv/publications/rare.aspx</u>)

UNICEF (2002) "Rapid Assessment and Response on HIV/AIDS among Especially Vulnerable Young People in Albania." (<u>http://www.unicef.org/albania/hivaidsalbania.pdf</u>)

WHO (1998) "The Rapid Assessment and Response Guide on Injecting Drug Use."

WHO (2003) "RAR Review: An International Review of Rapid Assessments Conducted on Drug Use" (http://www.who.int/substance\_abuse/publications/en/rar\_review.pdf)

<sup>&</sup>lt;sup>104</sup> Bryman A. (2012) "Social Research Methods." Oxford University Press, p.766

<sup>&</sup>lt;sup>105</sup> Atun RA, Lennox-Chhugani N, Drobniewski F, Samyshkin YA, Čoker RJ. (2004) "A Framework and Toolkit for Capturing the Communicable Disease Programmes within Health Systems: Tuberculosis Control as an Illustrative Example." European Journal of Public Health, 14(3): 267–73.

Kamineni VV, Turk T, Wilson N, Satyanarayana S, Chauhan LS. (2011) "A Rapid Assessment and Response Approach to Review and Enhance Advocacy, Communication and Social Mobilisation for Tuberculosis Control in Odisha State, India." BMC Public Health 11(1):463.

WHO (1998) "Rapid Assessment and Response Guide on Psychoactive Substance Use and Especially Vulnerable Young People (EVYP-RAR)" (http://www.who.int/substance\_abuse/publications/epidemiology/en/)

<sup>(</sup>http://www.who.int/substance\_abuse/publications/en/IDURARguideEnglish.pdf?ua=1)

WHO (2002) "SEX-RAR Guide: The Rapid Assessment and Response Guide on Psychoactive Substance Use and Sexual Risk Behavior" (http://www.who.int/mental\_health/media/en/686.pdf)

WHO (2003) "Rapid Assessment and Response Technical Guide Version 1.0"

<sup>(</sup>https://www.urbanreproductivehealth.org/toolkits/measuring-success/rapid-assessment-and-response-technical-guide)

WHO (2004) "Rapid Assessment and Response Adaptation Guide on HIV and Men Who Have Sex with Men." (http://www.who.int/hiv/pub/prev\_care/en/msmrar.pdf)

population may become more appropriate as the assessment moves forward and more information is obtained.

Example: The rapid assessment team was interested in interviewing people who use drugs in a section of town where users were known to buy drugs. As very little was known about people who use drugs overall, the initial aim of the interviews was to focus on a group of drug users suspected of being at very high risk for TB. Upon interviewing drug users at this location, it became apparent that there was another type of drug user who had previously not been recognized by the rapid assessment team. This type of drug user was smoking a new type of drug which was most commonly shared in crowded 'dens'. On asking about these drug users, it was discovered that they may be at much higher risk for TB than the group that had been initially identified. A member from the original subgroup introduced a rapid assessment team member to the newly identified group. It was quickly decided that interviews and a possible focus group was needed among this subgroup. With these findings, the rapid assessment team decided to focus more of the assessment on the newly identified subgroup since it appeared that they would have even greater barriers to and needs for TB interventions.

In addition to interviewing TB key populations, conduct meetings with community representatives including NGOs working directly with these populations, religious organizations, health-care professionals, government officials, and other groups and individuals who could provide additional information about TB among these populations.

Although it is important to establish clear aims with respect to selected target populations when conducting assessments, it is best to remain adaptable by following new leads. Conversely, if during the planning stage, the rapid assessment team is only able to find a small number of representatives from the community or key populations at higher risk to interview, it is common that the number of interviews will expand greatly as you progress.

#### **Geographical area**

Unless mapping has recently been conducted, the rapid assessment team will not know all of the locations where TB key populations can be found. Furthermore, even though NGOs or other groups working with these populations may be familiar with most areas where they are located, deeper penetration into the sphere of these populations will probably reveal areas previously unknown to researchers.

In specifying a geographical area to investigate, it is a good idea to list some of the places on which to focus. However, it is important to be open to modifying this focus during the course of the work. Generally, however, it helps to specify geographical scale. Thus, for example, if the rapid assessment is being conducted in a city, it may be decided to focus on a particular neighbourhood, or perhaps on various research sites around the city. Make an initial plan of the geographical area that will be covered in the assessment so that everyone involved may have a clear understanding of where the work will be carried out.

#### Time involved

Being adaptable to following leads as you progress in the assessment depends on the time available for these activities. When planning a rapid assessment, it is important to think carefully about how long the assessment work should take. Set clear dates as to when the assessment will begin and end. This will most likely also depend on the allotted budget. The initial assessment stages of an assessment should not last longer than a couple of months.

# Budget

The budget will affect the scope and focus of a rapid assessment. The planning stages should include the development of a detailed budget for the resources available, indicating how these will be allocated

to different aspects of the process. Specific sums of money should be allotted for payment to and/or expenses of those carrying out fieldwork, data analysis, paper work and printing costs. Other costs may include the provision of incentives or gifts for those interviewed.

#### Methodology

Finally, think carefully about the data collection methods to be used. Rapid assessments work best when a variety of methods are used to collect data. Data from these different methods will help to develop a more complete picture of the situation under investigation.

#### Concept note and interviewer guide

Once you identify the key gaps in data, create a template of core research themes and key questions to fill in data gaps. For instance, if there are only data about TB exposure among miners in urban mines but not in rural mines, then create a list of TB exposure questions to ask among rural miners through a rapid assessment. In some cases, a full survey may be needed to get representative data (see Section 7). Once your core research themes (i.e., using the example above, the theme would be TB exposure) and related questions are developed and identified, it is a good idea to create a short concept note describing the purpose of the rapid assessment as well as the target population, geographical area, timing, types of methods to be used and who will be interviewed. In addition, interview guides should be developed. An interview guide lists the questions, topics and issues that the team want to cover during the interview. It can include instructions on how to respond to certain answers, the order and wording in which the questions should be asked, and probes and prompts to encourage the respondent to speak so that a more in-depth response is elicited or certain topics elaborated. An interview guide should avoid:

- Ambiguity
- Double questions
- Leading questions
- Complex questions
- Technical questions

As the assessment progresses and new information is learned, parts of the interview guide will be modified. Once you have developed the concept note and an interview guide, it is good idea to share it with key decision makers for input.

#### Data collection team

A data collection team should include those familiar with research methods as well as members of key populations. Key populations are valuable for planning, collecting data and interpreting findings. Having staff members who are part of the key population will ensure that research is relevant and will be used.

#### **Data collection methods**

Data can be collected through existing literature, reports and other materials (see Section 5) or through interviews. Interviewing is the systematic collection of data, through asking questions and carefully listening to and recording or noting the answers. Interviews can take place in any location, at any time, and with different individuals or groups of people. They may be formal or informal. There are three main interview techniques that can be used: unstructured, structured and group.

# Figure 18: Interview Techniques and the Advantages and Disadvantages

Interview	What it is	What else	Advantages	Disadvantages
type Unstructured interview	Uses a loose interview guide (see below) and an open- ended question format to encourage interviewees to offer their opinions, knowledge and experience freely.	Requires careful thought about which questions to ask, how they are phrased and when to use probes and prompts; interviewers need good facilitation/ communication skills; useful for collecting background data in early stages of an assessment, when team has little knowledge of topic.	Flexible, allows follow-up of interesting responses and investigation of underlying motives.	Inexperienced interviewers may introduce bias by using poorly worded questions; can encourage the respondent to talk about irrelevant and unimportant issues; the uniqueness of each interview may make data coding and analysis difficult.
Structured interview	Uses a more detailed interview guide (see below) and questionnaire format so that interviewees respond to direct and specific questions.	Often undertaken after exploratory research, allowing findings from other methods to identify topics that the team wants to investigate further.	Offers more control over interview topics/ format; a common format for each interview makes it easier to code, analyse and compare data; keeps interviews within a more manageable time frame; easier for inexperienced interviewers.	Adherence to the guide may prevent collection of unexpected but relevant information.
Group interview	Involves asking several interviewees a question at the same time, with each providing answers individually; can use unstructured and structured interviewing techniques.	Unlike a focus group discussion, interviewees do not discuss the question among themselves; not normally useful in tackling delicate or personal issues.	Easy to organize when interviewees gather in naturally occurring groups such as friends, colleagues or clinic's clients; can obtain a lot of information from different people in one interview.	Answers may be influenced by group dynamics: prominent individuals can dominate, sensitive issues may be suppressed, or group pressure to express a "common" view can stop other views being expressed; interviewer may have less control over who takes part.

Focus group discussion	Involves interviewing a number of individuals collectively because they have had a common experience, come from a similar background, or have a particular skill or knowledge.	Good for identifying and exploring beliefs, attitudes and behaviours, and providing ideas for further investigation; encourages individuals to discuss and explore questions among themselves; useful for validating and cross-checking findings from other data sources and hypotheses, assessing the representativeness of emerging findings; judging the reaction to possible interventions.	Produces a lot of information quickly and at less cost than individual interviews.	Group dynamics and power structures can influence who speaks and what they say; number of questions that can be addressed is smaller than in individual interviews; requires considerable skill; taking good notes is difficult, and transcribing from tape recordings is time-consuming and costly; interviewer may have less control over the flow of the discussion.
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It is essential to maintain ethical standards in a rapid assessment as you would in any research activity. It is important to maintain anonymity and confidentiality and to do not harm directly or indirectly to those who are taking part in the research. In many situations, the assessment may need to go through an ethical review process before being conducted. Make sure to investigate the ethical review requirements of the country where the assessment is being conducted before collecting any data from persons.

#### Whom to interview

Given the short time available for an assessment, the team should adopt a systematic and pragmatic approach to selecting interviewees. Interviews should be conducted with a wide range of people rather than a few individuals or groups. The more specific the team can be about the information they want to collect, the easier it is to identify potential interviewees. For instance, one issue may be to understand the target population of interest and find out how they are involved in activities exposing them to TB. Discussion with key informants can be used to suggest who could be contacted in order to meet with target group members. Participants may be found in specific places such as workplaces, bars or public parks. Participants can also be recruited by contacting governmental organizations and NGOs.

Another issue may be to investigate what TB services exist in a given area and whether they service key populations at higher risk. Mapping (see below) could be particularly useful in identifying the locations of TB and related services and the environmental or community factors that may impede key populations from accessing them. Interviews with staff, outreach workers and key populations who access the services could be useful. Key informants can suggest and arrange access to individuals and groups that the team may be able to interview.

Interviews can occur spontaneously, for example, when a team member is observing an area or population they may have a chance to have a casual conversation with someone interesting or relevant to the assessment. Similarly, the team may find that individuals, who previously refused interviews, change their mind when they see other people talking to rapid assessment team members.

For focus group discussions, participants should have information on or the characteristics of the issues relevant to the assessment and be reasonably homogeneous (e.g. from the same population or type of job) as answers will be different for heterogeneous groups (e.g., people who live in rural areas vs. in urban areas, males and females, etc.).

# Mapping

Mapping is an important data collection tool in a rapid assessment. Mapping uses graphics (such as maps, drawings and pictures): to collect data about individuals, social groups and the wider environment; to present data so that complex or large amounts of information are reduced into clearer, simpler graphical overviews; to understand data by highlighting trends or relationships that were not previously obvious or fully understood; to plan action, including where to conduct future quantitative research. There are generally three types of mapping: spatial mapping, observation and visual.

# Spatial mapping

A spatial map is a graphic description of the environment in which the assessment is taking place and may include:

- Significant locations, areas of activity or boundaries;
- Key people or important population groups living in the environment;
- Behaviours or health and social conditions associated with these locations; and
- Other contextual factors such as ethnic groups, transport routes, health-care facilities.

The level of detail depends on the size of the environment being mapped, ranging from large geographical regions (such as a city, district or community) to smaller areas (such as a specific street, building or room). Initially, it may be useful to map the general geographical layout and broad social features of a community. This allows the team to quickly become familiar with the local area. Later on, the team may be more interested in the distribution of specific risk behaviours across a community. This may involve more detailed mapping.

Spatial mapping can include:

- Locations where people gather (e.g. clinics, parks, secluded places, sex and drug using venues, working locations, housing structures, markets, bus and train stations);
- Locations of key informants;
- Locations of behavioural indicators (e.g. discarded syringes or other drug paraphernalia, crowded working or housing situations);
- Boundaries affecting research (e.g. ethnic divisions, health or peer outreach boundaries, areas "unofficially" controlled by groups or gangs or likely to be raided by the police); and
- Main zones of activity of different organizations/health-care services.

The process of spatial mapping is helpful in:

- Introducing the rapid assessment to the local community (the team walks around an area noting down key features), and providing the team with a visible presence;
- Becoming familiar with the local environment; and
- Understanding the influence of the spatial environment on public health problems and risk behaviours.

Spatial mapping commonly involves the use of observations, visual methods, interviews and focus group discussions, and produces graphic descriptions of the environment in which the rapid assessment is taking place.

# Observation

The most natural and obvious way for observers to collect data is to simply watch, listen and record what is happening around them. It allows the team to gain first-hand experience of human behaviour, meanings, relationships and contexts. The observer learns by being present, seeing what people do and listening to what they say. Observation may also be used to look at environments independent of

behaviour, for example, to look at housing and working conditions). At an early stage of the assessment, observations may be used to:

- Highlight areas for research, map key areas, establish means of access, identify key informants;
- Identify risk exposures and behaviours; and
- Gain an understanding of local behaviours, vocabulary and customs.

At the concluding stage of an assessment, observations may be used to:

- Validate and cross-check findings from other methods, data sources and hypotheses;
- Assess the representativeness of the emerging findings (by repeating observations with different groups in different areas); and
- Outline potential problems and possible solutions for future interventions.

#### Visual methods

Visual methods involve the use of photography or video as data collection techniques. They can be used as aids to memory (as a form of "visual note-taking"); to enable more detailed analysis after the event; to improve data collection from interviews or focus group discussions; and as a tool for advocacy and social marketing. Visual methods should be used only if it is acceptable to those being recorded and when it will not cause harm to the population under study.

#### 6.2 Topics to Consider

In addition to filling in the gaps based on the Key Population TB Risks, Risk Drivers and Service Challenges Template (Annex A1) and National Key Populations Prioritization Template (Annex A4), there are other similar and important topics and questions to consider:

Figure 19. Topics and Questions to Consider During an Assessment
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Торіс	Questions
Know your epidemic	<ul> <li>What is the most recent HIV and TB prevalence, disaggregated by sex, age at national level and by regions?</li> <li>What is the most recent national TB notification rate (all new TB cases and all new smear-positive cases), disaggregated by sex, age at national level and by regions</li> <li>What are the mortality rates from TB disaggregated by sex, age at national level and by regions?</li> <li>Have population size estimations been performed for key and vulnerable populations?</li> <li>What is the TB prevalence among key and vulnerable populations?</li> <li>What information is available on estimated incidence in key populations disaggregated by sex and age, if available?</li> </ul>
Social, economic, cultural factors	<ul> <li>What socio-cultural norms and practices may contribute to increased risk of TB transmission among key and vulnerable populations.</li> <li>In what way do these socio-cultural norms and practices contribute to a higher risk of TB? Be specific, based on evidence.</li> <li>In what way do these socio-cultural norms and practices trigger the development of active TB? Be specific, based on evidence.</li> </ul>
Legal and political factors	<ul> <li>Are there any legal frameworks or policy, basic health policies, and other general government policies that include any of the following: women and girls, men and boys, transgender people and key and vulnerable populations in relation to HIV, TB, TB-HIV, or drug-resistant TB?</li> <li>If so, what aspects of their lives may be affected?</li> </ul>

# 6.3 Analysing Assessment Data

One part of a rapid assessment may involve the quick analysis of data and dissemination of findings. Begin analysis by thinking about all the different issues that have been explored. Organizing a group discussion among members of the assessment team can be a good way to start. These discussions can be informal, offering an opportunity for everyone to describe their impressions of the research and what they learned from it. These discussions will help decide on some of the key issues for later attention. The different types of research data will need to be linked together in a systematic manner, through a process of coding or organizing data and then triangulation. Organizing data involves categorizing data under different headings such as environmental risks/exposure to TB, biology, behaviour, access to services, and so on. You may want to use the Key Population TB Risks, Risk Drivers and Service Challenges Template (Annex A1) and National Key Populations Prioritization Template (Annex A4) to help you organize the data. Triangulation involves synthesizing different data sources to identify patterns, trends, differences and inconsistencies. Triangulation may involve members of key populations and other stakeholders to help make sense of the findings.

# 6.4 Validation of Findings

It is important to validate the findings with members of key populations and other important stakeholders. The validation will help you to make sense of the data and can provide more input into the triangulation of data (see above). Furthermore the validation can be used to help direct programmatic interventions based on the findings.

# 6.5 Using Rapid Assessment for Programmatic Interventions

One of the aims of the rapid assessment is to fill data gaps. Another aim is to plan programmatic interventions. The aim of an assessment in this framework is to develop interventions that will help you reach key populations at risk of TB infection and transmission and to scale up the access of TB services for TB key populations. Data from the assessment can be used to help develop an Action Plan. An Action plan will:

- Bring together key information;
- Focus and facilitate discussion to reach a consensus on what can be achieved;
- Recommend interventions;
- Help plan, promote and implement interventions;
- Use information to be applied in planning further assessments; and
- Serve as the basis for developing funding proposals.

Action grids can be used during data collection to evaluate and plan response strategies. Note that:

- Developing the Action Plan is a team activity in conjunction with the community and stakeholders;
- The consultations and discussions will normally be conducted through public meetings;
- One person, normally an assessment team member, should take responsibility for facilitating and coordinating the development of the Plan; and
- The time taken to complete the Action Plan will depend on the amount of information that has been collected, the problems being addressed and the complexity of the intervention being planned.

The end product is a set of grids for each proposed intervention that summarizes:

- The aims of the intervention;
- The objectives of the intervention;
- The activities required to fulfill these aims and objectives; and
- The resources, costs and time associated with these activities.

The results of the assessment can be brought together in a report, advocacy documents, and funding proposals.

# 6.5.1 Gather the key findings (Action Grid 1)

Bring together the key findings collected from the assessment and summarize them on Action Grid 1. Key findings are any that will help the team to:

- Identify particular problems or situations which require action;
- Understand why these problems and situations arise; and
- Plan appropriate responses.

Review the information recorded in the assessment grids and identify the most important findings. Additional information sources such as policy and strategy documents identified during the review of existing information can also be useful.

Example: Why former prison inmates have not been tested for TB in a particular city?						
•	The headings "key finding", "information source", "validity" and "general response" were written on three four					
-	aper. These sheets were then pinned to the walls of					
On the first						
sheet we listed	findings which were possible contextual factors	findings which could assist or obstruct the				
the key finding	related to why former prison inmates have not	development of interventions. An example				
which related to	been tested for TB in a particular city. These	of key findings might include difficult to				
why former	included, for example, the difficulty of getting access TB infection and treatment					
prison inmates	tested at clinics which are often too far,	knowledge, lack of staff training about				
have not been	discomfort with asking to a test, lack of	people who have been incarcerated and				
tested for TB in	knowledge about TB, type of staff at the testing	any special needs they might have, lack of				
a particular city.	center, costs related to services, confidentiality,	confidentiality. Other examples could be				
	availability of treatment and awareness of	that TB testing services are free and that				
	services.	treatment is available.				

Categorizing the key findings into these three groups is one way to make it easier to understand the numerous links between problems, local context and intervention development. It can also sort the key findings into two sections: (1) information which indicates the need for action or responses; and (2) data which could be used to plan effective responses and interventions to meet this need.

Use Action Grid 1 to summarize key findings. The grid has four columns:

- Key finding
- Information source
- Validity
- General response

Entries on the grid should be short and concise. The aim is to provide the team with a clear overview – too much information will impede this.

#### **Example of Action Grid 1**

Gather key findings and identify general response for TB intervention of former prison inmates.

- 1. Identify the key findings.
- 2. For each key finding, list the information source.
- 3. Assess the validity of the finding.
- 4. Indicate the general response/intervention to the key finding.

Key finding	Information source	Validity	General response
Former prison inmates are not adequately accessing TB testing and treatment	Review of TB clinic records	Most clinics do not record if clients are former prison inmates	Encourage clinics to record services provided to former prison inmates (and other important key populations).
	Interviews with TB clinic staff	Most staff are unaware of former prison inmates being in the community and are not trained on how best to serve former prison inmates.	Educate TB staff to improve awareness of former prison inmates and how best to serve them.
	Interviews with outreach workers	There are no outreach workers working to identify former prison inmates at risk of TB infection	Train outreach workers to provide education about TB to former prison inmates
	Focus group discussions with former prison inmates	Few former prison inmates have been for TB testing but may be infected. Most have heard that clinic staff treat former prison inmates poorly and that if positive for TB, there is nothing anyone can do about it anyway.	Enhance outreach worker programmes to include accompanying former prison inmates. Hire former prison inmates to conduct outreach. Develop educational materials specific to former prison inmates to explain TB and what they can do if they find out that they are infected.

#### 6.5.2 Describe the general response (Action Grid 2)

Take Action Grid 1 and discuss the general response to each key finding. At this stage, it is unlikely that the team will want to discuss and develop detailed intervention plans. It is more efficient to first describe

a general response strategy for each key finding. These brief descriptions indicate what actions or interventions might be developed.

Discuss each key finding and write a summary of the required action.

### Identify which responses to develop

The team should now identify which responses will be developed into more detailed intervention plans. Choose the three or four most important responses to develop into specific intervention plans and write these in Action Grid 2. If the team is unhappy with the content of these specific plans, it can return to this step later to choose further responses. For each response consider:

- *Priority.* How important is the response? How urgently is it needed? Is it important to act now rather than later?
- *Relevance*. Is the proposed response the correct one? Or could another response be more effective? If so, what would it be?
- Feasibility. Are there any obvious obstacles to its development?
- *Acceptability.* How acceptable is it to the target group, stakeholders, decision-makers and the public? What obstacles might there be?

#### Action Grid 2: Key action areas

The responses can be graded as high, medium and low.

	Priority	Relevance	Feasibility	Acceptability
Train outreach workers on the importance of TB education for former prison inmates	High	High	Medium	High
Hire and train former prison inmates to conduct outreach to increase TB knowledge, testing and treatment	High	High	High	High
Response 3				
Response 4				

# 6.5.3 Specify the aims and objectives of the intervention (Action Grid 3)

For each general response listed in Action Grid 2, the assessment team can specify the aims and objectives of the intervention using Action Grid 3. This grid has seven columns:

1. *Aims.* Having explicit aims will make it easier to plan activities. For each aim, several objectives can be identified.

- 2. *Objectives (for each aim).* Objectives are helpful for activity planning and should be clearly defined. Several objectives can be identified for each aim.
- 3. *Key activities (for each objective).* It is important to start brainstorming to define key activities by listing as many activities as possible without considering time resources or feasibility. The second part of the brainstorming will be to reduce the list by grouping similar items together and eliminating irrelevant or unrealistic ideas.
- 4. Cost and other resources (for each activity). Costs and resources are assessed by considering what resources might be needed (e.g. human resources such as trainers, more outreach workers, specialized staff; medical resources such as more facilities and tests; technological resources such as a computer or vehicle; information resources such as administrative support or publishing equipment [for leaflets, etc.]).
- 5. *Time frame (for each activity).* Time frame is assessed by considering how long each stage of the activity will take and anticipating events that could cause delays. For example, three to four months may be needed to design, pilot and produce a range of promotion leaflets in consultation with former prison inmates.
- 6. *Responsible person or organization.* Identify the key persons or organizations that are responsible for each of the activities listed.
- 7. *Indicator.* For each activity and objective, an indicator can be listed to measure success or failure.

Below is an example of Action Grid 3 using some of the activities identified above in Action Grid 1.

For each proposed intervention use a new grid. Insert the intervention type or name above. (1) Write the aim of the intervention. (2) Write the objectives for each aim. (3) List the activities for each objective. (4) Identify the resources and costs required for each activity. (5) Estimate the time frame for each activity. (6) Write down the name of the responsible person or agency. (7) List the indicator for measuring each activity and objective.							
Aim	Objectives	Activities	Costs and resources	Time frame	Responsible person/agency	Indicator	
Hire and train former prison inmates to conduct outreach to increase TB knowledge, testing and treatment	Create a job description for outreach workers	Develop a budget to hire outreach workers	Time taken to develop budget	Two weeks	Outreach coordinator working with Ministry of Health	Completed budget	
		Write up the roles and responsibilities of an outreach worker	Time taken to writ the roles and responsibilities	Two weeks	Outreach coordinator working with Ministry of Health	Completed job description	
	Identify, interview, hire and train former prison inmates	Meet with NGOs that work with former prison inmates to find potential candidates					
		Conduct interviews	Time to conduct interviews	3 days for interviews; 3 weeks to develop interview questions; 2 months for planning.	Member of Ministry of Health, member of HIV testing and counseling centre, member from prison authority, and member from the health clinic.	Interview questions; three hired outreach workers.	
		Provide specialized training on providing TB information to former prison inmates	Cost of trainer; training room donated by Ministry of Health	4 months to plan; 3 days for training.	Ministry of Health	Slides and materials from training; pre-and post-test on knowledge gained from training	
	Develop outreach materials for distribution to former prison inmates	Design pamphlet	Time taken for someone to design	2 months	Local NGO and Ministry of Health	Completed design	
		Produce pamphlet	Cost of paper and printing	3 months	Mr Speedy copy shop	Final pamphlet	
		Distribute pamphlet	None	4 months	Newly hired outreach workers	Number of pamphlets distributed	

#### Consider the wider response strategy

Once the assessment team completes *Action Grid 3*, it is time to discuss how the detailed intervention plans can be put into practice. Interventions should be developed in direct response to the greatest needs and a wider response strategy should recognize that any intervention needs a strategic and integrated approach. The Action Plan should provide the foundations for building a long-term response strategy. The effectiveness of such a long-term strategy depends on how well the selected interventions in the Action Plan fit together to meet the overall aims of scaling up TB services, testing and treatment for TB key populations.

# Bring the key findings together

After analysing assessment data, the assessment team will need to discuss the findings with all stakeholders involved. These include representatives of key populations affected by the findings, representatives from organizations such as development agencies, health ministries, health centres and organizations working in the area of TB. Such a discussion is useful for developing responses to the findings and addressing them through different types of programmes or interventions. Developing consensus around an action plan will help to advance the process.

# 7. Sampling Methods to Fill Data Gaps

Given the gaps in data to inform TB programme planning, it is essential that actionable data be collected on TB key populations. As described in Section 5, there are limited quantitative data related to TB prevalence, exposure and service access barriers such as stigma and discrimination among TB key populations. In addition, these data are of varying quality, ranging from high external validity (represents the population sampled) such as screening all members of a population<sup>106</sup> (which collects data on everyone, but usually only measures TB prevalence, and no information on risk and exposure) and sampling frames (a complete list) of households where key populations (i.e., miners) live (random sampling based on listed addresses), to low external validity such as convenience sampling, such as snowball or purposive sampling.

The manner in which quantitative data are collected affects the ability to interpret the results. For instance, screening, which captures TB prevalence on all persons of interest (but often collects little risk exposure, service access barriers and other information) and household sampling, which uses a sampling frame and random selection of households/participants (but are expensive to conduct) are most representative of the populations. Convenience sampling which selects people who are most easy to capture tends to be least representative of the populations. The sampling methods described in this section are for collecting quantitative, rather than qualitative, data from populations that are considered hard to reach. Quantitative research is the collection of data through the systematic empirical measurement of 'phenomena' (i.e., the percentage of people who have ever been diagnosed with TB) using statistical methods.<sup>107</sup>

This section provides recommendations for collecting data from TB key populations (many of which are considered hard to reach for research purposes) in order to improve the availability and usefulness of information to guide TB prevention policy, planning and responses and to monitor progress and accountability in achieving TB programme goals and objectives. Specifically, this section focuses on two important methodological topics: 1) Sampling key populations (especially those without sampling frames), and 2) estimating the sizes of key populations or population size estimations. Studies of key populations are usually specialized and geographically focused. Because key populations are often hidden and rare in general populations, sampling them through nationwide household or cluster surveys would be exceedingly expensive<sup>108</sup>. In some cases, multiple surveys of a key population in different geographic areas can be extrapolated to provide approximations for national estimates of that key populations are usually twofold: 1) to estimate the prevalence of TB; and/or 2) to measure exposure, risks, stigma, discrimination, service coverage and other factors related to TB. The objective will impact how the population is sampled.

This section is meant to provide an overview of the different methods available to sample and estimate the population sizes of TB key populations. Undertaking a survey using these methods will require additional resources beyond the scope of this section.

All methods presented in this section involve participation of key populations themselves and adhere to the human rights principles presented in Section 2.2 of this framework - privacy, confidentiality and informed consent in particular.

# 7.1 Sampling

# 7.1.1 Why is sampling needed?

Sampling is that part of statistical practice concerned with the selection of individuals from a population of interest.<sup>109</sup> Ideally, the goal is to be able to collect data from a much smaller proportion of a population, and because of the way the data are collected, that the information from those data describes the entire population sampled (not just the sample). Sampling methods are classified as either probability or non-probability.

<sup>&</sup>lt;sup>106</sup> IOM (2014) "Migration Health Annual Review 2014" (https://publications.iom.int/system/files/mhd\_ar\_2014.pdf)

<sup>&</sup>lt;sup>107</sup> Bryman A. (2012) "Social Research Methods" Oxford University Press p766

<sup>&</sup>lt;sup>108</sup> Kalton G, Anderson DW (1986) "Sampling Rare Populations" Journal of Royal Statistical Society Series A. 149(1):65.

<sup>&</sup>lt;sup>109</sup> Cochran WG, William G. (1977) "Sampling Techniques" Wiley p428

- In probability based sampling, each member of the population has a known probability of being selected. Probability based sampling includes random sampling, systematic sampling, stratified sampling, and for key populations, can include respondent driven sampling (RDS) and time location sampling (TLS). When implemented correctly, it yields unbiased estimates and has high external validity. Most probability-based sampling relies on the population being able to be listed so that everyone has an equal chance of selection from that list.
- In non-probability sampling, members are selected from the population in some non-random manner. Non-probability sampling includes convenience sampling, judgment sampling, quota sampling and snowball sampling, and it often yields biased estimates.

A sample (purple) is a subsection of the population (blue), but depending on how the data were gathered, the sample may represent the population (probability-based sampling) or may represent the (non-probability based sampling).

# Figure 21: Diagram of Probability and Non-probability Based Sampling.

The advantage of probability sampling is that sampling errors can be calculated (i.e., the degree to which a sample differs from the population). In non-probability sampling, the sampling error is unknown. In countries with increasing TB incidence, efforts to control the TB transmission and monitor programmatic success are



interested in key populations. Some of these populations are often considered hard-to-reach or hidden populations with regards to sampling. These populations include sex workers and men who have sex with men, as well as some of those populations selected in this guidance as TB key populations: Migrants, Miners, PWUD and PLHIV. In addition, these subpopulations often:

- Lack sampling frames (cannot list them)
- Are rare in the population
- Have behaviours that are stigmatized and/or illegal (So they prefer to remain 'hidden')
- Do not necessarily want to be identified by researchers or others.

This prevents researchers from obtaining unbiased estimates of important indicators because of the difficulty of using probability sampling methods.

# 7.1.2 Traditional random sampling

Traditional random sampling techniques require that the population has a list of members, also known as a sampling frame. This sampling frame is used to set up the selection of participants. If possible, these sampling methods should be used in place of convenience sampling methods. Three commonly used random sampling techniques are briefly described below.

# (a) Systematic sampling

Systematic sampling relies the target population being arranged according to some ordering scheme, usually having a random start, and then selecting persons at regular intervals through that ordered list. Let's say you have a list of 400 migrants who work at mill in a certain city. If you want to sample 100 of those migrants, you would calculate 400/100 to select the sampling interval. This would result in selecting every 4th subject on the list until the sample size is reached. Keep in mind that the list of subjects will finish before the sampling is complete so you will need to loop around to where the list started (but you will not end up sampling the same person twice) before you reach your sample size.

# (b) Simple random sampling

Using a sampling frame, a simple random sampling (SRS) is simply a sample in which all subjects in the frame are given an equal probability to be chosen. An example of this would be to select 100 migrant employees out of a hat from a company of 400 employees.

#### (c) Stratified Sampling

Stratified sampling is used when the population has important subgroups, such as males and females, or migrants from several different countries, and you do not want your sample to end up with subjects from only one subgroup. All subjects are organized in their appropriate strata, for instance migrants from country X, country Y and country Z. Each stratum is then sampled as an independent sub-population, out of which each subject is randomly selected using simple random or systematic random sampling.

#### (d) Cluster sampling

Many TB prevalence surveys are conducted using multilevel cluster sampling.<sup>110</sup> Cluster sampling is useful for sampling large geographic areas or subjects from groups, for sampling migrant workers at several mills in a large city. In cluster sampling, groups or clusters are selected and then from each cluster, individual subjects are sampled by either simple random or systematic random sampling. In some cluster surveys, all eligible subjects will be sampled from each cluster. If sampling from multiple levels of clusters, for instance, one level of clustering could be cities in a province and the next level could be factories in a city, the method is called multilevel cluster sampling.

#### 7.1.3 Convenience sampling

Convenience sampling or purposive sampling involves sampling people who are relatively easy to find or approach. This type of sampling method should be avoided if possible because it samples a select part of the population resulting in information only specific to the subjects in the sample. For instance, let's say you sample migrants as they are coming out of work using a convenience sample (e.g., interviewing those that will stop and talk with you). It may be that all people with children are in a hurry to get home and that only single people will stop and talk with you. This would result in a sample that has only single people in it. Purposive sampling can be used as a preliminary step to reach out and identify Zoonotic TB among those people living in communities at higher risk contracting M. bovis based on a set of risk factors.<sup>111</sup>

<sup>&</sup>lt;sup>110</sup> WHO (2011) "Tuberculosis Prevalence Surveys: A Handbook" p305

<sup>(</sup>http://www.who.int/tb/advisory\_bodies/impact\_measurement\_taskforce/resources\_documents/thelimebook/en/) 111 Zoonotic TB in humans, caused by Mycobacterium bovis (the causal agent of bovine TB) is a form of TB that affects people living in communities in areas in which animal TB is endemic and where socio-cultural practices favor the transmission of M. bovis to humans. The people most at risk are those consuming unpasteurized milk or untreated animal products from infected animals, people living in rural communities in which bovine TB is endemic, cattle herders, dairy workers, farmers, veterinarians, and slaughter workers who come in contact with infected animals or their products. The burden of zoonotic TB in humans is currently unknown due to the absence of systematic surveillance for M. bovis as a cause of TB in people in all low-income and high TB burden countries where bovine tuberculosis is endemic. Laboratory procedures most commonly used to diagnose human TB do not differentiate M. bovis from M tuberculosis. Thus laboratory methods capable of identifying M. bovis as the causal agent of human TB should be used for these populations at higher risk of zoonotic TB. Differentiation of the two species has potential clinical implications, as M. bovis is naturally resistant to pyrazinamide, one of the cornerstone medications used in the six-month regimen to treat drug-sensitive TB in humans. Efforts to identify persons with zoonotic TB should be conducted in an integrated manner including both human health and veterinary sector workers, in order to aid investigators in identifying those people most at risk based on factors and disease dynamics under local conditions.

# (a) Chain referral sampling

Chain referral sampling, also known as snowball sampling, relies on identifying initial subjects and having them recruit their peers.<sup>112</sup> In some cases, subjects who know more people are allowed to invite as many of those people as they can. This may result in some types of people recruiting more peers than others. For instance, if migrants living in city X use drugs and go out drinking and socializing know more people, and they happen to also be more prone to risky behaviours linked to TB, then the sample may end up being overrepresented by these types of people. In the end, the interpretation of migrants living in city X will be skewed to those who use drugs and go out drinking and socializing, rather than to the population of migrants in city X.

# (b) Institutional based surveys

These are surveys of persons who are found at an institution. For instance, persons who use drugs may be sampled through drug rehabilitation or needles exchange programmes. Although some effort may be made to randomize the selection of those using the service, the results will still represent those who are associated with the sampled service. For instance, those who use services may be those who have more money, more time or may be healthier or better educated.

# 7.1.4 Innovative probability based sampling method for key populations

Because key populations often do not have sampling frames, innovative probability based sampling methods have been developed. There are two recommended probability sampling methods for sampling hidden or highly marginalized populations. These methods are *Respondent Driven Sampling* (RDS) and *Time Location Sampling* (TLS) (also known as venue-day-time sampling) and are described in more detail below. Briefly, RDS samples the population as a network, relying on peers to recruit their peers in a systematic recruitment process. If the population members to initiate the sampling, then RDS may be a good sampling alternative. TLS relies on population members being accessible at visible sites. When these sites are completely listed and the population is enumerated through a mapping exercise, then the sites can be randomly selected and sampled as clusters. Each method should be considered in place of convenience, non-probability sampling methods. Although convenience sampling is easier to conduct than probability sampling, data collected through convenience biased samples and are not generalizable to the population from which the sample was collected. When a sampling frame is available, the most robust methods to use are simple random sampling or multilevel cluster sampling. All of these methods are described below.

# (a) Respondent Driven Sampling (RDS)

Basically, RDS is a modified form of chain-referral sampling whereby peers recruit their peers through the use of coupons with unique code numbers. This method requires that TB key populations belong to social networks (know each other by having similar exposures and behaviours and are connected through friendships, family ties, acquaintances, work, etc.) and are able to recruit their peers into a survey. Recruitment is initiated with a small, diverse and influential group of "seeds" (eligible respondents) selected by the researchers. Since seeds are expected to initiate recruitment, they should know a lot of other people (i.e., have large social networks). Each seed receives a set number of recruitment coupons (usually two or three) to recruit his/her peers who then present the coupons at a fixed site to enrol in the survey. Eligible recruits who finish the survey process are also given a set number of coupons to recruit their peers. The recruited peers of seeds who enrol in the survey become wave one respondents, and the recruits of wave one respondents become wave two respondents.

# Figure 22: Peer-to-peer Recruitment Starting from One Seed and Continuing for Thirteen Waves.

<sup>&</sup>lt;sup>112</sup> Erickson BH, H B. (1979) "Some Problems of Inference from Chain Data" Sociological Methodology 10(1):276.

<sup>&</sup>lt;sup>113</sup> For instance, people who use drugs know each other since they buy drugs from, sell drugs to and use drugs with each other. In addition, they have friendships, are roommates, are lovers, spouses, etc.


Peer to peer recruitment continues through successive waves until the calculated sample size is reached.<sup>114</sup> In the end, the waves produced by effective seeds make up recruitment chains of varying lengths. The goal is to acquire long recruitment chains (often as many as 8 or more) made up of multiple waves. Involved in the recruitment process are nominal incentives for survey participation and peer recruitment. Incentives, along with modified peer pressure (i.e., someone wanting to enrol in order to please their recruiter), encourage people to enrol in the survey and to, in turn, influence their peers to enrol as well.

In RDS, coupons are used to:

- 1. Provide information about the study, time and location of the study site to potential recruits
- 2. Link information about recruits and their recruiters through a unique numbering system
- 3. Track overall progress of recruitment and manage incentive payments to participants and recruiters

It is important that the coupon be inviting, not disclose stigmatizing information and instruct the potential respondents on how to proceed. Figure below shows an example coupon. This is a two-part coupon whereby the bigger part is given to a peer to invite them into the survey. And the smaller part is kept by the recruit in order for them to receive an incentive for having recruited an eligible person who enrols in the survey. Note that the title of the survey "Spreading Hope" does not identify the target population or the nature of the survey. Important key information about the survey include the survey phone number and the address and space to include a unique number and expiration date whereby the coupon will no longer be valid (often 5 to 10 days). While it may be tempting to put a lot of information about the project on the coupon, it should be kept simple and only include what is absolutely necessary. Remember that the recruiter will explain many things about the survey to any potential respondent.

<sup>&</sup>lt;sup>114</sup> See Annex A6 for sample size calculations.

### Figure 23: Example of a Coupon (Top is front and bottom is back)



RDS is considered both a sampling and an analysis method and every survey requires both in order to be called "RDS". One important piece of datum for analysis is the 'network size question'. The network size question is an open ended question which requires each participant to provide a number representing how many people he or she knows who also know him or her. Figure below<sup>115</sup> provides an example of a network size question from a survey on undocumented female migrants from Central American in Houston<sup>116</sup> divided into four separate questions with the first question being a general question about the number of people whom the respondent knows who are part of the eligibility criteria. If there are several parameters for eligibility, researchers may decide to use all of the eligibility parameters to make two separate questions. Having the first question be broad, allows respondents to more easily think about the population. The response to the first question, therefore, does not need to be precise. The second question in the figure below, which is often built into the first question, defines what it is to know someone to ensure that everyone has the same understanding of this concept and that relationships are reciprocal. The third question is a subset of the first and second questions and the response to this question is expected to become more precise. Finally, the fourth question sets up the time frame during which the respondent has seen members of his or her personal network. The response to this question, as subset of the previous question, should be as precise as possible since it will be used in analysis.

<sup>&</sup>lt;sup>115</sup> Johnston, LG & Rodriquez L. (2014) "Measuring Personal Network Size in Respondent Driven Sampling" in "Applying Respondent Driven Sampling to Migrant Populations: Lessons from the Field" (Eds. Tyldum G & Johnston LG.), Palgrave, London, UK.

<sup>&</sup>lt;sup>116</sup> Montealegre J.R., J.M. Risser, B.J. Selwyn, S.A. McCurdy, K. Sabin. (2013) "Effectiveness of Respondent Driven Sampling to Recruit Undocumented Central American Women in Houston, Texas for an HIV Behavioral Survey" AIDS and Behavior. 17(2):719-727.



### Figure 24: Example of the Network Size Question.

Data about each person's social network size are used to weight the data by giving those with larger social networks, less weight and those with smaller social networks, more weight. This helps to reduce the bias of over-representing those with larger social networks (i.e., more chances for being recruited) and underrepresenting those with smaller social networks (e.g., the elderly, sicker persons in the population, etc.). Information of who recruited whom and each participant's social network size (the number of peers they know) are used in the analysis of RDS data. Figure below describes some of the challenges and recommendations in using RDS to sample TB key populations.

### Figure 25: Current Challenges and Recommendations in using RDS<sup>117</sup>

Best used when TB key populations are sufficiently socially networked to sustain peer-to-peer rear ultrant and when TP key non-ulations are not appearible at public locations

recruitment and when TB key populations are not accessible at public locations.		
Challenges Recommendations		
Popularity of RDS has resulted	Review and understand relevant materials on conducting RDS; use	
in ignoring rigorous adherence	the RDS manual-; seek out others who have properly used RDS;	
to implementation and analysis	obtain professional technical assistance; use a written protocol that	
requirements	has been reviewed by experts and assure adherence to the protocol.	

(https://www.researchgate.net/publication/277172972\_Update\_for\_sampling\_most-at-

<sup>&</sup>lt;sup>117</sup> Adapted from: Johnston LG, Sabin K, Prybylski (2010) "Update for Sampling Most-at-risk and Hidden Populations for HIV Biological and Behavioral Surveillance" Journal of HIV/AIDS Surveillance & Epidemiology

risk\_and\_hidden\_populations\_for\_HIV\_biological\_and\_behavioral\_surveillance)<sup>118</sup> Johnston, LG and Malekinejad M. (2015) "Respondent-Driven Sampling for Migrant Populations" in Migration and Health: A Research Methods Handbook, Eds. Castaneda VMB. Rodriguez-Lai Schenker X:

Johnston, LG (2013) "Introduction to HIV/AIDS and Sexually Transmitted Infection Surveillance: Module 4: Introduction to Respondent Driven Sampling." WHO, Geneva, Switzerland (http://applications.emro.who.int/dsaf/EMRPUB\_2013\_EN\_1539.pdf)

Tyldum, G., Johnston, L. (2014) "Applying Respondent Driven Sampling to Migrant Populations: Lessons from the Field" (http://www.palgrave.com/us/book/9781137363602)

Ensuring that the recruitment chains are long within sample sizes and time-frame constraints	Ensure very long recruitment chains (ideally >8 waves); pay careful attention to the number, degree and diversity of selected seeds. Ensure ample number of TB high risk seeds to capture a sufficient number for analysis.
Selection of seeds to maximize equilibrium attainment	Conduct pre-survey research to select seeds that are broadly representative of the TB key population.
Determining the appropriate incentives to maximize participation	Conduct pre-survey research to determine appropriate types of incentives; assess the economic value of goods in each setting; ask TB key populations their motivation for participating in an RDS survey to plan incentives for future studies; be creative.
Determining the appropriate incentives to minimize repeaters	Conduct pre-survey research to determine appropriate types of incentives; assess the economic value of goods in each setting; explain to participants that if they give their coupon to someone found to be ineligible due to prior participation, they will not receive a recruitment incentive for that person; be creative.
Managing multiple data collection sites and staffing	Assess the reasoning behind having multiple recruitment sites; hire staff with either personal or work experience with key populations; have designated staff roles with adequate training; develop a communication protocol to ensure cross-over among sites and to coordinate data collection.
Verification of membership in the sampled group	Hire and train a 'screener' whose only job is to verify eligibility and enroll participants; use TB key populations as screening staff; know the behaviours and develop screening questions to which only the key populations can accurately respond.

### Figure 26: RDS Among People Who Inject Drugs in Ethiopia-TB Burden.

Respondent-driven sampling (RDS) was used to obtain a sample of 238 male and female PWID 2015 in an East African country. PWID were defined as persons who injected illicit drugs in the past six months, aged 15 years or older, and living in the capital city. Through peer-to-peer recruitment, eligible PWID with a valid recruitment coupon from a peer, enrolled into the survey at a fixed site connected to a well known hospital. In addition to testing for HIV, HCV, HBV and syphilis and asking several behavioral questions related to drug use and HIV testing, several questions related to TB were included. Data were weighted by network size and analysed using RDS Analyst. The findings from this survey indicated that between 10 and 15% of PWID in the capital city had one or more TB symptoms described as unexplained weight loss of more than 4 kilos, cough, unexplained fever, night sweats, unexplained chest pain, or unexplained fatigue for more than two weeks in the past six months.

### (b) Time-Location Sampling (TLS)

TLS can be used to sample TB key populations when they tend to gather or congregate in identifiable and accessible locations, such as certain street corners, markets, transportation centres or other areas.<sup>119</sup> The method entails identifying days and times when key populations congregate at specific locations (i.e., clubs, city blocks, bars, etc.), constructing a sampling frame of time and location units, randomly selecting and visiting time and location units (the primary sampling units), and systematically intercepting and collecting information from consenting TB key populations. The number of TB key populations at each location provides a sampling weight that can be used *a priori*, to draw a self-weighting sample, or *post priori*, in analysis. Data collection may take place at the venue, if space (or venue owner) permits, or in a mobile site near the location, such as a van, or by making appointments for TB key populations to come to a designated study site. The major contribution of TLS over other cluster sampling methods is the ability to account for the fact that populations during the course of a single day. As such, TLS allows researchers to construct a sample with known properties, make statistical inference to the larger population of location visitors, and theorize about the introduction of biases that may limit generalization of results to the target population. Below figure describes some of the challenges and recommendations in using TLS to sample TB key populations.

<sup>&</sup>lt;sup>119</sup> University of California – San Francisco (2010) "Time Location Sampling (TLS) Resource Guide" (<u>https://globalhealthsciences.ucsf.edu/sites/globalhealthsciences.ucsf.edu/files/tls-res-guide-2nd-edition.pdf</u>)

### Figure 27: Current Challenges and Recommendations in Using TLS<sup>120</sup>

Best used when key populations are accessible at several public locations in numbers large enough to build a sampling frame

Challenges	Recommendations
Representativeness of TB key populations found at accessible locations	Conduct high quality pre-survey research to understand TB key populations and where they are found.
Lack of appropriate analyses based on cluster sampling	Retain a statistician, use correct analyses, use appropriate weighting.
Systematic bias if locations are missed	Assess potential for missed locations and minimize these. Account for potential biases in reporting.
Bias if certain populations sub-groups do not attend locations	Assess potential for missed sub-populations, especially people with more illness, and minimize these. Account for potential biases in reporting.
Venue owners may block access	Meet with venue owners/gatekeepers before sampling. Document those sites with blocked access and collect as much information as possible about the types of individuals missed.
Venue owners may allow you to talk with the population briefly and then ask you to access them off- hours and at another venue	Meet with venue owners/gatekeepers before sampling. Be prepared to make appointments to meet with individuals at off-site. Keep track of those who are approached at the venue and who do not show up for an off-site appointment.
Safety issues	Develop and implement protocols to maintain the safety of staff, especially if using people, and respondents in the field and include security personnel on interview team if needed.

### 7.2 Selecting Which Sampling Method to Use

The type of key population and whether they have a sampling frame (i.e., we can list them in anyway) will dictate the most robust sampling method to use (figure below). In the table below, the most appropriate sampling method is suggested for each of the TB key populations highlighted in this document.

# Figure 28: Most Robust Methods to Sample and Estimate the Population Sizes of Select TB Key Populations

Key population	Methods to sample them	Notes
Migrants, refugees and internally displaced persons		
Documented migrants and refugees in camps (sampling frame)-	Sampling of all migrants (census), random sampling	Often captured through screening when leaving or retuning to a country

<sup>&</sup>lt;sup>120</sup> Adapted from: Johnston LG, Sabin K, Prybylski (2010) "Update for Sampling Most-at-risk and Hidden Populations for HIV Biological and Behavioral Surveillance" Journal of HIV/AIDS Surveillance & Epidemiology 2(1):2

<sup>&</sup>lt;sup>121</sup> Migrants who are based in refugee camps, documented or listed at their place of work.

Key population	Methods to sample them	Notes
Undocumented migrants and internally	RDS, TLS	As described in section 5,
displaced persons (no sampling frame)-		data on irregular and internal
		migrants and internally
		displaced persons are
		largely absent.
Miners		
Miners in the formal sector or unionized	Sampling of all migrants	Often screened through their
(sampling frame)	(census), random sampling	work in the mines.
Miners in the informal sector or not unionized	RDS, TLS	Usually sampled using
(no sampling frame)		convenience methods
Prisoners and Detainees		
Prisoners (assuming there is a sampling frame)	Sampling all prisoners,	Often screened while in
	Random sampling	prison; qualitative methods.
Detainees (assuming there is a sampling frame)	Random sampling	Often screened while in
		detention; qualitative
		methods.
PWUD	RDS, TLS₌	Limited data on TB
PLHIV	RDS, TLS	Often screened for TB at
	Random sampling (at	clinics, hospitals (but
	institutions only)	missing those who do not go
		to clinics)

Selecting the most appropriate sampling method requires assessing numerous factors such as whether there is a sampling frame or list of TB key populations, whether the population is socially networked, or whether they spend time at venues that can be mapped and approached. Figure below is useful for selecting a sampling method to sample key populations using an example of migrants. All methods have been described below in Section 7.3.

<sup>&</sup>lt;sup>122</sup> Internally displaced persons who are not in camps and undocumented migrants.

<sup>&</sup>lt;sup>123</sup> UNODC (2010) "HIV in Prisons: Situation and Needs Assessment Toolkit" (<u>http://www.unodc.org/documents/hiv-</u>

aids/publications/HIV\_in\_prisons\_situation\_and\_needs\_assessment\_document.pdf)

<sup>&</sup>lt;sup>125</sup> Methods will vary based on what type of drug used or by drug-taking behaviour. For instance, if PWUD are identifiable at visible locations, it is possible to use TLS. If they are socially networked, then it is possible to use RDS.



### Figure 29: Algorithm to selecting a sampling method<sup>126</sup>

\*Note that a simple random sample of migrants select neighbourhoods, streets, working places may miss segments of the population, such as those who are not found at visible locations.

### 7.3 Sampling Considerations

### 7.3.1 Eligibility criteria

A clear definition of the population being surveyed is essential to design the research and for interpretation of the data and the estimates that come as a result of analysis. Eligibility criteria describe the characteristics required for inclusion in a study. Aside from age, other characteristics used to define eligibility for studies of TB key populations might include:

- Sex (biologic and physiologic characteristics that define males and females)
- Sexual orientation
- Risk behaviour

<sup>&</sup>lt;sup>126</sup> For a complete description of all sampling methods described and further details on this figure see "Surveillance of Most at Risk Populations" at: <u>http://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings</u>.

- Reference period of behaviour (i.e., used drugs in the past six months, been in prison for at least one month)
- Geographic area or residence
- Period of exposure to TB
- HIV status

### Figure 30: Examples of clear eligibility criteria for select TB key populations.

Population	Eligibility criteria
Migrants (no sampling frame)	Males or females, 18 years and older, working in the textile industry for at least one month and living in country X (host country) for at least one year.
Prisoner	Male, 15 years or older, having been in prison for at least one year.
PWUD	Males and females, 15 years and older, have shared crack from the same glass pipe in the past 6 months, live in city X (city being sampled). Males, 15 years and older, have injected heroin in the past six months, live in city X.

### 7.3.2 Sample size calculations

Sample size calculations are dependent on the sampling design and the objectives of the survey. There are usually two objectives for conducting surveys of key TB populations: to estimate TB prevalence and/or to measure exposures associated with the disease or risk. Because TB prevalence is often very low, even in key populations, larger sample sizes are often needed in order to capture enough people to measure. It is recommended to only sample TB key populations that are estimated to have a TB prevalence of 1% or higher. If the objective is to measure exposures associated with TB, or programme coverage, then the sample size may be more manageable. Two types of sample size calculations are described for sampling TB key populations in Annex A6. One method is based on surveys being conducted every 2 to 5 years in order to assess trends. Keep in mind that when conducting surveys overtime, each survey round should have the same protocol, eligibility criteria and sampling method to ensure comparability. The other sample size calculation method uses a standard formula and can use an estimate of TB prevalence or an important indicator related to the objective of the survey (e.g., exposure or programme monitoring).

### 7.3.3 Include TB key populations

TB key populations should be included in the survey planning, design, data collection and dissemination. TB key populations have been effective as staff members in all sampling methods. TB key populations are essential in building an effective questionnaire that is understandable to the population under study. TB key populations are useful in screening out people who are not part of a TB key population being studied. And, most importantly, TB key populations are knowledgeable in interpreting findings and are essential in using those data to design prevention, intervention and treatment programmes best suited to their needs.

### 7.3.4 Children of TB key populations

Although most surveys will focus on collecting samples and population size estimations from adult TB key populations, understanding disease vulnerabilities among younger key populations should not be ignored. The methods to sample hard to reach TB key populations described above have successfully included participants in adult surreys as young as 15 years<sup>127</sup> and have been used for special surveys of children (with or without

<sup>&</sup>lt;sup>127</sup> UNICEF, UNESCO, UNFPA, UNAIDS (2013) "Young Key Populations at Higher Risk of HIV in Asia and the Pacific: Making the Case with Strategic Information" Bangkok, Thailand: UNICEF East Asia and Pacific Regional Office (<u>https://www.unicef.org/eapro/Young\_key\_populations\_at\_high\_risk\_of\_HIV\_in\_Asia\_Pacific.pdf</u>)

parents) of TB key populations, usually as young as 10 years old.<sup>128,129,130</sup> Despite barriers related to ethical considerations and difficulties sampling children who may be a member of or are related to someone who is a member of a TB key population, more discussion among those researching TB topics is needed about how to best include young TB key populations in surveys that address their risk of disease. If only conducting surveys among adult TB key populations, consider including questions that measure TB risk and exposure among their children.

### 7.4 Population Size Estimation Techniques for TB Key Populations Using Survey Data

Estimating the sizes of populations at highest risk for TB is essential for informing decision-makers and programme managers of the extent to which TB key populations are contributing to the TB epidemic, as well as how to target interventions, plan services, and measure programme coverage in ways that are specific to these populations. For those populations with sampling lists, the populations size estimation can just be a count of all those on the lists. For obtaining population size estimates for key populations who do not have sampling frames, a sample size estimation might need to be conducted in conjunction with a survey. There are several methods that can be used when conducting a probability-based survey: Multiplier, successive sampling-population size estimation (SS-PSE) and a capture-recapture (see figure below).



# Figure 31: Main Types of Population Size Estimations

### 7.4.1 Multiplier methods

The unique object and service multiplier methods involve overlapping independent population counts to extrapolate the overall population size.

### (a) Unique object multiplier

The unique object multiplier involves distributing unique objects to population members in each survey city one week prior to initiating a probability based survey (TLS, RDS) study. The number of objects distributed are counted (first multiplier) and used in a calculation with the proportion of those who reported receiving the object (second multiplier) to derive a population estimation. Unique objects should consist of an item

<sup>&</sup>lt;sup>128</sup> Kissin D. (2011) "Using Time-location Sampling for HIV Surveillance in Street youth PowerPoint Presentation" - ID:193604. (http://www.slideserve.com/Patman/using-time-location-sampling-for-hiv-surveillance-in-street-youth)

<sup>&</sup>lt;sup>129</sup>Johnston LG, Thurman TR, Mock N, Nano L, Carcani V. (2010) "Respondent-driven Sampling: A New Method for Studying Street Children with Findings from Albania" Vulnerable Child Youth Studies 2010 Apr 7;5(1):1–11.

<sup>&</sup>lt;sup>130</sup> Bjørkhaug I and Anne Hatløy A (2009). "Utilisation of Respondent Driven Sampling Among a Population of Child Workers in the Diamond Mining Sector of Sierra Leone." Global Public Health volume 4: Issue 1

that is of minimal monetary value, so people neither give them away nor sell them, and is easy to remember. Examples of unique objects include plastic key chains, a scarf, a card with a memorable slogan and picture on it, a bracelet, a pendant, a flashlight, etc. Unique objects are distributed in each of the survey cities by NGO staff, hired personnel, etc. to persons matching the eligibility criteria. No person should receive more than one object and each person who receives an object should be told to remember the object, not to give it away or sell it. Those distributing unique objects will record data about how many objects were distributed, how many were refused and the reasons for any refusals.

To measure how many participants received a unique object, each participant will be asked during the survey: "Did you receive a XXXXX in the week of [dates of distribution of unique object] that was given to you by XXXX?"

### (b) Service multiplier

The service multiplier uses service data consisting of the unique counts of population members who received a service in each survey city during a specified 6 month period. The second multiplier is enumerated during the probability based survey by asking each respondent whether they had exposure to the service at least one time during the same specified 6 month period. Service data will include [what types of services is the population likely to use]. To measure how many participants received services, they will be asked during the survey: "Did you visit [specific name service here] during [specified 6 month period]?"

### (c) Multiplier assumptions

The assumptions for the multiplier are:

- Two overlapping data sources (specific to the group being counted)
- One data source (i.e. the survey) must be random and encompass the group in the multiplier, but can include others as well
- Second data source (multiplier) need not be random but should be specific to the group being estimated
- No individual accounted for more than once in the multiplier
- Two data sources must be independent of each other (inclusion in one not related to inclusion in the other)
- Limited in- and out-migration

### (d) Multiplier calculation

The number of population members who received a unique object one week prior to the start of the survey or visited a service during a specified 6 month period will be used as a numerator (M) and the proportion who reported receiving an object prior to the start of the survey or visited a service during a specified 6 month period will be used as the denominator (P). The mathematical formula to calculate the population size was: N = M/P

Where:

N=Estimated Size

P=Proportion<sup>131</sup> of population members in survey who reported receiving the object/service. M=Number of population members to whom the object was distributed or service provided.

<sup>&</sup>lt;sup>131</sup> Calculated using the successive sampling estimator and adjusted standard errors in RDS Analyst.

### Figure 32: Service Multiplier among Francophone Sub-Saharan African Migrants in Rabat<sup>132</sup>

In 2013, a survey using RDS was conducted among males and females, 18 years and older, originating from francophone sub-Saharan African countries and living and/or working in an irregular administrative situation in Rabat and residing at least 3 months in Morocco. During the survey, participants were asked if they had visited a local non-governmental organization (NGO) between June 1 and December 31, 2012 (a distinct period of time just before the survey commenced). Twenty two percent of participants reported visiting this NGO. In addition, the same local NGO was asked to calculate the number of francophone sub-Saharan African migrants who had visited the NGO between June 1 and December 31, 2012. The NGO calculated that 916 francophone sub-Saharan African migrants had visited the NGO. The final calculation was 916/0.22 resulting in a population size estimation of 4,427 francophone sub-Saharan African migrants in Rabat.

### 7.4.2 Successive Sampling – Population Size Estimate (SS-PSE)

The SS-PSE method can only be used in surveys using RDS. This method uses each participants' social network size data gathered during the survey to quantify population sizes by assuming that the network size distribution of successive waves reflects a depletion of the population. The estimates use a Bayesian framework (i.e., quantifies uncertainty about unknown quantities by relating them to known quantities) incorporating information about a "guess" or prior knowledge of the size of the sampled population. Prior knowledge can come from expert opinion, previous surveys and other sources. The Bayesian framework also allows the computation of probability intervals. Needed information include the social network size of each participant, the date of enrollment, and who recruited whom (standard data collected during RDS surveys). Estimates are calculated in RDS Analyst software (www.hpmrg.org).

### 7.4.3 Wisdom of the crowds

These estimates are elicited by asking participants in each of the survey cities, their best guess about the most likely highest, lowest and accurate number of their respective population members in each the survey cities. This method may be the least accurate of all but can help to triangulate and validate other population size estimation methods and can be used as a basis for a prior for SS-PSE.

### 7.4.4 NGO and expert 'best guesses'

This method uses enumeration based on the estimates of key informants and NGOs working with the survey population in each of the study cities. Key informants and NGOs in each survey site will be asked to respond to questions about the most likely highest, lowest and accurate number of population members in each the survey township. This information can be used as a basis for a prior for SS-PSE.

### 7.5 Brief Overview of Capture-Recapture

### 7.5.1 Capture-recapture

Capture-recapture, also known as a "mark and recapture" and "capture and release", is implemented in the following manner:<sup>133</sup>

1. Map all the sites where the key population can be found.

2. Go to the sites and tag all of the members of the population at the site by giving them some memorable but inexpensive gift (Examples of unique objects include plastic key chains, a scarf, a card with a memorable slogan and picture on it, a bracelet, a pendant, a flashlight, etc.).

3. Keep a count of the persons tagged.

 <sup>&</sup>lt;sup>132</sup> Johnston LG, Oumzil H, El Rhilani H, et al. (2016) "Sex Differences in HIV Prevalence, Behavioral Risks and Prevention Needs Among Anglophone and Francophone Sub-Saharan African Migrants Living in Rabat, Morocco" AIDS and Behavior, 20 (4):746-753.
 <sup>133</sup> WHO, UNAIDS (2010) "Guidelines on Estimating the Size of Populations Most at Risk to HIV" (<u>http://apps.who.int/iris/bitstream/10665/44347/1/9789241599580\_eng.pdf</u>)

4. Return to the same sites a week later and retag all of the persons encountered and count the members who were counted in the first sample versus members who are being counted for the first time in the second sample.

### 7.5.2 Capture-recapture formula

The number of population members tagged in the initial capture (T1) is be used as a numerator (M) and the proportion who were tagged in the capture and the recapture (T2) is used as the denominator (P). The mathematical formula to calculate the population size was: N= MC/R

Where:

N=Estimated Size M=Total number of population members tagged at T1 C= Total number of population members tagged at T2 R= Number of population members who were tagged at T1 and T2

### 7.6 Deriving City and National Estimates

Once population size estimations are calculated from the methods above, they may be presented during a validation workshop comprised of NGOs, government representatives, members of key populations, and other stakeholders to:

### 7.6.1 Gain consensus

Gain consensus on the final population size estimates for each of the key populations in each of the survey areas. This may be done by having participants break into three groups, each representing one of the cities. Groups can assess each of the PSE multiplier methodologies and results according to specific biases inherent in those methods. The assessment of data can be inputted into a spreadsheet to adjust estimates based on over or underestimations. Groups can then gain consensus of the most reasonable PSE for each population in each city based on their own knowledge and experience. The final consensus can be presented by each of the three breakout groups to the entire group for a consensus by all.

### 7.6.2 Extrapolate these data to derive regional and national estimations

The extrapolation of some data to estimate a national population size is somewhat intuitive and will likely have a lot of biases. However, keep in mind that estimating a hidden population is a big challenge in itself and that the current methods to do so are limited. One way to try and get a national estimate is to derive population density group rankings for all cities/regions. During a consensus meeting, participants can use the agreed upon size estimations from individual surveys to develop density rankings of high (the cities and regions with the highest percentage of each of the key populations), medium and low. Criteria used to rank each population's density might include whether the areas have trades and/or industry, or high mobility, recreation and/or tourism, universities or military bases or were on a border or other factors which would influence the number of TB key populations who might be residing there. This process can be facilitated through the use of a national map, whereby participants fill in areas of the map with red (high concentration of a key population), blue (medium) or white (low or non-existent) and then use this to figure out what percentage of the adult population these colored areas represent. Keep in mind that surveys are most often conducted in urban areas where high concentrations of TB key populations may be found. Therefore, the existing calculated population sizes from survey data are likely to correspond to high density ranking areas.

Maps can be coloured by the working groups based on first-hand knowledge and experience as well as information from secondary sources. Some groups may use the internet and existing mapping of TB key populations online to discuss different areas and their situations. Completed maps can be presented back to all participants for final input, open discussion and consensus.

Following the workshop, the final consensus information can be combined with a secondary literature review of materials describing the TB key population to derive final percentages to represent high, medium and low key

population prevalence. These percentages can be calculated by dividing the corresponding populations of each survey city (i.e., for male PWUD, divide by the total population of males). The density ranking proportions (e.g., 1.5% of males are PWUD) will then be multiplied by the population sizes of the corresponding populations in all cities in the country. The population sizes for all cities in the country can be added up for a final total national number of a TB key population in the country.

### Figure 33: Getting the Number of TB Key Population Members Who Have TB or Received Coverage.

If the survey measured TB, the number of the key population members with TB can be found by multiplying the estimated population sizes by the proportion found to have TB. For instance, if 2% of migrants were found to have TB in the survey and there are 200,000 migrants in the country, then the number of migrants with TB could be .02 X 200,000= 4000.

Similarly, if a survey of PWUD found that 43% of PWUD received some sort of TB outreach in the past six months and the national population size of PWUD was calculated to be 150,000, then .43 X 150,000 = 64,500 PWUD received TB outreach (a measurement of programme coverage) in the past six months.

# 8. Service Planning at City/District Level

After the national and the local programme planning are done, the next phase is planning for the actual service delivery by both public TB services and CBOs at the city or district level. The Global Plan to END TB underlines the need to empower TB programmes at the local level to find innovative solutions, shifting part of the tasks related to key populations into the community is one such solution. It must not result in any decrease in funding available to the city or district TB services. On the contrary, additional funds may be necessary to support coordination and collaboration. Analysis by the Stop TB Partnership, conducted in 2015<sup>134</sup> showed that in both low-income and lower middle-income countries with high TB burdens, around half of the TB budget remains unfunded. Thus, in addition to innovations, strong budget advocacy is needed to increase the capacity of the local TB service delivery. Appropriate investments should be made into the city or district TB services, to be able to support and supervise the key populations program, implemented jointly with the community. For instance it may be necessary to hire a dedicated key population specialist if the city/district TB Coordinator's scope of work cannot be extended to include key populations work.

Just like national-level programme planning, local health authorities also need to ensure TB and HIV services are planned jointly, given TB being the leading cause of death among PLHIV.<sup>135</sup>

Experience from HIV suggests community-based programmes that invest in CBO/NGOs' capacity in both service planning and delivery and collaboration with local health authorities have much better outcomes (more case finding, less loss to follow-up) than programmes that require CBOs/NGOs to deliver services without any prior investment in service delivery and collaboration with local health authorities.<sup>136</sup> As most key populations are more difficult to reach and sometimes criminalized, CBOs involved in programme delivery that includes both case finding and treatment support need more time and support from the public TB services to prepare and plan their services. To fully reap the benefits of CBOs' knowledge of and access to key populations, local health authorities need to invest in a local service planning process.

The stages of the local-level service planning and the content of the services will depend on the specifics of key populations and the local situation:

- Existence and availability of city/district TB coordinators to spearhead the planning
- Extent of integration between TB programme and primary health services
- Legislation regarding drugs administering
- Experience of civil society organizations in case finding and treatment support
- Experience of city/district TB coordinators working with civil society organizations

Services must be gender responsive, evidence-driven and human rights-based (discussed in Section 2). Extra precautions must be taken when the key populations are criminalized in order to safeguard people's wellbeing, privacy, confidentiality and other rights such as informed consent.

There are three steps in this preparation phase to ensure CBOs/NGOs empowerment and smooth collaboration with public TB services. All steps need to be facilitated by a city/district TB Coordinator or a dedicated key

International HIV/Aids Alliance (2013 "Community-based TB and HIV Integration: Good Practice Guide" (https://www.aidsalliance.org/assets/000/000/719/90636-Good-practice-guide-Community-based-TB-and-HIVintegration\_original.pdf?1406297871)

<sup>&</sup>lt;sup>134</sup> Stop TB Partnership (2015) "Factsheet: Racing to the End TB Finish Line"

<sup>(</sup>http://www.stoptb.org/assets/documents/news/Factsheet\_05.pdf)

<sup>&</sup>lt;sup>135</sup> WHO (2017) "WHO Policy on Collaborative TB/HIV Activities: Guidelines for National Programs and Other Stakeholders" (http://apps.who.int/iris/bitstream/10665/44789/1/9789241503006\_eng.pdf)

<sup>&</sup>lt;sup>136</sup> Adapted from:

Malaysian AIDS Council (2015) Global Fund HIV grant Case Management Pilot among MSM in 2014-2015 (unpublished programme notes). USCDC (2014) "Planning and Implementing HIV Testing and Linkage Programs in Non-clinical Settings: A Guide for Program Managers." (https://effectiveinterventions.cdc.gov/docs/default-source/public-health-strategies-docs/HIVTestingImplementationGuide\_Final.pdf) USCDC (2009) "Program Collaboration and Service Integration: Enhancing the Prevention and Control of HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis in the United States." (https://www.cdc.gov/nchhstp/programintegration/docs/207181c\_nchhstp\_pcsi-whitepaper-508c.pdf)

population specialist. The figure below is a template outlining key activities for to be managed by the city/district TB Coordinator or the dedicated TB key population specialist.

### Figure 34: Service Planning by District/City TB Services

(For City/District TB Coordinator or TB Key Population Specialist)

Steps	Objectives	Key Activities	Progress Update
Step 1 - alignment Project		Facilitate meetings and communication to secure local and provincial governments' endorsements of (a) increased TB response	
Planning		among key populations, (b) collaboration between public TB services and relevant local	
(6 months)		government departments and (c) the	
		involvement of CBO in TB service delivery	
	CBO staffing	Support to CBO to recruit a project manager	
	Operational alignment	Align health services with other government services relevant to a particular key population (social, women, police, immigration, labour, prison and narcotics control) and with CBOs	
	CBO staffing	Support CBO project manager to recruit project peer case workers	
	Community	Support CBO project team to hold face-to-	
	consultation	face community consultation on project approach and identify key populations service needs and gaps	
	CBO-government	Assist in developing a collaboration standard	
	Collaboration	operating procedure (SOP) outlining the	
	SOP design	roles/responsibilities of primary health care (PHC) facilities, other relevant government departments and CBOs from outreach, testing to treatment	
	Work planning	Review with CBO project team project targets and principles and develop project and staff work plans	
	CBO-government	Introduce the nature of the collaboration,	
	Collaboration SOP workshop	present working approach and present and finalize the collaboration SOP	
	CBO capacity building	Facilitate and get experts to train CBO project team	
Step 2 -	Work plan finalization	Support CBO project team to finalize work plans	
Project Dry Run	Pre-Dry Run preparation	Ensure CBO project team visits all PHC facilities to discuss with each PHC facility	
(3 months)		practical details per SOP	
	Dry Run	Ensure a number of clients per CBO peer case worker are recruited and trial activities start and then are evaluated	
Step 3 -	CBO capacity building	Meet with CBO project team once a week to discuss challenges and brainstorm solutions	
Project Roll Out	Stakeholder engagement	Support CBO project manager prepare project update for each PHC facilities and	
(3 months)	-	city/district TB coordinators	

Further details of above activities to be coordinated by the city/district TB Coordinator or the dedicated TB key population specialist are included in Annex A7 as reference.

# 9. Tracking Performance

### 9.1 Monitoring and Evaluation

A clear framework at the local level is important to track implementation and performance. Such tracking is enabled through monitoring and evaluation (M&E). M&E is primarily the task of the service provider. Following the multi-stakeholder approach, the M&E can be a joint framework used by all district stakeholders to continuously learn to improve services for key populations. The stakeholders will need assistance to design this joint framework. Key indicators for the local level programme should be based on the service targets set during local-level service planning (Section 8).

Ensuring the continuity of the TB service cascade for key populations is of particular importance. The TB service cascade can be considered to include:<sup>137</sup>

- Size of the key population
- Number with latent TB infection
- Number who develop active TB
- Number of people with active TB tested at diagnostic facilities
- Number of people tested are diagnosed with TB
- Number of people diagnosed with TB are notified
- Number of people notified with TB started treatment
- Number of people started TB treatment retained in treatment
- Number of people in TB treatment successfully completed treatment
- Number of people who receive treatment for TB infection (i.e., preventive therapy)

The Global Plan to End TB suggests top 10 priority indicators (figure below); it also recommends "setting the operational target of reaching at least 90% of people in key populations-through improved access to services, systematic screening where required, and new case-finding methods – and providing all people in need with effective and affordable treatment".

<sup>&</sup>lt;sup>137</sup> Adapted from: B. Subbaraman, R. Nathavitharana, S. Satyanarayana, M. Pai, B. Thomas, V. Chadha, K. Rade, S. Swaminathan, K. Mayer. (2016) "The Tuberculosis Cascade of Care in India's Public Sector: A Systematic Review and Meta-analysis". PLOS Medicine, October 25, 2016 <u>http://dx.doi.org/10.1371/journal.pmed.1002149</u>

### Figure 35: Top-10 Priority Indicators (not ranked) for Monitoring the Implementation Progress of the End TB Strategy at Global and National Levels

(Recommended target levels that are applicable to all countries)

	Indicator	Recommended target level*	Main rationale for inclusion in top-10		
1	TB treatment coverage Number of new and relapse cases that were notified and treated, divided by the estimated number of incident TB cases in the same year, expressed as a percentage	≥90%	High-quality TB care is essential to prevent suffering and death from TB and to cut transmission. High coverage of appropriate treatment is a fundamental requirement for achieving the milestones and targets of the End		
2	TB treatment success rate Percentage of notified TB patients who were successfully treated. The target is for drug- susceptible and drug-resistant TB combined, although outcomes should also be reported separately.	≥90%	TB Strategy. In combination, it is likely that these two indicators will be used for monitoring progress towards universal health coverage (UHC) within the post-2015 Sustainable Development Goals (SDGs).		
3	Percentage of TB-affected households that experience catastrophic costs due to TB Number of people treated for TB (and their households) who incur catastrophic costs (direct and indirect combined), divided by the total number of people treated for TB.	0%	One of the End TB Strategy's three high-level indicators; key marker of financial risk protection and progress towards UHC and social protection for TB-affected households.		
4	Percentage of newly notified TB patients diagnosed using WHO-recommended rapid tests Number of newly notified TB patients diagnosed with WHO-recommended rapid tests, divided by the total number of newly notified TB patient.	≥90%	Accurate diagnosis is a fundamental component of TB care. Rapid tests help to ensure early detection and prompt treatment.		
5	LTBI treatment coverage Sum of the number of people living with HIV newly enrolled in HIV care and the number of children who are contacts of cases started on LTBI treatment, divided by the number eligible for treatment, expressed as a percentage	≥90%	Treatment for latent TB infection (LTBI) is the main treatment intervention available to prevent development of active TB disease in those already infected with <i>M. tuberculosis</i> .		
6	Contact investigation coverage Number of contacts of people with bacteriologically-confirmed TB who were investigated for TB divided by the number eligible, expressed as a percentage	≥90%	Contact investigation is a key component of early TB detection and TB prevention, especially in children.		
7		100%	Drug susceptibility testing (DST) is essential to provide the right treatment for every person diagnosed with TB.		
8	Treatment coverage, new TB drugs Number of TB patients treated with regimens that include new TB drugs, divided by the number of notified patients eligible for treatment with new TB drugs, expressed as a percentage	≥90%	An indicator that is relevant to monitoring the adoption of innovations in all countries. NB. Indicators related to the development of new tools are needed at global level but are not appropriate for monitoring progress in all countries.		
9	Documentation of HIV status among TB patients Number of new and relapse TB patients with documented HIV status divided by the number of new and relapse TB patients notified in the same year, expressed as a percentage	100%	One of the core global indicators used to monito collaborative TB/HIV activities. Documentation o HIV status is essential to provide the best care for HIV-positive TB patients, including anti-retroviral treatment (ART)		
10	Case fatality ratio (CFR) Number of TB deaths (from a national VR system)divided by estimated number of incident cases in the same years, expressed as a percentage	≤5%	This is a key indicator for monitoring progress towards 2020 and 2025 milestones. A CFR of 6% is required to achieve the 2025 global milestone for reductions in TB deaths and cases.		

In addition to indicators of the service cascade, the M&E framework should contain other key indicators to measure the main inputs, activities, outputs, outcome and impact of the interventions. It is also important to evaluate the process of the programme, which reflects how the system works.

Tracking performance at each step of the service cascade is useful to detect at which steps there may be considerable drops in the numbers of clients, indicating bottlenecks to be addressed. The indicators should be valid and reliable (i.e. clearly defined), consistently understood and producing the same results when measured by different stakeholders. The indicators should also be feasible, the stakeholders, including the government and the civil society need to decide what proportion of the key population is realistic to reach and then ensure

as little loss at each step of the cascade as possible. The indicators should also be comparable to allow measuring the results for the same activities across time and geographical space.<sup>138</sup>

In accordance with the Global Plan to END TB, "the data collected to measure progress against all indicators and targets<sup>139</sup> should be appropriately disaggregated by age, sex, and relevant key populations".<sup>140</sup>

Whereas M&E is the task of the service provider, all stakeholders involved in it, including the communities, need to have assess to the M&E data converted into simple, actionable information.<sup>141</sup> Public (government), community (key population CSOs, NGOs) and private (health practitioners, businesses) stakeholders can then engage in, for example, quarterly multi-stakeholder meetings to review each stakeholder's achievements and challenges faced during collaboration and propose corrective steps to continuously improve their services for the key populations.

Monitoring and evaluation should also be part of any survey conducted among TB key populations as described in Section 7. During data collection, questions about programme coverage can be measured. If using a probability based sampling method, information should be of high external validity and include key populations who use services and do not use services. Important information to assess from key populations is the quality and accessibility of services as well as why some key populations do not access services.

### 9.2 Support Rolling up District-level Quarterly Results to National Level

The Global Plan to End TB also calls on countries to make greater use of the local quantitative and qualitative data for identifying local issues, hot spots and barriers to access".<sup>142</sup> The monitoring and evaluation framework should include mechanisms by which district-level quarterly results are compiled and fed into the national level data. The district-level data results should be accurate, complete and timely and verified systematically. The national level should also systematically provide feedback on TB data quality to the district-level.

### 9.3 Independent Community-Based Monitoring

The Global Plan to End TB puts people with TB and their communities as central partners in monitoring and evaluation. Community-based monitoring (CBM) may be understood as a mechanism enabling service users or local people to gather and use information on service provision and service-access barriers in order to inform and hold service providers accountable to the key populations they serve.<sup>143</sup> In the context of this framework, CBM is an independent process, run by the key populations or the local community. The service provider's M&E does not replace the need for independent CBM.

CBM provides support to:

- Improve service quality;
- Develop more nuanced understandings of local processes that have bearings on health services;
- Enable localised production, processing and analysis of programmatic data;
- Enhance community-level knowledge and foster a culture of joint problem solving and learning;
- Equip user communities to engage in evidence-based policy dialogue and cultivate media and wider public support for locally relevant issues; and
- Inculcate necessary flexibility and adaptability to the overall service delivery system.<sup>144</sup>

<sup>&</sup>lt;sup>138</sup> PATH (2013) "Guide to Monitoring and Evaluation of ACSM to Support TB Prevention and Care" (<u>https://www.path.org/publications/files/TB\_acsm\_me\_guide.pdf</u>)

<sup>&</sup>lt;sup>139</sup> The 90-(90)-90 Global Plan target is to reach at least 90% of people with TB and place all of them on appropriate therapy, reach at least 90% of the most vulnerable, underserved, at-risk populations and achieve at least 90% treatment success for all people diagnosed with TB through affordable treatment services, adherence to complete and correct treatment and social support.

<sup>&</sup>lt;sup>140</sup> The Stop TB Partnership (2015) "The Paradigm Shift - The Global Plan to End TB, 2016-2020"

<sup>&</sup>lt;sup>141</sup> Ibid. <sup>142</sup> Ibid.

<sup>&</sup>lt;sup>143</sup> N. Dhungana, F. Cornish, M. Skovdal, G. Mburu (2016) "Four Models of Community-based Monitoring: A Review" (paper submitted to the Global Fund, unpublished)

<sup>&</sup>lt;sup>144</sup> Ibid.

Service-providing CBOs, city/district TB Coordinators or dedicated key population specialists are good candidates to advise and facilitate the establishment of CBM, possibly with external technical assistance. The choice of which CBM model to follow is up to the key population. What is important is that it has to be independent, resourced and systematic. It should also incorporate mechanisms to make changes tangible to the members of that key population community. To help guide the choice of a suitable CBM model, one approach is to look at impact, which can be broadly classified into four areas.

Based on the existing the TB risk drivers, service access barriers and service packages and targets for key populations, the programmes can prioritize availability, accessibility, acceptability or appropriateness of services or a combination of these four.

- 1. Availability qualified health care workers, drugs and diagnostic tools, equipment and materials that are necessary to prevent TB exposure and to diagnose and treat TB either in certain geographical area or to specific key populations.
- 2. Accessibility of the health facilities and services, that can be influenced by privacy and confidentiality rights, gender norms, presence of discrimination and stigmatizing behaviour by service providers, remoteness, hours of operation.
- 3. Acceptability health workforce characteristics and ability (e.g. gender, language, cultural sensitivity, attitude toward key populations, age, etc.) to respect service recipients' human rights and provide them services in non-discriminatory way.
- 4. Appropriateness the fit between the services provided and the needs of the key population.

Four models of CBM are commonly found and applicable to key populations:

- 1. Downward accountability in which key population service recipients act as watchdogs:
  - Tends to focus on if service is sufficient and of high quality in accordance with the standard.
  - Its premise is key population clients and communities have vital information relevant to ensuring high quality service provision, as well as the rights to be heard. And service providers, in turn, are obliged to listen and respond to the key populations.
  - Examples include community hotlines, service feedback meetings between key populations and service providers, stigmatization and discrimination documentation and complaints.
- 2. Citizens as service delivery watchdogs:
  - Focuses on making services acceptable and available for a wider community.
  - Citizen groups (not necessarily key populations) work to address systemic problems affecting health service delivery.
  - Examples include advocacy campaigns, Web-based or SMS-based reporting on service provision.
- 3. Local health governance mechanisms as watchdogs:
  - Formal community structures, involving different stakeholders, operate at the local level and are linked to one or more service delivery facilities or service points where they provide monitoring or oversight.
  - Besides monitoring, it also can focus on local decision-making related to overall key populations programme and context in which the programme operates.
  - Examples include community health councils conducting regular round-tables with local governments, civil society and private practitioners engaged in TB response with the purpose of promoting cooperation, holding implementers accountable and removing bottlenecks.
- 4. Social audits:

- Focus on local health governance and the performance of health facilities and programmes.
- Audits could be combination of the three aforementioned models where key populations are involved in systematic, long-term continuous evaluation.
- Examples include report cards on each health facility's performance, public hearings and community 'testimonies'.

One CBM model is not better than the other. The choice depends on the local situation and the priority impact area.

	CBM Model				
Impact Area		Downward accountability	Citizens as service delivery watchdogs	Local health governance mechanisms	Social audits
	Availability	~			
	Accessibility		~	~	
	Acceptability			~	~
	Appropriateness	~			~

### Figure 36: Matching Impact Areas and CBM Models

Looking at the table above, where availability and fast response are a priority, the recommended CBM model is "downward accountability". It can be put in operation relatively quickly and can easily be standardized. This model usually relies on mechanisms/standards developed by the service provider, e.g. the national TB program's complaints handling procedure. It can increase trust and demand for services. A disadvantage is the limited participation of the key population in the problem-solving phase after complaints are filed, often leading to the disengagement of the key populations concerned.

Where accessibility is a priority, one of the CBM models that can be used is "citizens as service delivery watchdogs". This model helps promote the rights of a broader community, not individual service-users. Community members should be trained to follow up on the collected information through to decision-making and advocate for concrete actions. An alternative model to be used is "local health governance mechanisms" that include key population representatives, these will require lengthier groundwork - advocacy and more resources to be established and maintained. If well received and integrated, they present a long-term and institutionalized solution. Their disadvantage is the slow speed due to sometimes numerous and formal procedures, variety of views and thus the need to build consensus between different stakeholders, so their ability to improve routine processes quickly is diminished.

Where acceptability is a priority, the CBM models that can be used are "local health governance mechanisms" and "social audit". "Social audit" requires time for systematic collection of standardized information, collaborative problem solving by the community representatives, health care workers and other stakeholders. Government's accord is usually required. In the process of this collaboration, mutual trust and understanding of a rights-based approach are developed. It requires training for the community and key population members who want to be 'social auditors', as well as standardized tools to allow comparison between health facilities. Where appropriateness is a priority, the CBM model to be used could either be "downward accountability" or "social audit".

One CBM model does not necessarily take longer or is more difficult to set up than another model, it depends on what the local situation: how active and engaged are the key populations already, what training have they received, what other platforms exist that could be used. A CBM model can be simple, scaled up over a period of time or complex, developed in a pilot area and then rolled out in more locations. A combination of measures and activities is always possible.

### 9.4 Role of the National Level Monitoring Bodies

Most countries that receive Global Fund support have a Country Coordinating Mechanism (or CCM), which is a national coordinating body, responsible for identifying the work that needs to be done, submitting funding requests to the Global Fund and overseeing the implementation of the grants. CCMs in countries where there is a TB epidemic are required to have members representing PWTB and relevant TB key populations. These members have to represent their respective communities and are required to have communication and feedback mechanisms to collect inputs from and provide information to their constituencies. Besides, CCMs are instrumental in updating the key population communities on the health policy issues, funding and technical assistance opportunities to strengthen capacities of TB CSOs. New key population CCM members however will need support from both within and outside CCMs on how to effectively represent and advocate for their constituencies in a national forum such as CCMs where key population members may struggle to be given the space to contribute meaningfully.<sup>145</sup>

CCMs or similar national level governance bodies that are engaged in overseeing TB key population programme should review the quarterly results of the key population programme at the national level. This should be done in accordance with their mandate, whether this is monitoring or oversight (as is the case with the CCMs). In any case, these national level bodies will benefit from using the data to inform their key population TB activities to help remove implementation bottlenecks at the national level. To reach an optimal way of collaboration, National TB Key Population Working Group's (within CCM or other national health coordination bodies) is critical in identifying exactly what information is to be exchanged, discussing mutual expectations, and defining the role and authority of the national level governance bodies.

<sup>&</sup>lt;sup>145</sup> Global Fund (2016) "Achieving Inclusiveness of Country Coordinating Mechanisms Case Studies" (<u>http://www.theglobalfund.org/documents/publications/other/Publication KeyPopulations CaseStudy en/</u>)

# **10. Resourcing Issues**

Every resource has a strategic value and a cost. For successful functioning a programme needs money, human resources, space, equipment, information and scientific expertise.<sup>146</sup> Local level service planning depends heavily on the stewardship of the city/district TB Coordinator. It is likely that this area of work is currently not included in the job description and, if included, will make the workload excessive. In which case, it is advisable to hire a key population specialist dedicated to managing TB work with key populations on behalf of the TB Coordinator. Alternatively many national TB programmes (NTP) have Advocacy, Community and Social Mobilization (ACSM) specialists who can carry out key population related tasks. These human resources within the NTP must be supported, in addition to the other resources (space, equipment, information and scientific expertise), in order for TB services to be efficient and effective.

Initial support for national and sub-national coordination and the programmes of the local level service providers, capacity building for both public and CSO service providers, can come from donors such as the Global Fund. However after the first year or two, the country's own budget needs to start absorbing these costs by showing increasing share of financing of key population TB services, including financing services by CSOs. In order to ensure this, provisions need to be made in advance, such as developing a sustainability and transition plan already at the start of the program. These plans can be based on the national transition plans, if such exist. If there are no such plans, please consult the transition readiness assessment tools to be made by development partners and the Global Fund.<sup>147</sup> It usually considers policy, governance, finance and programmatic activities. Based on the outcomes of such an assessment, all country stakeholders, including key populations, can develop transition plans, reflecting their country conditions. In this section we touch upon four of the resources: financial, human, information and expertise that are required for the civil society.

### 10.1 Costs, Savings and Financial Resources

### **Costs and Savings**

The interventions to identify and manage TB among vulnerable groups can either be cost effective, cost saving or not cost effective. However, the effectiveness and savings of the intervention depend on the burden of TB in a particular key population and also how much time is allowed to elapse before the evaluation of the intervention is carried out. In key populations where the burden of TB is medium to high, screening, treatment and enhanced case management are likely to be cost effective, particularly in the long term.<sup>148</sup> For example, the modeling analysis included in the Stop TB Partnership's Global Plan to End TB demonstrates accelerating TB responses (frontloading that includes key populations) would be more cost effective than the "business-as usual" scenario over the 5-year period of the Global Plan.<sup>149</sup> And an integrated approach between the public and civil society services are likely to improve health outcomes and reduce transmission, which in turn would also enhance the effectiveness of TB responses among key populations and lower costs in the long run.<sup>150</sup> Building up service delivery programmes for key populations require long-term investments in both health and community systems. Hence cost-effectiveness assessment of TB programme for key populations should not be done on a short-term basis (e.g., less than 5 years) before systemic investments in public and community services are institutionalized and begin to produce both public health benefits and financial savings.

<sup>149</sup> The Stop TB Partnership (2015) "The Paradigm Shift - The Global Plan to End TB 2016-2020"

<sup>&</sup>lt;sup>146</sup> N. Themudo (2000) "NGOs and Resources: Getting a Closer Grip on the Complex Area." Documentos de discusion sobre el Tercer Sector, Nm. 5, 2000

<sup>&</sup>lt;sup>147</sup> References to transition readiness tools will be available as part of the Global Fund guidance document, which is currently being finalized (forthcoming).

<sup>&</sup>lt;sup>148</sup> National Institute for Health and Care Excellence (2013) "Tuberculosis in Vulnerable Groups: Local Government Briefing" (<u>https://www.nice.org.uk/advice/lgb11/resources/tuberculosis-in-vulnerable-groups-60521141388229</u>)

<sup>&</sup>lt;sup>150</sup> European CDC (2016) "Guidance on Tuberculosis Control in Vulnerable and Hard-to-reach Populations"

<sup>(</sup>https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/TB-guidance-interventions-vulnerable-groups.pdf)

### **Financial Resources**

Two investment scenarios: standard and accelerated, are considered in the Global Plan.<sup>151</sup> It is also possible that the investment in the country remains at baseline level, without a scale-up, meaning an incremental increase from year to year. The highly recommended accelerated scenario requires a lot of the investment at the beginning (frontloading), but as more people are treated, lives are saved, and less transmission of TB occurs (averting new cases), in the long run the accelerated scenario is the much more cost effective than the business-as-usual scenario. Costs disaggregation estimates that 3-5% of the total investment, necessary to achieve the Global Plan's objectives, should go to community strengthening and involvement. The Plan specifies that this includes "community TB care, the strengthening of community-based organizations and TB survivor support groups, policy development, incentives, and enablers" (Global Plan p. 106). For the key population programme to be successful, the financial resources should be provided to cover service-implementation CBOs:

- Wages and benefits that comply with national labour laws and regulations
- Monitoring and evaluation
- Professional development, including training
- External supervision to the implementing NGO/CBOs
- Other programme management costs
- All costs related to case management from active case finding and testing (including HIV testing) to participation in monitoring after treatment completion

### 10.2 Human Resources

### **Roles and Tasks**

For programme staff, including management and the peer case workers, it is important to develop job descriptions, outlining the necessary skills and experience, tasks, responsibilities and authority, reporting line and evaluation.

### Recruitment

It is advisable to recruit as many qualified and/or engaged and willing-to-learn members of the key population community to work as peer case workers with pay. Recruitment procedures should be transparent and clearly defined. Required skills and attitude should be outlined and should include people-orientation (i.e., enjoy working with people, ability to listen and being non-judgmental).

### Training

Training is an important part of building up the capacity of an organization's members. It is also a source of motivation.

Possible training topics for the peer case workers are in Annex A7 (Project Planning – Step 1) mentioned as part of a 10-day practical skills building workshop (or two 5-day workshops). Additional possible training topics for project managers can include:

- o Community health programme management
- o Strategic planning
- Community mobilization
- Community-based monitoring and advocacy
- Standard Operating Procedure development
- Case management supervision of peer case workers (weekly discussion of cases with each case worker to ensure no clients fall through the cracks)

<sup>&</sup>lt;sup>151</sup> The Stop TB Partnership (2015) "The Paradigm Shift - the Global Plan to End TB 2016-2020"

- Good communication (ability to see things from others' perspective first) including negotiations with local health authorities for win-win solutions for both the key population community and local health authorities
- $\circ$  Staff motivation

### **External Supervision**

If there is a functioning primary health care supervision system, routinely provided by the NTP to the local level staff, it needs to be adapted and expanded to include the key population programme staff. Key population CBO programme staff could be included in the supportive supervision. A combination of individual and team supervision can be used to promote shared responsibilities and collaboration between peer case workers. Both are critical to successful implementation of case management. The nature of supportive supervision should not be control or monitoring, but facilitating improvements. Supportive supervision features are: <sup>152</sup>

- Structured and detailed
- Focused on systems and processes
- o Emphasizes mentoring and joint problem solving, using quality improvement tools
- Assists in planning quality improvement goals
- Based on two-way communication

The following tools should be used for supportive supervision: <sup>153</sup>

- A clear supervision schedule developed and agreed in advance (no surprise visits)
- Supervision check-list
- Meeting with the key population CBO programme staff on site at the end of the supervision to give feedback
- o Supervision report that is shared within a reasonable time after the visit

If supervision from the NTP is not available, other alternatives can be explored, such as community supervision or peer supervision. For community supervision to work there needs to be a history or a culture of community engagement, strong and preferably trained community leaders. Community then plays a role in defining expectations from the programme and the staff and provides feedback. Prerequisites to peers supervision where peers play a major role in supervising each other are the availability of oversight from the health system for supplies, skills, and training and the availability of peers, e.g. in a near-by location, engaged in similar key population programme activities. The main objectives of supervision by peers are joint problem solving, skills development and moral support.<sup>154</sup>

### Motivation

The key population programme can adjust certain dimensions and elements of work in order to create a positive and motivating environment for the staff members:

- Employment quality including wages, working hours, participation, professional development and autonomy
- Work quality including organizational culture and trust, safety and health, work organization and pace and social work environment

More information about motivation is in Annex A8.

<sup>&</sup>lt;sup>152</sup> PATH (2003) "Guidelines for Implementing Supportive Supervision: A Step-by-step Guide with Tools to Support Immunization" (<u>http://www.path.org/vaccineresources/files/Guidelines\_for\_Supportive\_Supervision.pdf</u>)

<sup>&</sup>lt;sup>153</sup> Kenyan National Leprosy, Tuberculosis and Lung Disease Programme "Kenya TB Course Module 8, Supportive Supervision", PPT hard copy shared with the authors of this document.

<sup>&</sup>lt;sup>154</sup> L. Crigler, J. Gergen, H. Perry (2013) "Supervision of Community Health Workers"

<sup>(</sup>http://www.mchip.net/sites/default/files/mchipfiles/09\_CHW\_Supervision.pdf)

### **10.3 Information Updates**

It is important that the newly released WHO guidelines reach the countries soon, are translated, adjusted to the country's specifics, adopted and implemented. These international and national level documents should be available to the key population programme. Besides, there are documents produced by TB advocacy organisations and partner organisations, targeting or relevant to key population communities. Having access to the latest information on both clinical and programmatic TB advances, will allow better advocacy, faster implementation of the innovations and better outcomes for the clients.

### **10.4 Scientific Expertise**

Information and also technical assistance is usually available from the following sources:

- WHO Global TB Programme <u>gtbprogramme@who.int</u> where you can subscribe to the newsletters, national and regional WHO offices;
- The Global Fund Communities, Rights and Gender (CRG) department, at the GF website information a form to request technical assistance (TA) and a list of TA providers can be accessed;
  - Regional CRG Platforms for Communication and Coordination:
    - Eastern Europe and Central Asia platform http://eecaplatform.org/
    - Asia And The Pacific Platform host: APCASO http://apcaso.org/
    - Anglophone Africa Platform host: Eastern Africa National Networks of AIDS Service Organisations
       (EANNASO) <u>www.eannaso.org/anglorccp</u>
    - Middle east and North Africa Platform Host: International Treatment Preparedness Coalition (ITPC-MENA) - <u>www.facebook.com/PlateformeRegionalMENA</u>
    - Francophone Africa Platform host: Réseau Accès aux Médicaments Essentiels (RAME) <u>www.prf-</u> fondsmondial.org/fr
    - Latin America And The Caribbean Platform host: Centro Regional de Asistencia Técnica para Latinoamérica y el Caribe/ CRAT (Via Libre) - <u>http://plataformalac.org</u>

Annexes

# A1 – Key Population TB Risks, Risk Drivers and Service Challenges Template

	Key Population Name:				
	ТВ	Risks		TB Risk Drivers	
Environment (Over-crowded, poor ventilation)	Biology (Reduced immunity)	Behaviour (Prone to transmission)	Limited Access to Services (Health, social and economic)	Legal & Economic (criminalization, poverty) Gender & Human Rights (stigma, discrimination)	TB Case Finding and Treatment Service Challenges
•	•	•	•	•	•
•	•	•	•	•	•

# A2.1 – A Migrant's Journey and Other Issues that May be Relevant

	Vision is the although developing for the forence phildren (2)					
A Journey	Vivian is the eldest daughter in a family of seven children. She received a good education as elementary school					
	teacher and was hoping to work in her village but there were no job openings in any of the schools in the					
	mountainous district where the family lived. In the meantime Vivian got married and got a child of her own. Her					
	husband worked in construction abroad, because the possibilities of finding work in the country were very limited.					
	Vivian's husband would be away almost the whole year, coming home for a short break in winter. There were jobs at a					
	textile factory in the same city where he worked, although people said that the factory would not provide working					
	permits to foreigners. Since the family was still struggling financially, Vivian decided to try and get work at that					
	factory. She and her husband could share a small apartment with two other migrant worker families, while their child					
	stayed with the grandparents. Vivian and her husband would send all the money back to the family in their homeland.					
	After a few months Vivian started coughing, she also had chest pain, back pain and headache. Her husband who was					
	already coughing for a few months said that it must have to do with the cold climate, which they couldn't get used to.					
	The good news was that they found out that they would be parents again soon: it turned out Vivian was pregnant.					
	Vivian asked her husband if she could use some money to go for a consultation to a private gynaecologist, since					
	without having a residence permit she could not go to a public policlinic. The gynaecologist assured that the					
	pregnancy was fine, but got very worried about the cough and the other complaints, suggesting Vivian does					
	something to make sure it was not TB. Vivian and her husband decided that she should go back to their home					
	country immediately before the families with whom they shared the apartment would suspect anything. They were					
	afraid that both of them would be kicked out of the apartment if the rumours spread. When back to her village, Vivian					
	went to the local policlinic where they quickly collected and tested her sputum samples, which confirmed she had TB.					
	Vivian was put in the district hospital for treatment, which was for free, and she also did not have to pay for the food.					
	Still Vivian had to buy vitamins to make the treatment side effects go away. She also had to go regularly for					
	consultations related to her pregnancy, which were at the policlinic in her village. These already put a lot of strain on					
	the family budget. After receiving information about TB from the hospital nurses, Vivian was sure her husband had TB					
	too. She was very worried about him, but at the moment, until she got better, he had to continue his construction work.					
Other issues	Origin					
that may be	<ul> <li>Migrants and refugees often originate from countries and communities with a high burden of TB.</li> </ul>					
relevant	<ul> <li>Health care services in the countries/communities of origin may be limited or unavailable sometimes due to</li> </ul>					
relevant	political instability and conflict.					
	<ul> <li>Access of migrants/refugees to care is limited.</li> </ul>					
	<ul> <li>Socio-economic status often low.</li> </ul>					
	<ul> <li>Lack of education, limited knowledge about TB, hindering beliefs or misinformation about TB transmission,</li> </ul>					
	symptoms and prospects of being cured.					
	Transit					
	<ul> <li>Physical travel conditions linked to overcrowding, food shortages, violence and poor ventilation.</li> </ul>					
	• Potential distrust for authorities including public health officials; fear of being identified as migrant/refugee and					
	being deported.					
	Women are particularly vulnerable.					
	Experience treatment interruption if already on anti-TB treatment.					
	Destination					
	No continuity of care for those previously on anti-TB treatment.					
	Sometimes no legal status, distress and psychological issues.					
	Lack of access to adequate housing.					
	• Underpaid and occupationally insecure jobs (overcrowding, poor ventilation, overexposure to small particles),					
	lack of sick-leave.					
	Malnutrition as a result of poverty, women and children can be particularly vulnerable.					
	No social security benefits, no health insurance or lack of information about the entitlements.					
	Language and cultural barriers.					
	• Stigmatization by the host community, health care workers, self-stigmatization and related fears.					
	Return to origin (in some cases)					
	Availability and accessibility of health care services/ No continuity of care for those previously on anti-TB					
	treatment.					
	Stigma and family pressure.					

### A2.2 – A Miner's Journey and Other Issues that May be Relevant

A Journey	Michael's father and uncles are all miners, his grandfather used to work in the mine too. It is hard work, but it's not far from their home and the mine has provided a living for the family and the whole small community they live in. Michael's ancestors have always lived here, even before the mine was opened, but many other miners who work here come from far away, even from other countries. Everyone in Michael's family is in good health, except for the grandfather, the working conditions back the days were not too good, grandfather says, and after about 10 years of work in the mine he already had much difficulty breathing. Only years later, after he had retired, grandfather was diagnosed with silicosis. It cannot be treated. Now everyone at the mine has to wear a respirator. Michael looks forward to starting working at the mine next month after finishing school, his father told him to go to the nearest health centre (there is no health centre at Michael's village) and get a "chest X-ray", that is something needed to get a permission to work at the mine, there are other medical tests too, but the mine takes care of those. So, tomorrow Michael will travel to the health centre to get the X-ray, it takes one whole day to reach it. He will take along his grandfather, whose health has been declining lately: he coughs, complains of chest pain and fever and has become very thin. Coughing is not uncommon, especially among the mineworkers who live in dormitories, saving up on food and accommodation, so that they can send more money back to their families. Often it's just a cough and when they go back to their homes they have it treated, but then it's time to return to the mine, the cough comes back again too.
<b>A</b> 11 1	
Other issues	Before employment
that may be relevant	• Miners often are migrant workers (e.g. circular migration in Southern Africa), coming from rural communities where access to TB treatment and care can be limited due to remoteness and economic factors.
	<ul> <li>During employment</li> <li>Industrial mining employers do not always adhere to the regulations related to occupational health and safety (e.g. dust concentration) health benefits and protection are not always parts of the employment contracts; the artisanal or small-scale miners do not observe such regulations.</li> </ul>
	<ul> <li>Up to 30% of mine workers could become infected with HIV within 1.5 years of employment<sup>155</sup>. The TB risks of silicosis and HIV infection combine multiplicatively.<sup>156</sup> HIV together with silicosis means that the likelihood of latent TB infection progressing to TB disease increases by 15 times.<sup>157</sup></li> </ul>
	• Circular migration poses challenges to treatment adherence, monitoring, and gives rise to MDR-TB; it also increases the exposure of the sending communities to TB and HIV.
	• In some countries in order to secure employment TB tests can be forged by the employment-seekers. Mine medical facilities provide tertiary care (for accidents) but weak primary care and often such primary care facilities (of which TB is a part) are inaccessible near mining sites.
	After employment
	<ul> <li>Former miners who had had silica exposure, even in the absence of silicosis, have a life-long increased risk of TB.<sup>158</sup></li> </ul>
	• It is not easy for former miners to find employment elsewhere, so there is high unemployment and poverty among them.

 <sup>&</sup>lt;sup>155</sup> https://epianalysis.wordpress.com/2011/07/25/miningandtb/
 <sup>156</sup> Eugene Cairncross, Sophia Kisting, Mariette Liefferink, David van Wyk (2013) "Case Study on Extractive Industries prepared for the Lancet Commission on Global Governance: Report from South Africa" (<u>http://www.thejournalist.org.za/wp-content/uploads/2014/09/Lancet-Study-Gold-Platinum-Mines-in-SA.pdf</u>)
 <sup>157</sup> https://epianalysis.wordpress.com/2011/07/25/miningandtb/
 <sup>158</sup> R. Eisler (2003) "Health Risks Of Gold Miners: A Synoptic Review" Environmental Geochemistry and Health 25: 325–345.

### A2.3 – A Prisoner's Journey and Other Issues that May be Relevant

A Journey	Tom was arrested by police for pickpocketing. He was detained in the local detention centre while waiting for his trial. It had been two weeks in the detention centre, which was basically a small room with only a small window and little fresh air circulation. He had not been screened for TB or even asked if he had any other health conditions. Then another detainee was put into the room and he was coughing badly. Two more weeks went by and still without a trial date for Tom and the coughing of the other detainee continued. Then Tom started coughing himself. He reported his and other detainee's coughing to the officials of the detention centre a week later. But they told him his court date was set and he should just wait. His coughing continued even when he appeared in court, which sentenced him to prison for 6 months. He was put into prison immediately, again without any screening for TB or other health conditions, despite his coughing. Luckily, a health NGO running a pilot working with new prisoners noticed Tom's coughing and took Tom to the prison's nurse, who immediately tested Tom for TB. Tom was subsequently put on TB treatment. Tom felt he was very lucky that he was spotted by the health NGO which was crucial in getting on treatment for TB. He would not have known how to get the attention of the prison nurse. On the other hand, he noticed many other prisoners were not as lucky as he was. He wished the prison officials would let the health NGO extend the pilot to screen for TB orall prisoners, including existing ones, as he feared many of them had TB. Tom was released two months early due to his good behaviour in prison. But he was discharged with no medical record on that he was on TB treatment. A month later after discharge, he started coughing again. He went to his neighborhood clinic, which diagnosed TB again. Tom told the clinic he had started TB treatment tup the did not want to tell them he started it in prison for fear of being stigmatized. So he agreed to start TB treatment again but his coughing d
Other	Before incarceration
Issues that	Often homeless and poor (illegal migrants in particular).
may be	• Many may be already infected with HIV, HCV, HBV or other STDs (drug use, sex work, sexual abuse victims).
relevant	Often with limited access to health services (some may be on Methadone Maintenance Treatment, HIV
	<ul><li>antiretroviral treatment or even TB treatment).</li><li>May be socially isolated and separated from family (women separated from their children in particular).</li></ul>
	<ul> <li>Often subject to harassment and extortion by law enforcement authorities in exchange for bribes in monetary and sexual terms to avoid prosecution (female sex workers who often use drugs are particularly vulnerable).</li> </ul>
	<ul> <li>During incarceration</li> <li>Over-crowdedness and lack of isolation facility for TB cases (conducive for airborne transmission diseases such as TB).</li> <li>Usually not screened for anything, particularly in detention centres, which are supposedly short-term, elevating the risk of treatment disruptions of existing Methadone Maintenance Treatment/ART/TB treatments initiated prior to imprisonment/detention.</li> <li>Poor nutrition, coupled with being HIV without treatment, lowers immunity and increases TB risks.</li> <li>Easy access and prone to taking drugs (both injecting and non-injecting) as being locked up most of the time having nothing to do.</li> <li>May be engaged in unprotected sex (both men and women) in exchange for preferential treatment by fellow inmates or prison guards including access to health services.</li> <li>If untreated and with poor infection control, inmates with active TB often infect other inmates, prison workers and visitors who then can infect communities outside the prison.</li> <li>Inmates' daily struggle (women in particular) within a crowded environment means less attention paid to the importance of adhering to TB drug taking regime even when TB treatment is available, increasing drug resistance risks.</li> <li>Many pre-trial detainees often end up spending years in detention due to overloaded court system or harsh criminal codes for minor offenses such as non-violent crimes such as use or possession of drugs).</li> <li>Female inmates could be very vulnerable in a mostly male-dominated environment, ranging from prison officials being insensitive to women's needs, particularly in the areas of mental and sexual health, to sexual abuses by prison officials or male inmates when gender segregation is inadequate.</li> </ul>
	<ul> <li>After incarceration</li> <li>Often no discharge or inter-facility transfer planning, no linkages to stigma-discrimination free government health services and community support (PWIDs who need Methadone Maintenance Treatment and TB drugs, PLHIV who need ART and TB drug, some needing coordination of all three) leading to treatment disruptions (drug use relapse, drug resistance for both TB and HIV) and increased infectivity and transmission risks to the community or other prisons or detention centres.</li> <li>Sometimes not even basic treatment records would be given to the released/transferred inmates, leading to unnecessary re-testing, re-diagnosis and treatment disruptions (drug use relapse, drug resistance for both TB</li> </ul>

and HIV) and increased infectivity and transmission risks to the community and other prisons or detention centres.
• Ex-prisoners/detainees are often socially stigmatized and often socially isolated without family support making
them prone to taking drugs or engaging in sex work again, particularly when they face difficulty in securing a job,
increasing their risks of being incarcerated again (vicious cycle).
• For ex-PWID, the first 2-4 weeks after release from prison/detention centre is most likely to experience overdose
due to lowered drug intake while in custody and this elevated mortality risks can be mitigated by coordinated TB-
HIV-Methadone Maintenance Treatment by health and social authorities and NGOs (peer workers in particular).

# A2.4 – A Person Who Use Drugs' Journey and Other Issues that May be Relevant

A Journey	Jennifer was introduced to crack cocaine by friends at a party she attended. She thought it was cool and everyone was doing it at the party and just a few smokes won't be addictive. Throughout the party, she smoked from the same glass pipe of her friend who offered it to her as a friendly gesture. They were doing it in a small windowless room in the back of the friend's house. This small room was also packed with other smokers throughout the night. She did not think too much about the risk of getting TB. She was in such a high that before too long she found herself inhaling from smoke exhaled directly from her friend's and others' mouths. She kept going to this friend's party every weekend. Within a month she started coughing. She bought cough medicine from the neighborhood pharmacy but kept going to her friend's party for two more weeks. Then she felt really sick and finally went to the polyclinic in her neighborhood. At the entrance of the polyclinic there was this huge banner of the national antidrug campaign. Jennifer thought to herself that she definitely should not tell the clinic staff anything about her use of crack cocaine in the past two months for fear she would be referred to the police and put into jail. The doctor diagnosed her as having a spell of bronchitis and gave her medicine for that. Within a week her coughing got really bad and went back to the polyclinic and this time the doctor thought it might be TB and ordered a chest X-ray. But the polyclinic does not the X-ray machine. Jennifer took a day off from work and travelled the half-day journey to the district TB hospital in the city nearest to where she lives. The hospital quickly diagnosed Jennifer with TB and put her on treatment. Jennifer felt better within two weeks of treatment. She was grateful that the district hospital did not ask any questions about her drug use and wished that the polyclinic in her neighborhood did not have a big anti-drug campaign banner outside for she learned from the district hospital nurse taking drugs in a c
Other Issues	Before drug use
that may be relevant	<ul> <li>Often faced with daily pressures or some catastrophic events (family deaths, unemployment) or social pressure (private parties for marginalized sub-populations such as gay men).</li> <li>Smoking cigarettes often used to relieve pressures or, in the case of private sex parties, taking drugs to enhance sexual pleasure.</li> </ul>
	<ul> <li>Often under peer pressure making one prone to friends' persuasion that drugs can help relieve pressure from daily grinds (forget about your problems for a while) and just a smoke won't be addictive (these friends/acquaintances are often drug dealers).</li> <li>Drugs are often easily available through "Friends" offer different drugs to try.</li> </ul>
	<ul> <li>Getting addicted</li> <li>First just smoking one drug, then smoking other drugs to test other drugs out (just a minor relief to forget for a while all the problems).</li> <li>Then start injecting drugs as smoking is not effective or fast enough to get "high".</li> </ul>
	• Then start injecting multiple drugs or increase dosage to maintain effect, including sexual pleasure in the case of
	<ul> <li>party drugs among the gay population.</li> <li>If injecting, increased dosage would lead to poor performance at work and usually end up losing the job.</li> <li>Then any waking moments would revolve around injecting (3-5 times a day in the case of heroin) and finding money to pay for the drugs (sex work, first borrowing then stealing from family, friends and fellow co-workers, stealing from the public).</li> </ul>
	<ul> <li>Skim on injecting equipment in order to save money in order to buy as much drugs as possible - sharing needles, containers and water to dilute and heat drugs – huge HIV and HCV risks.</li> <li>Injecting or smoking with friends take place in hidden places (drug use being illegal) with poor ventilation and hygiene – increases TB risks – further heightened if HIV+ (sharing needles and other equipment), poor nutrition (homeless and all money spent on drugs), inhaling and exhaling directly into each other's mouth (short-gunning).</li> <li>Social isolation – family and friends disserting due to financial burden and social stigma against PWUD – vicious cycle of more despair, more drug use, more despair.</li> </ul>
	<ul> <li>Getting off drugs</li> <li>Many PWID, after years of vicious cycle of despair and drug use, would like to quit but detoxification success rate is extremely low (with most PWID have multiple episodes of detoxifications) – social stigma limits their chance of finding work after detoxification, and without work when "friends" show up, relapse takes place.</li> <li>Detoxification failures reinforce despairs (hence more drugs) and abandonment by family.</li> <li>Yet few would consider harm reduction measures such as Methadone Maintenance Treatment and needles and syringes exchange and continue to chase the "detoxification" utopia (driven by social expectation detoxification is the only socially acceptable option despite proven effectiveness of harm reduction in keeping PWUD from getting infected by HIV/HBV/HCV/TB while maintaining a normal life with gainful employment and family reapost)</li> </ul>
	<ul> <li>respect).</li> <li>Being criminalized in most countries, PWID do not feel comfortable accessing public health services even with the knowledge services such as Methadone Maintenance Treatment can help them. They are wary of health care providers might stigmatize or discriminate them. Stories about fellow PWID being apprehended by police outside public health facilities, including Methadone Maintenance Treatment, reinforce PWID fear of public health services.</li> </ul>
	• Even when PWUD willing to use harm reduction, the often fragmented services between different public health units (e.g., TB with district health, ART with national ART hospital, Methadone Maintenance Treatment clinics operated by anti-narcotics authorities) often leads to Methadone disruptions (hence relapse, which then leads to

TB and HIV treatment disruptions, which then leads to drug resistance and increased infectivity among the community).
<ul> <li>NGOs and their ex-PWUD peers can help PWID navigate (and many even provide needles and syringes exchange to tie PWID over during relapses to prevent HIV infection) but NGOs, particularly those run by ex- PWUD who have access to drug users and are knowledgeable of drug users' needs) are often excluded from the government health system, limiting their effectiveness in helping PWID navigate the public system and adhere to treatment.</li> </ul>

# A2.5 – A Person Living With HIV's Journey and Other Issues that May be Relevant

A Journey	Andrew was diagnosed with HIV when he underwent a surgery after a car accident. All hospitals in the country are now required to counsel and test all hospitalized individuals for HIV before any surgeries. He agreed to the HIV test after being counseled by the nurse. Despite initial shock he came to terms with his wife about how he contracted HIV before they got married. He recovered well from the surgery and at the same time started antiretroviral treatment. He was extremely nervous about his HIV status for fear of being fired from his job as a school bus driver. One day a week after he started HIV treatment, he by chance walked past a mobile clinic of an NGO conducting HIV testing in the community. And he saw a poster on the van that TB often occurs for people living with HIV. He joined the queue and had a session with the mobile clinic nurse, who asked him right away has he had any coughing recently and did the hospital, which diagnosed with HIV. The mobile clinic nurse on the spot called his hospital and arranged for him to get tested for TB. The nurse also explained to him that if he has not coughed for two weeks he should be OK but went ahead and informed him he should get tested for TB nonetheless as even he might not have any symptoms of active TB such as two weeks of coughing he may have latent TB. And being HIV positive will increase the likelihood of latent TB becoming active TB and there is preventive treatment for that. He went to the hospital the next day and was given an apology by the ART clinic that somehow they neglected to test him for TB and tested him right away found that he indeed had latent TB and put him on isoniazid preventive treatment as well. Andrew now volunteers with the NGO's local PHLIV peer support group one day a week at the ART clinic working with the nurses there to educate and support other PLHIV including TB prevention and treatment.
Other issues that	Getting tested for HIV
may be relevant	<ul> <li>HIV key populations – people who inject drugs (PWID), female sex workers (FSW), men who have sex with men (MSM), transgender people (TG) - usually through community-based voluntary counseling and testing (VCT) programmes.</li> <li>General population usually through provider-initiated testing and counseling (PITC) at government hospitals and primary health clinics such as antenatal clinics and general hospitals.</li> </ul>
	Upon diagnosis
	<ul> <li>Most experience shock and denial, then blame game starts.</li> <li>Would not be able to comprehend any prevention or treatment information, including TB.</li> <li>Extremely prone of suicidal thoughts, particularly socially marginalized populations (PWID, FSW, MSM, TG) and women as they experience double stigma/discrimination being PWID, FSW, MSM, TG or women and now HIV.</li> <li>In many countries where anti-discrimination laws and policies or their enforcement are weak or non-existence, being diagnosed HIV means losing one's job and livelihood, or getting cut off from family.</li> </ul>
	<ul> <li>Getting on treatment</li> <li>Many socially marginalized PLHIV become so despair, even though they know there is treatment that would keep one healthy despite of HIV, but the fact that diagnosis would expose one's drug use, sex work, being gay or transgender often deters the person from following up on HIV treatment and other follow-up services such as TB screening, preventive therapy and treatment - they choose to disappear from the public system (i.e., loss to follow up after diagnosis - a major challenge for public health authorities) and forgo HIV and TB treatments even when they are provided for free. They see the costs of one's identity being exposed far outweigh any health benefits of treatment.</li> <li>Thus the biggest challenge for getting PLHIV on treatment is not just finding them, but supporting them – socially, financially and administratively, to feel completely safe to undergo treatment - this means confidential and stigma-free treatment, contact tracing and social security services by government stakeholders and the community peer-based support to increase PLHIV trust in the public system and community support.</li> </ul>
	<ul> <li>PLHIV often have to go to a clinic or health care provider different from their current HIV clinic/provider to get their TB services for both screening and treatment. This deters them from getting TB services.</li> <li>TB services (case finding and treatment among PLHIV) needs to be integrated (health, social and community) with confidential and stigma-free HIV treatment, contact tracing services and harm reduction such as Methadone Maintenance Treatment run by government clinics and needles and syringes exchange run by NGOs (if the PLHIV is also a drug user).</li> </ul>
	<ul> <li>When HIV service is not confidential and stigma-free or social security support not in place, TB programmes need to work with HIV authorities to ensure both HIV and TB services are integrated, confidential and stigma-free and social services looking for ways to mitigate any associated catastrophic costs of TB.</li> <li>TB programmes should also align their services with those of NGOs whose peer outreach workers are</li> </ul>
	serving the PLHIV community and its sub-communities (MSM, FSW and PWIDs). Otherwise the chance of PLHIV using TB services will be significantly diminished as long as stigma and discrimination are still widespread in society and social security protection against catastrophic costs is absent. NGOs and peers can help but they are most effective in contributing to treatment adherence when their work is integrated with the public health and social care systems.

# A3 – Key Population Service Access Barriers and Potential Responses Template

Key Population Name:		
Barriers Key Population Might Face (From the perspective of the key population, TB service access difficulties in particular)		
Potential Responses (To meet the health, psychosocial and financial needs of the key population and maximize public health benefits for the general population)	• • • • • •	
## A4 – National Key Populations Prioritization Template

	Score 1	Score 2	Score 3	Score 4	Score 5	Score 6		bined Score to Facilitate oritization Discussion
Key Populations to Consider	Estimated 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%)	Faced with Environm ent Risks (Over- crowded, poorly ventilated space, reside in zoonotic TB areas) 0 - No 1 - Yes	Faced with Biology Risks (Reduced immunity, poor nutrition) 0 - No 1 - Yes	Faced with Behaviour Risks (In/exhaling from/into other's mouth, sharing smoking equipment) 0 - No 1 - Yes	Legal & Economic Barriers to Accessing Services (Criminalizat ion, poverty) 0 - No 1 - Yes	Human Rights & Gender Barriers to Accessing Services (Stigma, discrimination) 0 - No 1 - Yes	Total Score (Sum of Scores 1-6, Max 10)	Prioritization Discussion and Rationale for Prioritized Key Populations
People Living								
with HIV People with								
Silicosis								
Miners								
Migrants								
Refugees								
Internally Displaced People								
Nomadic								
Populations Prisoners &								
Detainees								
People who Use Drugs								
People with Alcohol Dependency								
Smokers								
Sex Workers								
Lesbian, Gay, Bisexual & Transgender								
Indigenous Populations								
Homeless								
People with Mental or Physical Disabilities								
Urban Poor								
Rural Poor								
People with Diabetes								
Children Elderly								
						<u> </u>		
Hospital Workers								
Prison Workers Refugee Camp								
Workers								
Community Health/ Outreach Workers								
Hospital Visitors								

	Score 1	Score 2	Score 3	Score 4	Score 5	Score 6		bined Score to Facilitate ioritization Discussion
	Estimated Contribution to the Country's TB Disease Burden	Faced with Environm ent Risks	Faced with Biology Risks	Faced with Behaviour Risks	Legal & Economic Barriers to Accessing Services	Human Rights & Gender Barriers to Accessing Services	Total Score	
Key Populations to Consider	(Active TB cases of all forms) 1 – Very Low (<1%) 2 – Low (1-3%)	(Over- crowded, poorly ventilated space, reside in zoonotic TB areas)	(Reduced immunity, poor nutrition)	(In/exhaling from/into other's mouth, sharing smoking equipment)	(Criminalizat ion, poverty)	(Stigma, discrimination)	(Sum of Scores 1-6, Max 10)	Prioritization Discussion and Rationale for Prioritized Key Populations
	<b>3 – Medium</b> (3-5%) <b>4 – High</b> (5-10%) <b>5 – Very High</b> (>10%)	0 - No 1 - Yes	0 - No 1 - Yes	0 - No 1 - Yes	0 - No 1 - Yes	0 - No 1 - Yes		
Prison Visitors								
Peri-prison								
Communities								
Peri-mining								
Communities								
Sex Worker Clients								
People who								
Use Drug								
Family								
Members								
Miners Family Members								
People at risk								
of zoonotic TB								

After key populations have been prioritized (with rationale), the working group should follow the WHO screening guidelines to conduct further analysis on the prioritized key populations to check their potential case finding yields, risks and costs of different screening algorithms.<sup>159</sup> Further discussion will need to address how to address capacity and resource gaps in the country's health system to reach these prioritized key populations.

If a country determines a specific population group that belongs to more than one key populations (e.g., PWUD in prison), just add this specific group to the bottom of the table.

<sup>&</sup>lt;sup>159</sup> WHO (2015) "Systematic Screening for Active Tuberculosis: An Operational Guide"

<sup>(</sup>http://apps.who.int/iris/bitstream/10665/181164/1/9789241549172\_eng.pdf?ua=1&ua=1).

WHO (2017) "Ethics Guidance for the Implementation of the End TB Strategy, Ch. 16 on Screening (http://apps.who.int/iris/bitstream/10665/254820/1/9789241512114-eng.pdf).

A corresponding online tool "ScreenTB" (https://wpro.shinyapps.io/screen\_tb/) is available to help countries assess the pros and cons of different screening algorithms for a prioritized key population in terms of number of individuals needed to screen and cost per case detected and estimate number of cases of true positive, false negative (cases missed) and false positive (particularly in situations where TB is highly stigmatized). WHO added the tool is meant to serve only as an aid in the process of prioritizing risk groups for screening and choosing screening algorithms. It should not be used for detailed planning, or for projection of future impact on TB epidemiology. Countries should refer to "Systematic Screening for Active Tuberculosis: An Operational Guide" and "Ethics Guidance for the Implementation of the End TB Strategy" for other elements of the planning and implementation process.

# A5 – National Key Populations Programme Planning Template

Key Populations <u>Prioritized</u>	Estimated Size of prioritized key populations (age and sex disaggregated) in the country	Where are they concentrated (geographically, digitally)?	What are their <u>key TB</u> <u>risks</u> and related <u>drivers</u> ?	What are their TB case finding and treatment <u>services</u> <u>challenges</u> ?	What <u>TB service</u> package (and integration with other health, harm reduction, social, community, immigration, labour,	Preliminary national targets	Service and Data gaps that need to be addressed?
					police) is needed?		
				<u> </u>			

#### A6 – Sample Size Calculations

There are two sample size calculations that might be useful for sampling TB key populations. One of the methods is for surveys that are conducted over consecutive years (i.e., every 2 to 5 years) in an effort to measure changes in exposures, programme coverage, disease prevalence, etc. The other is a standard method that is best used if measuring prevalence of TB but it can also be used if the objective of the survey is to measure exposure or programme coverage. The objective of the survey (i.e. to measure TB prevalence or to measure an important indicator) will affect the size of your sample.

#### Formula for sample size calculation for measuring trends over time

The sample size calculation needed to conduct surveys that are planned to be repeated over time is based on the number of participants needed in each round (or year) to detect a change in the proportion of an indicator from one round to the next. Even though there may be several indicators of interest, it is possible to select one or two upon which to calculate the sample size. For instance, in a survey of migrants, the indicator could be whether migrants were ever positive for latent TB infection or if migrants ever received counselling about TB at a clinic. For the former indicator, one might want to see a decrease over time and for the latter indicator one might want to see an increase over time. For the latter indicator, let's say that there is some information that the number of migrants who have received counselling about TB is 20% in 2014 and that by 2017 the percentage is estimated to increase by 30%. The general formula for the needed sample size (n) is:

$$n = \frac{D\left[Z_{1-\alpha}\sqrt{2P(1-P)} + Z_{1-\beta}\sqrt{P_1(1-P_1) + P_2(1-P_2)}\right]2}{(P_2 - P_1)^2}$$

Where:

which		
n	=	Sample size required per survey round (year)
D	=	Design effect (see below)
Ζ <sub>1-α</sub>	=	The z score for the desired confidence level, usually 1.96 for 95%
Ζ <sub>1-β</sub> Ρ <sub>1</sub>	=	The z score for the desired power, usually 0.83 for 80%
P₁ <sup>′</sup>	=	The proportion of the sample reporting indicator in year 1
P <sub>2</sub>	=	The proportion of the sample reporting indicator in year 2
Р	=	$(P_1 + P_2)/2$

Choosing the values of these numbers is based on the following considerations:

**D** design effect: The design effect is an adjustment for how much a cluster or other type of sampling method differs from a simple random sample. The design effect multiplies the sample size by the factor of D to account for the loss of diversity by using a sampling method other than a simple random sample. Surveys using respondent driven sampling, time location sampling, multilevel cluster sampling and other types of sampling method with complex designs (not simple random sampling) require a design effect of at least 2 in the calculation. *The bigger the D, the larger the sample size needed.* 

**P**<sub>1</sub> and **P**<sub>2</sub>: P<sub>1</sub> and P<sub>2</sub> are the measures of interest for which you wish to see a change between survey rounds. For example, to show an increase in the percentage of migrants who have received counselling about TB from 20% in 2014 (P<sub>1</sub>) to 30% or greater in 2017 (P<sub>2</sub>). P<sub>1</sub> is usually based on previous surveys in the same or similar population, or an educated guess at what the level will be. P<sub>2</sub> is ideally set at the goal you would like to achieve (for example, a 10% or greater increase in condom use). In practise, it is usually set at the smallest change you think is meaningful; for example, a 10% increase in TB counseling would be considered a meaningful improvement, whereas a 1% increase would not be considered meaningful. The smaller the change you wish to detect, the larger the sample size needed. Also, the closer P<sub>1</sub> and P<sub>2</sub> are to 50%, the larger the sample size needed. If nothing is known about the population 50% is used in the calculation of the sample size.

 $Z_{1-\alpha}$ : The  $Z_{1-\alpha}$  score is a statistic that corresponds to the level of significance desired. Usually, a significance level of 0.05 (or equivalently, a 95% confidence level) is selected and corresponds to a value of 1.96. This value is used when the change in the indicator might be either up (an increase) or down (a decrease) from year to year (a "two-tailed" statistic). *The smaller the significance level (i.e., the higher the confidence level), the larger the sample size needed.* 

 $Z_{1-\beta}$ : The  $Z_{1-\beta}$  score is a statistic that corresponds to the power desired. Usually, 80% power is selected and corresponds to a value of 0.83. This value is used when the change in the indicator might be either up (an increase) or down (a decrease) from year to year (a "two-tailed" statistic). *The higher the power, the larger the sample size needed.* 

Table 1 provides pre-calculated sample size estimates for a range of possible scenarios in measuring changes in an indicator over time.

Table 1: Sample size needed per survey wave to detect a change in the proportion of an
indicator between survey waves, using a 95% confidence level, 80% power, and a design
effect of 2.0.

Indicator level in wave 1 (P1)	Indicator level in wave 2 (P2)	Sample size needed each wave with a design effect of 2.0
.10	.20	395
.10	.25	197
.20	.30	581
.20	.35	274
.30	.40	706
.30	.45	322
.40	.50	768
.40	.55	343
.50	.60	768
.50	.65	336
.60	.70	706
.60	.75	301
.70	.80	581
.70	.85	239
.80	.90	395
.80	.95	149

#### Formula for sample size calculation for measuring TB prevalence

п

The sample size needed to conduct a survey can be based on the number of participants needed to accurately measure TB prevalence in a population. This sample size calculation can also be used in place of the method described above using a risk indicator. The general formula for the needed sample size (n) to measure TB prevalence is:

$$= D * \frac{Z_{1-\alpha}^{2} P(1-P)}{SE^{2}}$$
  
n = Sample size required
  
D = Design effect
  
 $Z_{1-\alpha}^{2} = The z \text{ score for power, .95 is often used, but may need to be narrower if the prevalence of TB is below 1%.}$ 
  
P = Expected proportion
  
SE = precision or standard error (usually set at .01)

#### Example of sample size calculation for complex sampling designs

For instance, to calculate the sample size for a survey to estimate the prevalence of TB among PWUD, it is necessary to have an estimate of TB prevalence in this group. For an estimated TB prevalence of 0.1%, a design effect at 2 (D=2), confidence at 99% and precision/standard error at .01, the calculation would be as follows:

	P - Expected Frequency (%)	0.10%
ions	Z <sub>1-a</sub> 2 - Target Confidence Interval 1/2 Width (%)	0.10%
mpt	D - Design Effect	2
Assumptions	Non-response Rate (%)	0.00%
	SE - Confidence Level	99%
	Lower Confidence Interval	0.00%
put	Upper Confidence Interval	0.20%
Output	Sample Size (Unadjusted)	6629
	n Sample Size (Adjusted for Design Effect and/or Non-response)	13257

In this situation, conducting a survey on a population with such low prevalence is likely not feasible. If you know the size of the population, you can use it to calculate a finite population correction factor using this formula:

**FPC =** n = nN / n + (N - 1)

N = population size, n = sample size.

For instance: (13, 257) (10,000) / 13,257 + (10,000-1) = 5700

If using a finite population size correction factor, the sample size would reduce to 5700, given that the population size is lower than the calculated sample size.

Another consideration is to sample populations that have higher TB prevalence. It may not be valuable to know that a population with very low prevalence still has low prevalence after conducting an expensive survey of them. Below is an example of the population with a prevalence of 1%. This formula assumes an estimated TB prevalence of 0.1%, a design effect at 2 (D=2), confidence at 98% and precision/standard error at 1.0,<sup>160</sup> the calculation would be as follows:

	P - Expected Frequency (%)	1.00%
ions	Z <sub>1-a</sub> 2 - Target Confidence Interval 1/2 Width (%)	1.00%
Assumptions	D - Design Effect	2
nss	Non-response Rate (%)	0.00%
▲	SE - Confidence Level	98%
-	Lower Confidence Interval	0.00%
put	Upper Confidence Interval	2.00%
Output	Sample Size (Unadjusted)	536
	n Sample Size (Adjusted for Design Effect and/or Non-response)	1072

<sup>&</sup>lt;sup>160</sup> As the estimate of TB increases, the confidence levels can become more relaxed. In the example using 0.1% TB prevalence, the confidence was 99% (so that the lower bound did not go below 0). For the example using 1% TB prevalence, the confidence is 98%.

### A7 – Local Key Populations Service Planning Process – An Example

The stages and the detailed table below<sup>161</sup> are an example that needs to be adjusted to the local situations. This example is a 12-month preparation process to plan and pilot community-based case management in which community-based organizations (CBOs) of key populations (or NGOs serving key populations) collaborate with local TB health and other related government services to increase TB case finding and support treatment adherence. It assumes the CBO/NGOs involved have none or very little case management experience and the local TB health authority has no experience in integrating CBOs/NGOs into its TB services. For localities with CBOs experienced in case management and health authorities experienced in integrating CBO/NGOs into their services, the 12-month period could be shortened according to their level of experience, but a minimum of six months is recommended.

There are three steps in this preparation phase to ensure CBO/NGOs are truly empowered and ready to maximize the case finding and treatment adherence benefits of collaboration with public TB services. Both CBO/NGOs and public health officials must be patient and recognize this initial investment is critical to accelerating case finding and improving treatment adherence.

Step 1 – Project Planning (6 months)

<sup>&</sup>lt;sup>161</sup> Adapted from:

Malaysian AIDS Council (2015) Global Fund HIV grant Case Management Pilot among MSM in 2014-2015 (unpublished programme notes). USCDC (2014) "Planning and Implementing HIV Testing and Linkage Programs in Non-clinical Settings: A Guide for Program Managers." (https://effectiveinterventions.cdc.gov/docs/default-source/public-health-strategies-docs/HIVTestingImplementationGuide\_Final.pdf) USCDC (2009) "Program Collaboration and Service Integration: Enhancing the Prevention and Control of HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis in the United States." (https://www.cdc.gov/nchhstp/programintegration/docs/207181c\_nchhstp\_pcsi-whitepaper-508c.pdf)

Month	Activities	Stake- holders	City/district TB Coordinator's (or a dedicated TB key population specialist) To-Do List
1-3	Political alignment	Province TB coordinator/ province TB dispensary	<ul> <li>Secure official endorsements of the local government of: (a) increased TB response among key populations, (b) collaboration between public TB services and relevant local government departments and (c) the involvement of CBO in TB service delivery</li> <li>Meet with Province TB coordinator, provincial HIV manager, provincial harm reduction manager, provincial police head, head of prison service, or other relevant stakeholders depending on the key population specifics, to ensure understanding of the case management approach of the project - linking clients to and supporting clients to stay with Primary Health Care (PHC) facility services (referring and following up on clients from outreach, testing to treatment)</li> <li>Get Province TB coordinator's endorsement which facilities the CBO should work with</li> </ul>
		СВО	<ul> <li>Meet with CBO leaders (typically board chair and project proposal lead) to ensure understanding of the case management approach of the project - linking clients to and supporting clients to stay with PHC TB services (beyond simply referring clients to government health services without follow up)</li> <li>Communicate with CBO leaders about the PHC facilities that have been endorsed by the Province TB coordinator</li> <li>Assess if the CBO is ready to take on new challenges or simply submitting the proposal to get money (if latter, might need to reconsider if the CBO is suitable for the project and re-do the call for proposals process)</li> </ul>
	CBO staffing – project manager	CBO	<ul> <li>Support the CBO to recruit the project manager first (job description and ads, selection panel, process and criteria) and let the project manager recruit his/her own project staff later (project manager will be held accountable by the CBO director, which in turn will be held accountable for the project by the city/district department of health which funds the CBO)</li> <li>Essential qualities of CBO project manager include strong reputation among the community (not necessarily being from the community but usually is), strategic thinking (solutions-focus), people skills conducive to working with stakeholders (government, key populations, doctors and nurses), project staff (peer case workers and finance officer) and the community alike</li> <li>Ensure the CBO understands the project manager needs to dedicate full time to this project (case management from outreach, prevention, testing to treatment is very intensive and differs from just referral)</li> <li>Support the CBO to document the process and outcome of the project manager recruitment to demonstrate transparency to the community</li> </ul>
	Operational alignment	PHC facilities CBO	<ul> <li>Introduce CBO project manager to the PHC facility (doctors, nurses) and to whoever does contact tracing (if such position exists)</li> <li>Support CBO project manager (accompany the programme manager) to meet with individual PHC facility staff to listen to their needs and feedback on the case management approach, timeline for next steps (collaboration SOP development, clients referral, registration, contact tracing)</li> </ul>
			telling what the project is), show willingness to learn from doctors/nurses, then describe case management approach (highlighting and exploring with PHC facility staff how the case management approach could help address issues/challenges PHC facilities have), listen to PHC facility feedback on the case management approach, timeline for next step - collaboration standard operating procedures (SOP) draft, clients referral, registration, and contact tracing
	CBO staffing – peer case workers	СВО	<ul> <li>Support CBO project manager to recruit project peer case workers (job description and ads, selection process and criteria)</li> <li>Essential qualities of CBO project peer case workers - being from the community (this is a must particularly if the project targets marginalized populations), client-focus (genuine concern about the well being of the clients instead of just doing the job), willing to learn from doctors/nurses (respect and follow protocols in clinical settings), ability to understand and follow strict client privacy and confidentiality (zero tolerance policy – dismissal upon first instance of breach of client privacy and confidentiality even to fellow case workers), comfortable with using computer (formal tertiary education or case work qualifications would be nice to have but not critical)</li> </ul>

	Community	СВО	Support CBO project team (project manager and peer case workers) to hold face-to-
	consultation		face community consultation on project approach and identify community needs and appropriate outreach strategies
			<ul> <li>Support CBO project team to ensure a wide spectrum of individuals (typically a mix of ethnicity, age and gender) from the target community are invited to the consultation</li> </ul>
			<ul> <li>Do not take over the community consultation from the CBO project team, defer to the CBO project team during the consultation and provide information when asked (particularly on the nature of the project from the perspective of the National TB Program)</li> </ul>
			<ul> <li>Support CBO project team to summarize key community recommendations after the consultation and start thinking about which recommendations should be integrated and how to integrate them into the collaboration SOP</li> </ul>
4-6	Collaboration standard operating	СВО	<ul> <li>Support CBO project team to design collaboration SOP (1<sup>st</sup> draft, 1-2 page flow charts showing roles of PHC facility and CBO from outreach, testing to treatment) that reflects community consultation's recommendations and address PHC facility issues/challenges</li> </ul>
	procedures (SOP) design		<ul> <li>Support CBO project team to share the 1<sup>st</sup> draft of the collaboration standard operating procedure (SOP) with the community via emails or meetings</li> </ul>
			<ul> <li>Support CBO project team to revise and come up with the 2<sup>nd</sup> draft of the collaboration SOP per community feedback</li> </ul>
			<ul> <li>Support CBO project team to collect feedback (email first and followed up over the phone) by PHC facility on the 2<sup>nd</sup> draft of the collaboration SOP</li> </ul>
			• Support CBO project team to further revise and come up with the 3rd draft of the
			collaboration SOP per PHC facility feedback (to be presented at the Collaboration SOP workshop, see below in month 6)
	Work planning	СВО	<ul> <li>Review with CBO project team project targets (performance framework), principles (case management, linking clients to PHC services, mitigating risks of losing clients and</li> </ul>
			CBO's own community reputation during contact tracing, advocacy through win-win solution-seeking collaboration) and the 3 <sup>rd</sup> draft of the collaboration SOP
			<ul> <li>Support CBO project team to develop project and staff work plans (outreach, screening at CBO, testing at PHC facility, contact tracing, treatment, recording and reporting)</li> </ul>
			<ul> <li>Support CBO project team to design the presentation of the 3<sup>rd</sup> draft of the collaboration SOP and CBO's TB work at the Collaboration SOP Workshop (see below in month 6)</li> </ul>
	Collaboration SOP	Province TB coordinator,	<ul> <li>Facilitate a 3-day workshop (1-2 PHC facilities assumed, might need to stretch to 4 days if 3-4 PHC facilities or more than 1 CBO are involved):</li> </ul>
	workshop	PHC	<ul> <li><u>Day 1 morning</u> – City/district TB coordinator's introduction of pilot</li> </ul>
	with participation of	facilities	(epidemiological data, project history and principles, project's potential contribution to country's response to TB, how the CBO and PHC facilities were chosen) and Q&A
	stakeholders,		<ul> <li>Day 1 afternoon – PHC facilities present their TB (TB/HIV, MMT) work and</li> </ul>
	relevant to the key population		<ul> <li>Q&amp;A</li> <li><u>Day 2 morning</u> – CBO presents TB work approach and collaboration SOP (3<sup>rd</sup> draft), Q&amp;A and plenary discussion to further revise the collaboration SOP</li> </ul>
	(local police, harm reduction, prison officials, mines managers, labor department,		<ul> <li><u>Day 2 afternoon</u> – Participants randomly split into minimum 3 groups (testing/diagnosis, contact tracing, treatment) with each group having 5-6 participants (roles could include client, doctor, nurse, CBO peer case worker, client's family/friend, and participants should play the role that they are not in real life, e.g., doctor playing the role of client, CBO peer case worker playing nurse, nurse playing client, etc.) to design a 15-minute play per revised collaboration SOP to illustrate participants' own experience and how these experiences would be addressed by the revised SOP</li> </ul>
	immigration department, other NGOs		<ul> <li><u>Day 3 morning</u> – 15-min play performances (testing/diagnosis, contact tracing, treatment), Q&amp;A, issues surfaced requiring the collaboration SOP to be further revised</li> </ul>
	key population, etc.)		<ul> <li><u>Day 3 afternoon</u> – Plenary discussion to agree on final collaboration SOP and issues to be followed up, including when will the dry run take place (CBO referring 1-2 clients to each PHC facility), what day of the week would the PHC facility designate as the day for CBO to refer clients, recording and reporting provisions, and how many cases on average would be expected to be referred to PHC facility in a week</li> </ul>
		СВО	• Ensure CBO project team revises the collaboration SOP per workshop output (changes agreed at the end of the workshop) and emails final version of collaboration SOP (4 <sup>th</sup> draft) to all PHC facilities, noting the collaboration SOP is subject to further revision per feedback from PHC facilities during dry run and subsequent 3 months of roll out
			<ul> <li>Ensure CBO project team follows up with individual PHC facilities to get their endorsements of the final collaboration SOP (4<sup>th</sup> draft) to be trialed during the dry run (see next table, Stage 2 – Dry Run)</li> </ul>

СВО	СВО	Facilitate and get experts to train CBO project team (project manager, case workers,
capacity		finance officer) in a 10-day practical workshop (or two 5-day workshops or another
building		suitable combination, such as a series of half a day workshops):
		<ul> <li>TB basics (transmission, pathogenesis, prevention)</li> </ul>
		• TB infection control
		<ul> <li>Latent TB Infection vs. TB disease</li> </ul>
		• MDR and XDR-TB
		<ul> <li>Side effects of anti-TB treatment (preparing clients psychologically there will be side effects and practical tips how to minimize the negative impact of side effects, recognizing side effects and when there is a need to refer to a specialist, being aware of interactions between TB treatment and other treatments/drugs that the clients may be taking)</li> </ul>
		<ul> <li>Community-based TB screening, diagnosis and treatment (process, setting, protocol), particularly new technologies that enable on-the-spot service</li> </ul>
		<ul> <li>TB/HIV co-infection, HIV testing and treatment</li> </ul>
		<ul> <li>Issues specific to the key population (economic, psychosocial, advise clients how to handle stigma and discrimination, seek redress, work with local health services to remove stigma and discrimination at TB health and social service</li> </ul>
		<ul> <li>points)</li> <li>Intensified case finding among the key population (strategies)</li> </ul>
		<ul> <li>Intensified case finding among the key population (strategies)</li> <li>DOTS (if empowered by local health authorities to be the observer)</li> </ul>
		<ul> <li>Case management - principles (do not use the word "case" in front of clients and use clients instead, no clients would fall through the crack, best possible health outcome, information provision to empower clients to decide, do not</li> </ul>
		tell clients what they should do, client privacy and confidentiality) and process (assessment of client social and health situation and need for support, informing and educating about TB, DOT, promoting treatment literacy and adherence)
		<ul> <li>Good communication (empathy and NOT sympathy, listening rather than telling socially marginalized what to do right away).</li> </ul>
		<ul> <li>Counseling (providing options for clients to choose and explain pros and cons of options rather than instructing which specific option the client should do) to recruit key populations for testing and if diagnosed with TB (or LTBI) staying on treatment</li> </ul>
		• Nutrition health education
		<ul> <li>Outreach strategies and community mobilization such as self-help groups</li> <li>(action leafs) test of the self-self set of the self set of the set</li></ul>
		(particularly useful for clients who are already stable in adhering to TB treatment and require less frequent follow-up by the peer case worker, for those who successfully finished treatment can become group leaders, the group can also become community advocate to remove TB stigma and discrimination (e.g., giving testimonies at schools, community gatherings, professional bodies meetings such as law enforcement officers, doctors,
		nurses and social workers) or pursue other priorities as set by the group itself,
		e.g. poverty alleviation/income generation.
		<ul> <li>Dealing with emotions and burnout prevention.</li> </ul>
		• Relevant information technology skills, including recording and reporting
		Train CBO project manager covering:
		<ul> <li>Case management system</li> <li>Design case file</li> </ul>
		<ul> <li>Design case me</li> <li>Process of individual case review with peer case worker (ensure not</li> </ul>
		even one client falls through the crack)
		<ul> <li>Recording and reporting</li> </ul>
		<ul> <li>Monitoring and evaluation system</li> </ul>
		<ul> <li>Not just to fulfill reporting requirements</li> </ul>
		<ul> <li>But more importantly on how to use service cascade to improve services for client's well being</li> </ul>
		<ul> <li>Staff management</li> <li>Weakly project team macting (identify shallanges and calutions, plan</li> </ul>
		<ul> <li>Weekly project team meeting (identify challenges and solutions, plan next week's work, empower peer case workers to feel good and proud about their work)</li> </ul>
		<ul> <li>Managing staff performance (3 month probation, quarterly reviews</li> </ul>
		to empower peer case workers, enforce zero-tolerance client confidentiality policy)
		Train CBO project finance officer:
		<ul> <li>Accounting system, records keeping and monthly financial reports</li> </ul>

## Step 2 – Project Dry Run (3 months)

Month	Activities	Stake- holders	City/district TB Coordinator's (or a dedicated TB key population specialist) To-Do List
7	Work plan finalization	СВО	<ul> <li>Support CBO project team to finalize work plans         <ul> <li>Project targets by month (clients screened, cases of TB and/or HIV found, cases on treatment, treatment adherence rate, TB treatment completion rate)</li> <li>Individual case workers' targets by month (clients screened, cases of TB and/or HIV found, cases on treatment, treatment, treatment adherence rate, TB treatment completion rate)</li> </ul> </li> </ul>
8	Pre-Dry Run Preparation	CBO, PHC facilities	<ul> <li>Ensure CBO project team visits in-person all PHC facilities involved to discuss with each PHC facilities practical details per SOP:         <ul> <li>PHC facility's contact designated by the facility management for CBO peer case workers to schedule appointments (sputum collection, test results, etc.)</li> <li>Location and availability of private room in PHC facility for peer case workers to provide on-site counseling if clients are diagnosed with TB and/or HIV</li> <li>Support and counseling to for hospitalized individuals</li> <li>People with TB groups</li> <li>Contact tracing</li> <li>Treatment monitoring and adherence</li> </ul> </li> </ul>
9	Dry Run	CBO, PHC facilities	<ul> <li>Ensure each CBO peer case worker recruits 2-3 clients, refer and accompany them to PHC facility, unless sputum collection is done on-site at the CBO</li> <li>Ensure CBO project manager observes each CBO peer case worker at least once</li> <li>Ensure CBO peer case workers get initial feedback from clients about CBO case worker's services (and PHC facility's services if the client visited the facility)</li> <li>Meet with CBO project team at the end of the month on lessons learned of the dry run</li> <li>Support CBO project team to communicate with PHC facilities involved to:         <ul> <li>Collect feedback on dry run from PHC doctors and nurses</li> <li>Discuss if and where the collaboration SOP needs further fine-tuning (set timeline when the 5<sup>th</sup> draft, if needed, of the collaboration SOP would be circulated to all PHC facilities)</li> <li>Agree on the date of formal roll out of the project</li> <li>Confirm with each PHC facility the day of the week when CBO case workers would refer clients and other follow up services</li> <li>Confirm with each PHC facility who is the point of contact within the facility for CBO case workers to schedule appointments</li> </ul> </li> </ul>

Step 3 – Project Roll Out (3 months)

Month	Activities	Stake- holders	City/district TB Coordinator's (or a dedicated TB key population specialist) To-Do List
10 - 12	CBO capacity building	СВО	<ul> <li>Meet with CBO project team once a week to discuss challenges and brainstorm solutions (outreach, working with PHC facilities, active case finding including contact tracing, peer case worker work load, clients feedback)</li> </ul>
			<ul> <li>Mentor CBO project manager on case management system (walk through a few cases), monitoring and evaluation system, document and analyse issues observed at PHC facilities (why PHC facilities acted in a certain way, articulate why and how not addressing these issues could deter clients continuing their services, come up with solutions), staff competencies (case worker end-of-probation, PHC facilities feedback on peer case workers' ability to work with doctors and nurses)</li> </ul>
			Empower CBO project manager to be in direct communications with PHC facilities directors
			<ul> <li>Ensure CBO project manager would in turn empower peer case workers to be in direct communications with doctors and nurses to build trusting working relationships</li> </ul>
			Ensure CBO project manager accompanies each case worker at least once a month to ensure peer case workers' service quality and observe first hand PHC facilities' services
	Stakeholder engagement	CBO	<ul> <li>Support CBO project manager prepare project update for each PHC facilities and city/district TB coordinators during the first 6 months (3 months dry run, 3 months roll out)         <ul> <li>Statistics</li> <li>Client feedback on PHC facilities' services</li> <li>Feedback from PHC facilities</li> <li>Suggest solutions to address issues (win-win to address both community needs and challenges facing PHC facilities to ensure the best possible health outcome for clients)</li> <li>Agree with each facility management that future project updates will take place on a quarterly basis</li> <li>Agree with city/district TB coordinators when the next update meeting with him/her will take place</li> </ul> </li> </ul>

### A8 – Motivation

At the level of the key population programme the following dimensions and elements can be adjusted in order to create a positive and motivating environment for the staff members:

Dimension	Element	Description
Employment quality	Wage	Transparent standards of pay and benefits to recognize peer case workers' contributions (competitive with local CBO/NGO market) and support project manager to manage peer case workers' performance.
	Working hours	Working hours should not only be convenient for the clients, but also to the staff members. This can be in form of flexible working hours, working from home and other suitable arrangements that do not contradict the country's labor legislation.
	Participation	Taking part in the organizational processes of developing strategies, planning, setting realistic targets, designing the interventions, designing the supervision system - besides capitalizing on their expertise, all increase the engagement and the commitment of staff.
		Feedback loops among the team members and between the staff and the management must function well. Giving effective feedback is part of the recommended communication training.
	Professional development	Simple personal development plans can be made for each staff member, based on their professional aspirations. The organization should seek possibilities to offer relevant training and development possibilities in line with the personal development plans of the staff.
	Autonomy at work	Many people appreciate being able to make relevant decisions and assume responsibilities in their work place, in line with the professional standards. In any case, the authority and responsibilities should be very clear in the job descriptions. It is advisable to review the job descriptions yearly and make changes if necessary.
Work quality	Organizational culture and trust	Teamwork within the organizations and win-win solution-seeking approach with external partners such as local health authorities and TB clinic doctors and nurses.
	Safety and health	Peer case workers should be trained on TB infection control and have access, where necessary, to the means of personal respiratory protection: particulate respirators for staff and surgical masks for the persons with TB disease.
		Further, measures must be taken in order to eliminate or minimize the possibilities of any kind of harassment and violence against the staff.
		The organization must ensure discrimination free working environment for all staff members.
	Work organization	The positions of peer case workers are best filled by people-oriented staff. These people are likely to be motivated by:
	and pace of work	<ul> <li>Teamwork, the opportunity to interact with and help others</li> </ul>
	WOIK	Public recognition and appreciation of their contribution
		• Varied activities <sup>162</sup> Such staff would often prefer to work at a steady to fast pace. Given the nature of the work, there should be a focus on accuracy, confidentiality, collegiality and strengthening relationships.
	Social work environment	A network of (social) support among colleagues can help deal with the work-related stress.
		Especially because much work will be implemented in a team, team-building activities need to be integrated in the training program.

Note: Dimensions and elements are based on WHO and European Observatory on Health Systems and Policies (2010) "How to Create an Attractive and Supportive Work Environment for Health Professionals".<sup>163</sup>

<sup>&</sup>lt;sup>162</sup> Guy Harris (blog) "Employee Motivation Tips: Their DISC Behavior Style" (<u>http://recoveringengineer.com/leadership-skills/employee-motivation-tips-their-disc-behavior-style/</u>) accessed 15 Jan 2017

<sup>&</sup>lt;sup>163</sup> WHO & European Observatory on Health Systems and Policies (2010) "How to Create an Attractive and Supportive Work Environment for Health Professionals" (http://www.euro.who.int/\_\_data/assets/pdf\_file/0018/124416/e94293.pdf)