



# South African Community Rights and Gender Assessment



Exploring the impact of gender, key population membership and the legal environment on TB vulnerability, treatment access and quality of care



## Message from Stop TB Partnership

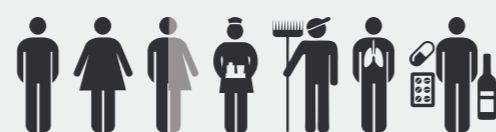
**The tuberculosis (TB) response needs a paradigm shift – becoming people and community centered, gender sensitive and human rights based.** There is a need for country specific data and strategic information on key, vulnerable and marginalised populations. There is a need to facilitate an enabling environment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

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

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

In order to advance a rights-based approach to TB prevention, care and support, the Stop TB Partnership developed tools to assess legal environments, gender and key population data, which have been rolled out in thirteen countries. The findings and implications from these assessments will help governments make more effective TB responses and policy decisions as they gain new insights into their TB epidemic and draw out policy and programme implications. This provides a strong basis for tailoring national TB responses carefully to the country's epidemic – the starting point for ending discriminatory practices and improving respect for fundamental human rights for all to access quality TB prevention, treatment, care and support services. The development of these tools could not be more timely, and the implementation of these tools must be a priority of all TB programmes.

Lucica Ditiu,  
*Executive Director*  
Stop TB Partnership



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## Abbreviations

ART	Antiretroviral Therapy
ARV	Antiretroviral
CHW	Community Health Worker
COIDA	Compensation for Occupational Injuries and Diseases Act
CRC	Committee on the Rights of the Child
CRG	Community, Rights and Gender
DoH	Department of Health
DOTS	Directly Observed Treatment, Short course
DS-TB	Drug-Sensitive TB
DR-TB	Drug-Resistant TB
GAC	Gender Affirming Care
HCW	Healthcare Worker
HIV	Human Immunodeficiency Virus
LTBI	Latent tuberculosis infection
IBBS	Integrated Biological and Behavioural Study
IPT	Isoniazid Preventive Therapy
MDR-TB	Multidrug-Resistant TB
MSF	Médecins Sans Frontières
NDMP	The National Drug Master Plan
NDoH	National Department of Health
NGO	Non-governmental Organisation
NIMART	Nurse-initiated and Managed Antiretroviral Treatment
NSP	National Strategic Plan
NTP	National TB Programme
OHSA	Occupational Health and Safety Act
OST	Opioid Substitution Therapy
PLHIV	People living with HIV
PTB	Pulmonary Tuberculosis
RR-TB	Rifampicin-resistant TB
SA-DSS	The South African TB Demonstration, Scale and Sustainability Consortium
SANAC	The South African National AIDS Council
SDG	Sustainable Development Goal
STI	Sexually-Transmitted Infection
TB	Tuberculosis
TST	Tuberculin Skin Test
WBPHCOT	Ward-based Primary Healthcare Outreach Teams
WHO	The World Health Organization
XDR-TB	Extensively Drug-Resistant TB

## Executive Summary

### Introduction

International bodies and national TB programmes have scaled up their efforts to meet the aims outlined in the Global Plan to End TB (2016 – 2020), which include reaching at least 90% of all people with TB, reaching at least 90% of TB key populations (defined as the most vulnerable, underserved, at-risk populations), and achieving at least 90% treatment success for all people diagnosed. The Stop TB Partnership (<http://www.stoptb.org>) has engaged an array of countries to implement national Community, Rights and Gender (CRG) Assessment processes, which examine the ways in which gender, affiliation to certain selected TB key populations, and the legal and policy environment impact on vulnerability to TB infection and disease, and access to care and treatment.

The South African assessment, led by TB HIV Care, had the following objectives:

- 1 To determine gender-related barriers and facilitators to accessing TB services, and develop recommendations for overcoming barriers and scaling up any facilitators.
- 2 To assess available baseline data on selected key populations likely to be missed by current services, to develop additional data on the barriers to access to care, and to develop recommendations on how to increase available data and facilitate access to care.
- 3 To determine legal and human rights-related barriers and facilitators to accessing TB services, and develop recommendations for overcoming barriers and scaling up any facilitators.



GLOBAL PLAN TO END TB

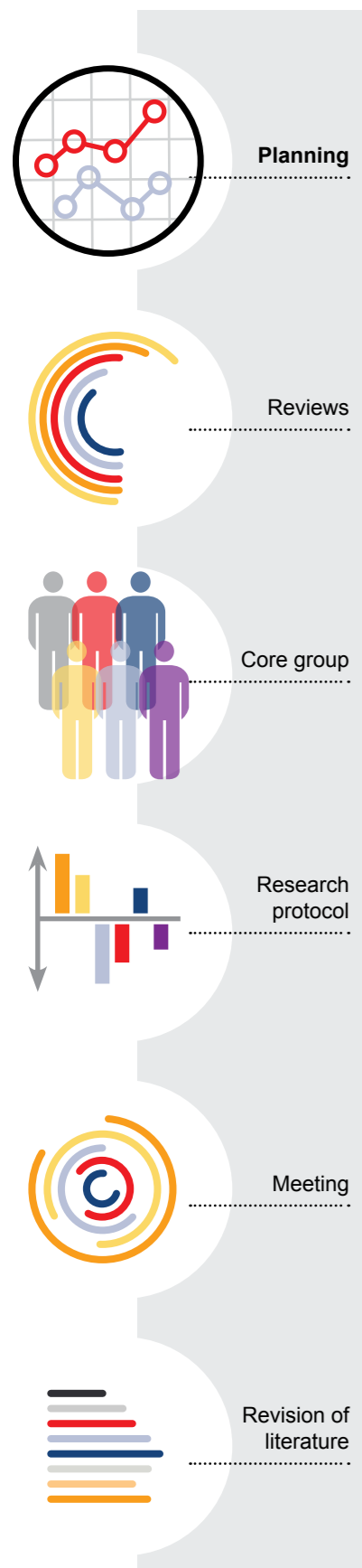


REACH AT LEAST 90% OF ALL PEOPLE WITH TB

REACH AT LEAST 90% OF TB-KEY POPULATIONS

AT LEAST 90% TREATMENT SUCCESS FOR ALL PEOPLE DIAGNOSED





## Process

The assessment process followed the following steps:

1. **Inception planning**
2. **Initial literature reviews:** to provide baseline data for core group meeting
3. **Core group meeting:** to nominate members for the workstream teams and the multi-stakeholder working group, approve the grant application and narrow down key populations to be proposed to multi-stakeholder working group
4. **Research protocol draft:** for presentation at the first multi-stakeholder meeting
5. **Meeting of multi-stakeholder working group:** to discuss and approve ethics protocols, tools, and to select key populations for further research through a prioritisation process
6. **Revision of literature reviews:** to include areas and additional highlights in the multi-stakeholder meeting and to expand on reviews for the selected key populations
7. **Revision and submission of ethics protocols:** to include refinements based on the multi-stakeholder meeting
8. **Development of scoping reviews:** to provide insight into national guidelines and processes related to assessment areas
9. **Implementation of qualitative research processes:** to gather new insights into the areas of the assessment
10. **Data analysis**
11. **Drafting of findings**
12. **Meeting of multi-stakeholder working group to validate findings**
13. **Report compilation**
14. **Report dissemination**

## Qualitative research methodology

The qualitative research asked the following key questions:

1. How do gender identity, belonging to one or more of the selected key populations, and the current legal and policy environment impact on TB vulnerability, care access and treatment outcomes?
2. What policy and programmatic changes could be made to improve the TB response to ensure service provision that is:
  - Inclusive of members of the selected TB key populations
  - Gender sensitive and responsive
  - Grounded in a human-rights based approach

The research used a combination of key informant interviews, facility observations, focus group discussions with healthcare providers and people affected by TB, and facilitated research activities with people affected by TB. The research tools were designed to broadly capture the dynamics and experiences of TB infection, diagnosis, care access and quality and treatment completion from the perspectives of people affected by TB (patients and family members), healthcare providers and stakeholders (including civil society advocates and government representatives).

The qualitative research included the following populations:

- Men, women and transgender people affected by TB. In this case, 'people affected by TB' refers to people who are ill with TB and their family members, dependents, communities and healthcare workers who may be involved in caregiving or are otherwise affected by the illness.
- People who self-identified as belonging to one of the following first three selected key populations, and have been affected by TB:
  - **Farm dwellers.** We focused on people working and living on farms as a subset of the rural population that faces particular difficulties in relation to care access.

- **Healthcare workers.** Focus groups and facilitated activities focused on community health workers (CHWs) as members of the community working as part of the healthcare system to provide frontline care and support for people with TB. We chose this focus because we found less information available in the literature about their experiences than that of other healthcare workers. Our facility-based research and discussions and key informant interviews included healthcare workers more generally, where healthcare workers is taken to mean all people working within healthcare settings, or directly for the provision of healthcare.

- **People who use substances.** In this category, we have included both individuals who use alcohol in ways that might disrupt treatment and those who use unregulated drugs. This inclusion is premised on the fact that there are many overlapping concerns between these two groups of people who use these substances. We distinguish between people who use alcohol and people who use drugs only when the literature makes this distinction, or as far as it is important for the analysis.

- **Contacts of TB index patients.** We also included an exploration into accessing contacts of TB index patients, but this was done through incorporating questions about contacts and contact tracing into the other research areas.

Research was conducted in the Eastern Cape and Western Cape. These provinces were selected in the first multi-stakeholder meetings because they have high TB burdens, had representations of the key populations included in the research, and had partner organisations that could assist with accessing the selected key populations. Key informant interviews were either conducted at a place suitable to the interviewee, telephonically, or over Skype. In the Western Cape, facility-based research was conducted at two facilities – one TB hospital, which provides inpatient treatment to people in Boland towns and surrounding farm areas, and another urban facility in Cape Town. In the Eastern Cape, research was done in one healthcare facility on the outskirts



## TB-related stigma and discrimination is pervasive.

of Port Elizabeth, which provides services to urban and rural populations. Sites for key population focus groups were selected by partner organisations based on the accessibility of the location to the people in the key populations being engaged.

All participants were required to be 18 years old and older (based on self-reports) and to provide informed consent for their data to be included in the research report. In addition, participants had to have been affected by TB in the past five years; and/or self-identify as belonging to one of the selected key population groups; and/or work with, or have an interest in one of the selected key populations and the TB response; and/or work with or have an interest in gender-related aspects of the TB response.

Data was collected by two trained social scientists between September and November 2018. Research processes were guided by data collection tools set out in the approved research protocol. Data was recorded through a combination of audio recordings, written notes and participant-drawn images. Audio recordings were transcribed and, where necessary, translated. Data was analysed thematically in NVivo.

Research was conducted with careful attention to the vulnerability of the included populations. All processes were approved by the Human Research Ethics Committee at the University of Cape Town, as well as by the Department of Health in the Western Cape and Eastern Cape.

Key limitations to the work include the focus on the perspective of TB-affected individuals, rather than that of healthcare providers and policy makers; limited geographic coverage, which limits generalisability; the inclusion of only a few key populations; limited inclusion of gender minorities other than transgender women; and the selection bias resulting from accessing participants through service providing non-profit organisations. We were notably not able to access the perspectives of people actively avoiding any healthcare.

## Findings

**This section provides a summary of the findings in the report.** It prioritises the findings of the qualitative research, but also draws on insights in the relevant available literature on TB in South Africa. It starts with the overarching findings that apply across the board to the genders and key populations included in this assessment. This is followed by the findings per researched population.

### Overarching findings

1. **TB knowledge is limited in people affected by TB.** All people have the right to access to information and the right to health, which includes health information. The National Strategic Plan (NSP) makes clear provision for information and social behaviour change com-

munication around TB. However, it appears that messages are not reaching TB-affected people and the people with whom they have close contact. This is possibly a resource and implementation issue rather than a legal and regulatory issue.

2. **TB-related stigma and discrimination is pervasive.** Stigma impacts negatively on the psychosocial well-being of TB-affected individuals, access to care and TB status disclosure. While law and policy protect all people's right to equality and non-discrimination, this is not TB-specific. The NSP also provides for various measures to address TB-related stigma and discrimination, but this work is still in its infancy and needs further understanding, expanding and strengthening. Criminal laws that prohibit drug use and sex work have also been found to exacerbate stigma and discrimination against affected populations, increasing barriers to health care.
3. **TB counselling and support processes are concentrated at the beginning of the treatment period.** These processes are also overly focused on adherence to treatment, without providing support for potential psychosocial or structural barriers to taking treatment. TB plans and guidelines do provide for counselling at various intervals during the treatment period, including for contacts of TB index patients. They also provide for training of healthcare workers, including counselling training for CHWs. However, the TB Management Guidelines do not provide for sufficient ongoing counselling and education processes. In addition, it appears that in practice facilities do often not have sufficient capacity and resources to implement holistic counselling and support.
4. **Gender impacts on vulnerability to infection, access to TB diagnosis and treatment, quality of care and treatment completion.** Men are markedly more vulnerable to TB infection and disease and have higher mortality than women. Structural barriers to accessing TB services for men include cultural attitudes towards health-seeking behaviour and insufficiently tailored healthcare services. Women have lower morbidity and mortality rates and access care with greater

ease than men, but suffer additional strains in their roles as care providers. Transgender people face extreme vulnerabilities and extensive stigma, which inhibits treatment access and care. Yet gender differences are not adequately reflected in health and TB policy and guidelines. As a result, healthcare providers are not educated on, or able to respond to gendered needs and gender diversity in TB management processes.

5. **Human rights contraventions are occurring frequently in TB care provision in the public healthcare sector, especially for members of key populations, and there is limited access to justice for violations.** Violations include stigmatising attitudes and behaviour, inequitable care and exclusion from treatment, including to gender minorities and key populations. Law and policy provide for non-discriminatory access to healthcare, although not specifically on the grounds of TB. All persons also have the right to legal redress for rights violations. Furthermore, The NSP provides for intensified efforts to reduce healthcare-related stigma and discrimination in the context of TB, including sensitisation training for healthcare workers, strengthening monitoring and complaints mechanisms, and improved access to justice. It appears that these measures need strengthened implementation.

### Men

1. **Men's TB risks largely exist outside the home.** This includes risks in public transport and social spaces and, notably, in male-dominated work environments such as construction and agriculture.
2. **Broadly speaking, South African labour law provides all employees with the right to be protected from occupational injury and disease and the right to compensation.** In practice, however, participants in this research seemed unaware of their rights to a safe working environment, to compensation for occupational injury and disease and to access to justice for rights violations.
3. **Men affected by TB tend to experience chal-**



allenges accessing healthcare due to cultural norms that discourage healthcare access unless illness is severe. Men reported that accessing traditional healers was more acceptable than accessing the public healthcare system.

4. **Clinics are not seen or experienced to be male-friendly spaces.** This is because the majority of patients are women and services are focused on mothers and children.
5. **Healthcare workers may prefer and encourage fewer men in clinics.** This is because groups of men can feel threatening and security is limited.

### Women

1. **Women generally frame their TB risk as existing within the home, often from men who are infected and not on treatment.**
2. **Women access healthcare with speed and ease, but they suffer additional difficulties when ill due to their role as care providers.** This is because while self-care, including ensuring health, is seen as an expression and requirement of good womanhood and motherhood, conversely, these social requirements place additional pressures on women to be care providers, even when they are in need of care themselves.

### Transgender women

1. **There is extremely limited data available on TB in transgender persons in South Africa, including a dearth of incidence and prevalence data.**
2. **Transgender women face numerous and layered vulnerabilities to TB infection and disease.** Social marginalisation results in homelessness, joblessness, sex work and drug use. These, in turn, increase risk of HIV infection and rates of incarceration, which further exacerbate vulnerability to TB infection and disease.
3. **As an extremely marginalised population, transgender women suffer daily stigma and discrimination in the general community and in the healthcare system.** This discrimina-

tion serves as a critical barrier to access to care and treatment and continues, despite the fact that South African law and policy protects all persons, including transgender persons, from discrimination.

4. **HCWs are not sensitised to the difficulties faced by transgender women or equipped to understand and respond to the needs of transgender women accessing TB services.** While the NSP provides for the needs of transgender people, including for stigma and discrimination reduction, this is largely in relation to HIV, for which transgender persons are a key population.

### Farm dwellers

1. **Farm dwellers face numerous reported vulnerabilities to TB infection and disease.** These include crowded living conditions; a substantial migrant population; lung conditions consequent of exposure to silica dust and pesticides; exposure to other people who are not on treatment; and poor knowledge about TB infection and spread. Farm workers have the right to safe working conditions under general labour laws. However, unlike in the case of mines, there are no TB-specific, agriculture-related policies or guidelines relating to safe working conditions, access to care and compensation for occupationally acquired TB.
2. **Access to TB treatment and care depends on the attitude of the farm owner or manager.** Despite protective labour laws, power imbalances between farm workers and employers limit the ability of farm workers to access care and legal redress. They fear losing their jobs based on a positive TB diagnosis. Where farm owners are sensitive to the needs of TB care and engaged in supporting workers, it facilitates care, but may compromise confidentiality.
3. **Farm dwellers face substantial barriers to appropriate care access, despite the fact that all persons have the right to accessible and appropriate health care services.** Barriers include long distances from local clinics; dif-

ficulty getting time off work, especially for contract workers; difficulty finding transport to local healthcare facilities; local clinic resourcing not always matching the size of the population served; and small local clinics that lack the capacity to deal with complex cases.

4. **Healthcare providers are not always sufficiently accommodating of the barriers to care access faced by farm dwellers and workers.** Practices that serve to exclude farm dwellers and workers from care include refusal of care to those who arrive at the healthcare facility late in the day (due to difficulties with transport or getting time off work), and insisting on daily facility attendance in the early treatment period, despite the impossibility of regular facility access for some people. Conversely, some health workers are adapting treatment protocols to be more flexible based on patient health and needs.

### Healthcare workers

1. **HCWs are at high risk of contracting TB in their work contexts.** High levels of risk are largely because healthcare workers are inadequately educated about their own vulnerability; in-facility infection control is inconsistently implemented and poorly measured; and accountability for safe working conditions remains a challenge. This despite their right to be protected from occupationally acquired pulmonary TB infection being recognised in South African labour law, as well as in policy, including the Occupational Health and Safety Act (OHSA), NSP, the DR-TB Treatment Guidelines and infection control policies.
2. **CHWs face significant difficulties protecting themselves when working in the homes of patients.** This is due to poor community knowledge of TB and infection control; difficulties in using an N-95 respirator with patients in a home-based context prior to TB diagnosis; and lack of information about whether TB-affected people being recalled have drug-sensitive (DS) or drug-resistant (DR) TB. Furthermore, N-95 respirators may not always be regularly supplied to HCWs or correctly fitted, especially when they are provided by non-governmental organisations (NGOs). Despite these vulnerabilities, CHWs who are 'volunteers' are not protected by current labour regulations applying to employees, although the recent Policy Framework and Strategy for ward-based primary healthcare outreach teams (WBPHCOT) seeks to improve provision for their occupational health and safety.
3. **Systems of support and compensation for occupationally acquired TB for healthcare workers are currently not uniform, exclude extra-pulmonary TB, and only apply to healthcare workers who are employees.** Healthcare workers who contract occupationally acquired TB are not always supported to apply for



**CHWs face significant difficulties protecting themselves when working in the homes of patients.**







**A harm reduction approach to drug use and dependence is a key approach in the forthcoming National Drug Master Plan.**

compensation, as responses are dependent on facility management, despite the fact that in South African law pulmonary tuberculosis (PTB) is recognised as an occupational disease in the healthcare setting.

4. **HCWs affected by TB experience TB-related stigma and discrimination in the community and in their places of work.** This is despite the fact that all persons, including employees, have the right to equality and non-discrimination and fair labour practices. This undermines accessing TB testing and care at work. The availability of treatment at work facilitates access, but undermines confidentiality, which is particularly problematic where stigma levels are high.

#### People who use substances

1. **Various laws and policies serve to exclude or discourage people who use substances, particularly the most marginalised, from TB care access and treatment.** These include laws criminalising drug use, procedures for admission and referral for medically complex TB cases (e.g. requirements for an ID document and fixed address) and policies that serve to limit the availability of opioid substitution therapy for people who use heroin and require inpatient TB care.
2. **Stigma and discrimination to people who use substances within the healthcare setting undermines treatment quality and access.** People who use substances are routinely subject to shaming, scolding, confidentiality breaches and conditional access to care.
3. **People who use drugs avoid the healthcare system because of past experiences of discrimination and withdrawal while waiting for assistance.**
4. **HCWs are not equipped to effectively manage people who use substances.** HCWs are generally ill-informed as to if and when there may be interactions between alcohol, unregulated drugs and TB medication. They consequently often provide incorrect information to people who use substances, for example, propagating the myth that complete abstinence is a requirement for TB cure. This contributes towards poor treatment outcomes.
5. **A harm reduction approach to drug use and dependence is a key approach in the forthcoming National Drug Master Plan (NDMP) but is presently not integrated into the TB management system.**

#### Contacts of TB index patients

1. **Effective tracing and linkage to care for contacts of TB index patients, especially children, is inadequate due to healthcare facilities lacking the training, capacity and resources.** Although linkage to care for contacts of TB index patients is provided for in TB policy and treatment guidelines, there is some confusion between various health guidance documents as to who should be regarded as a contact patient and whether or not these are necessarily household members.
2. **Tracing of the contact of TB index patients is undermined by pervasive TB-related stigma and discrimination, and poor levels of knowledge about TB.** All persons have the right to protection from unfair discrimination in South African law. However, poor knowledge feeds into pervasive stigma and discrimination and shame in TB-affected people, which undermines TB status disclosure and the willingness of contact patients to be linked to care. Poor understanding and knowledge about the availability of preventive therapy - currently isoniazid preventive therapy (IPT) - further undermines effective prevention.
3. **Clear guidelines and standardised processes for systematic reporting and monitoring of contacts identified, screened and linked to care are not in place.** The exclusion of TB index patient contact tracing data from key performance indicators undermines the emphasis on this aspect of work in TB care facilities. There is a need for standardised reporting and monitoring and evaluation of contact management and preventive therapy delivery.

#### Recommendations

1. **Implement a national TB education campaign as provided for by the NSP.** A national education campaign that focuses on ensuring that the general population has a better understanding of what TB is, how it is spread, as well as how it can be prevented should be implemented. This

should include comprehensive education about prevention strategies, information about children's vulnerability to TB infection, information about the gendered dynamics of TB infection, and information on health rights.

2. **Develop a comprehensive and coordinated national stigma and discrimination reduction plan.** This should include further efforts to understand TB-related stigma at a community and facility level and to coordinate and fully implement, monitor and evaluate the scale up and expansion of existing strategy and policy commitments and programmatic responses.
3. **Improve counselling and support processes for TB-affected people in policy and in practice.** Building on the provisions in the NSP, review TB Treatment Guidelines to provide for continuous counselling and support processes through the illness period for people affected by TB that, among other things, fully integrate rights-based issues.
4. **Build recognition in policy makers and healthcare providers that gender impacts on vulnerability to TB infection and on care access, to review and improve gender-sensitive and transformative policies, plans and programmes.**
  - 4.1 Support the use of the gender-disaggregated data gathered by healthcare facilities to review and strengthen gender-transformative TB policies, planning and programming.
  - 4.2 Ensure implementation of gender-transformative policies and programmes, through provision of training and resources.
5. **Ensure that all measures to prevent and address TB-related stigma and discrimination, especially for vulnerable and key populations, as outlined in the NSP, are implemented.**
  - 5.1 Ensure that healthcare workers receive sound, continuous training on a human rights-based approach to service provision.



**Ensure that there is adequate psychosocial support for women affected by TB who are care providers.**



5.2 Strengthen awareness of and access to complaints and accountability mechanisms to facilitate reporting of violations and to ensure consequences for healthcare providers who contravene human rights in the process of care provision.

### Men

1. **Recognise men's particular risks of TB infection in TB policy and programming.**
  - 1.1 Consider law and policy review to encourage all risky work environments to develop TB-specific prevention and care protocols and processes. These can build on the example provided by the mining industry.
2. **Review policy and guidelines and develop programmes to recognise and work with notions of masculinity and cultural norms that discourage treatment seeking in TB programming and planning.**
  - 2.1 Seek to actively include traditional healers and cultural leaders in the TB response.
3. **Implement a drive to create male-friendly TB diagnosis and treatment facilities, times and locations.** Experience and insights gathered from services for men who have sex with men could be used to create safe spaces for men in general.
4. **Ensure that healthcare providers are sensitised to the difficulties men face accessing care, and trained on their responsibility to provide equitable care to all people.**
  - 4.1 Ensure that staffing and security provisions in clinics are adequate, and that facility staff are trained in managing gender dynamics and de-escalating potential conflicts, while still upholding the right to treatment access.

### Women

1. **Review policy and guidelines and develop programmes that seek to fulfil the right of access to information, including health information, to minimise women's risks at home and as care providers to men.**
  - 1.1 Provide additional counselling and support to women to enable them to disclose to healthcare workers when they have a partner or cohabitating person who is potentially putting them at risk of TB infection.
  - 1.2 Provide TB education and support processes that target couples, families and cohabitating units. This should include training on communication about managing TB in intimate relationships.

2. **Ensure that there is adequate psychosocial support for women affected by TB who are care providers.**

### Transgender women

1. **Ensure that transgender women, and transgender people more broadly, are included in the Integrated Bio-Behavioural Surveillance (IBBS) and population size estimation activities for key and vulnerable populations, as provided for by the NSP.**
2. **Ensure that there is adequate policy and programmatic focus on TB prevention for transgender people in addition to the law reform recommendations for decriminalisation of sex work made by the NSP.**
3. **Integrate the needs of transgender people into a comprehensive plan to tackle TB-related stigma and discrimination.**
  - 3.1 Implement further efforts to understand transgender-related stigma at a community and facility level.
  - 3.2 Coordinate and fully implement the scale up and expansion of existing policy commitments and programmatic responses, including "know your rights" campaigns, peer navigation systems and various measures to strengthen access to justice.
4. **Scale up human rights and gender sensitivity training and education processes for all healthcare workers.**
  - 4.1 Ensure the involvement of gender minorities in design and implementation of gender-transformative programming as provided for by the NSP.

### Farm dwellers

1. **Consider law and policy review to encourage TB-specific prevention and care protocols and processes for farm workers and dwellers.** This should include reasonable accommodation within the working environment to access healthcare.

2. **Engage with farm owners and managers to educate them about TB, to improve cooperation with healthcare services and ethical, rights-based care access and provision.** Engage further with farm workers to educate them about their rights and access to legal redress.
3. **Improve the capacity of rural service provision:**
  - 3.1 Extend the reach of mobile clinic facilities to rural areas where possible.
  - 3.2 Ensure that all facilities are matched to the size of the population they serve.
4. **Improve healthcare workers' ability to provide effective, human rights focused care:**
  - 4.1 Sensitise healthcare workers to the difficulties faced by farm dwellers in terms of accessing care to ensure that those who arrive at the clinics late in the day are still provided with assistance.
  - 4.2 Allow for sufficient flexibility in treatment protocols so that they can be adapted to the capacities and needs of individual patients.
  - 4.3 Empower healthcare workers to make patient-centred decisions about how and when treatment should be provided.

### Healthcare workers

1. **Improve infection control implementation, accountability and support for TB infected HCWs in all healthcare facilities.**
  - 1.1 Implement a process of tracking occupational TB and providing infection control support to facilities with high rates of HCW infection.
  - 1.2 Implement an assessment of latent TB in HCWs and develop a policy on the provision of preventive therapy for HCWs with latent TB.
2. **Improve CHWs' capacity to protect themselves.**



- 2.1 Provide education on HCW vulnerability to TB infection, training on what a respirator is and how it should be worn.
- 2.2 Improve training and support for CHWs to ensure they are equipped to manage home-based situations where potentially infectious people are reluctant to take preventive measures.
- 2.3 Advocate for government-funded full-time employment (directly or through civil society organisations) for CHWs, with fair pay and opportunities for career development.

### 3. Finalise the Draft Policy on Occupational Health for Healthcare workers in respect of HIV and Tuberculosis to strengthen protection for occupationally acquired TB.

- 3.1 Ensure adequate budget allocations for strengthening occupational health services at a facility level.

### 4. Ensure that healthcare workers are educated on the policies that protect them and know how to act on policy recommendations.

- 4.1 Ensure that the government amends the Compensation for Occupational Injuries and Diseases Act 130 of 1993 to include criteria on extra-pulmonary TB for HCWs.

### People who use substances

#### 1. Actively seek to minimise and remove the barriers to care that are entrenched in current policies and treatment guidelines experienced by people who use substances.

- 1.1 Support calls to decriminalise the use of drugs.
- 1.2 Amend procedures to provide for referrals and hospital admission for people who do not have a fixed address or identity document.
- 1.3 Amend policy to provide for the routine availability of opioid substitution therapy (OST) during and after inpatient TB care.

#### 2. Strengthen the implementation of human rights-based training and sensitisation for healthcare providers, as provided for by the NSP, to provide non-judgemental, non-stigmatising and inclusive services to people who use substances.

- 2.1 Include people who use substances in designing and implementing training.
- 2.2 Set up peer navigation systems and harm reduction champions in healthcare facilities.

#### 3. Seek to create a more inclusive response for people who use substances.

- 3.1 Integrate TB prevention, diagnosis and treatment into programmes that provide services for people who use substances, to reduce waiting times and overcome reluctance to access the healthcare system.
- 3.2 Implement peer navigation processes, in which trained and knowledgeable peers provide support to people who use substances accessing healthcare services.

#### 4. Ensure that healthcare workers are educated on how to respond supportively to people who use drugs.

- 4.1 Ensure health care providers are equipped to provide evidence-based messaging about TB and substance use to TB-affected people and their contacts in order to facilitate treatment completion.
- 4.2 Ensure healthcare providers are equipped to manage and support people who are intoxicated or withdrawing.

#### 5. Align TB programming with harm reduction principles as outlined in the forthcoming NDMP.

### Contacts of TB index patients

#### 1. Implement an assessment of the capacity, education and resource requirements of effective TB index patient contact tracing to ensure that any policies and processes are possible and adequately supported.

- 1.1 Develop and implement a comprehensive plan and guidelines that clearly define and guide TB index-patient contact tracing implementation, as provided for in the NSP.

#### 2. Implement a national TB education campaign as provided for by the NSP.

- Inter alia this should include information on the risks faced by contacts of TB index patients, why linkage to screening and testing is important, and how preventive therapy functions. This should include a focus on children's vulnerability and engaging with parents/caregivers.
- 2.1 Improve counselling and support processes for people diagnosed with TB, including support processes for addressing stigma and discrimination (including self-stigma), diagnosis and linkage to care for TB index patients' contacts.
- 2.2 Strengthen efforts to understand and address the impact of stigma and discrimination on TB index patient contact tracing, within the comprehensive national stigma and discrimination reduction plan.

#### 3. Include contact tracing indicators and targets in Department of Health monitoring and evaluation processes

- 3.1 Work towards integrating existing electronic data sources to minimise the administrative burden on staff and enable efficient clinical management of identified contacts.
- 3.2 Evaluate impact of 2017 Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions on contact tracing, and on the health rights of patients in general.

## Conclusion

South Africa has, or for the most part, a progressive legal and policy framework that protects the equality and health to TB that leaves no one behind. Health policies and guidelines have, to a large extent, echoed these provisions. There is, however, room for improvement in terms of strengthening protection of the rights of key populations and gender minorities. This includes decriminalisation of sex work and drug use and updating health and labour guidelines and protocols to fully reflect rights-based commitments to TB. There is also the need to strengthen implementation of strategic plans and commitments – including stigma and discrimination reduction initiatives as well as monitoring and evaluation processes and accountability frameworks. Furthermore, there is scope for an improved focus on a gender-transformative approach to TB vulnerability, care and treatment in strategic plans, policies and guidelines.





# South African Community Rights and Gender Assessment

## 1. Introduction

**Tuberculosis (TB) is the world's leading infectious disease killer.** International incidence declines of 1,5% per year are lagging well behind the declines required (7-10%) if the Sustainable Development Goal of ending TB by 2030 is to be met (Stop TB Partnership 2016). The recognition that more needs to be done – particularly in meeting the needs of the approximately 4.5 million people per annum globally who are not diagnosed or successfully treated – has resulted in a revitalised focus on how to improve the TB response.

International bodies and National TB Programmes (NTPs) have scaled up their efforts to meet the aims outlined in the Global Plan to End TB (2016 – 2020). These include: i) reaching at least 90% of all people with TB; ii) reaching at least 90% of TB key populations (defined as the most vulnerable, underserved, at-risk populations); and iii) achieving at least 90% treatment success for all people diagnosed. The Stop TB Partnership (<http://www.stoptb.org>) has engaged an array of countries to implement national Community, Rights and Gender (CRG) Assessments to support these ambitious targets.

South Africa has one of the highest TB burdens in the world, fuelled by the HIV epidemic. In 2017 there were an estimated 322 000 incident cases - 135 000 females and 187 000 males (WHO 2018). An estimated 60% of people with TB are also living with HIV (WHO 2018). TB control efforts are being challenged by the growing epidemic of drug-resistant TB (Cox et al. 2017); in 2017, there were approximately 14 000 incident cases of multidrug-resistant tuberculosis (MDR-TB) (WHO 2018). While incidence rates have declined on average 7% per year between 2010 and 2017 (WHO 2018) more needs to be done to combat the epidemic.

In April 2018, TB HIV Care, a local non-profit organisation was contracted by the Stop TB Partnership to lead a South African CRG Assessment process to support the TB response to be more inclusive of TB key populations, better grounded in human rights, and more gender-responsive. The mandate underscoring this work was to be done in collaboration with the National Department of Health (NDOH) and the National TB Programme (NTP) through consultative processes involving a broad array of government and civil society stakeholders.<sup>1</sup>

The proposed CRG assessment constituted three separate processes: a Key Populations Assessment, a Gender Assessment, and a Legal and Environment Assessment, each guided by a separate document.<sup>2</sup> The South Africa country team merged and adapted these three processes into one unified assessment, the findings of which are presented here. This includes key aspects of the suggested separate assessments, while using one

1 A further process, a baseline assessment of Programs to Reduce Human Rights Barriers to Access, Uptake and Retention in HIV and TB Services was implemented by HEARD. We have referenced this where appropriate.

2 The Gender Assessment was guided by the 'Gender Assessment Tool for National HIV Responses. Towards a gender transformative HIV response' (Stop TB Partnership and UNAIDS, n.d.). The Key Populations Assessment was guided by 'Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations' (Stop TB Partnership 2017) and the Legal Environment Assessment was the Stop TB Partnership Legal and Environment Assessment Guide.



qualitative research process to gain insights into the local context beyond that which was available in the local literature.

**The assessment objectives were to:**

1. Determine gender-related barriers and facilitators to accessing TB services, and develop recommendations for overcoming barriers and scaling up any facilitators.
2. Assess available baseline data on selected key populations likely to be missed by current services, develop additional data on the barriers to access to care, and develop recommendations on how to increase available data and facilitate access to care.
3. Determine legal and human rights-related barriers and facilitators to accessing TB services, and develop recommendations for overcoming barriers and scaling up any facilitators.

## 2. Process Outline

Using the guidelines provided by the Stop TB Partnership, a process that was designed to be inclusive was implemented. This is described in Figure 1 below.

A core group was selected to provide oversight and to nominate participants for the assessment teams and the multi-stakeholder working group. The core group was comprised of representatives from the National TB Programme, the South African National AIDS Council (SANAC), civil society working in TB, people affected by TB, TB HIV Care and the consultants performing the assessments.

The core group suggested participants for a multi-stakeholder working group to ensure it was comprised of members of key populations, people affected by TB, civil society organisations working with TB, relevant government departments, gender advocates and experts, the National TB Programme and bilateral and multi-lateral organisations. The multi-stakeholder working group was responsible for reviewing the project methodology, selecting the key populations for the qualitative research, and later, validating the findings of the assessment.

The assessment process followed the following steps:

1. **Inception planning**
2. **Initial literature reviews:** to provide baseline data for core group meeting
3. **Core Group Meeting:** to nominate members for the workstream teams and the multi-stakeholder working group, approve the grant application and narrow down key populations to be proposed to multi-stakeholder working group
4. **Research protocol draft:** for presentation at the first multi-stakeholder meeting

5. **Meeting of Multi-Stakeholder Working Group:** to discuss and approve ethics protocols, tools, and to prioritise key populations for further research
6. **Revision of literature reviews:** to include areas and additional highlights in the multi-stakeholder meeting and to expand on reviews for the selected key populations
7. **Revision and submission of ethics protocols:** to include refinements based on the multi-stakeholder meeting
8. **Development of scoping reviews:** to provide insight into national guidelines and processes related to assessment areas
9. **Implementation of qualitative research processes:** to gather new insights into the areas of the assessment
10. **Data analysis**
11. **Drafting of findings**
12. **Meeting of Multi-Stakeholder Working Group to validate findings**
13. **Report compilation**
14. **Report dissemination**

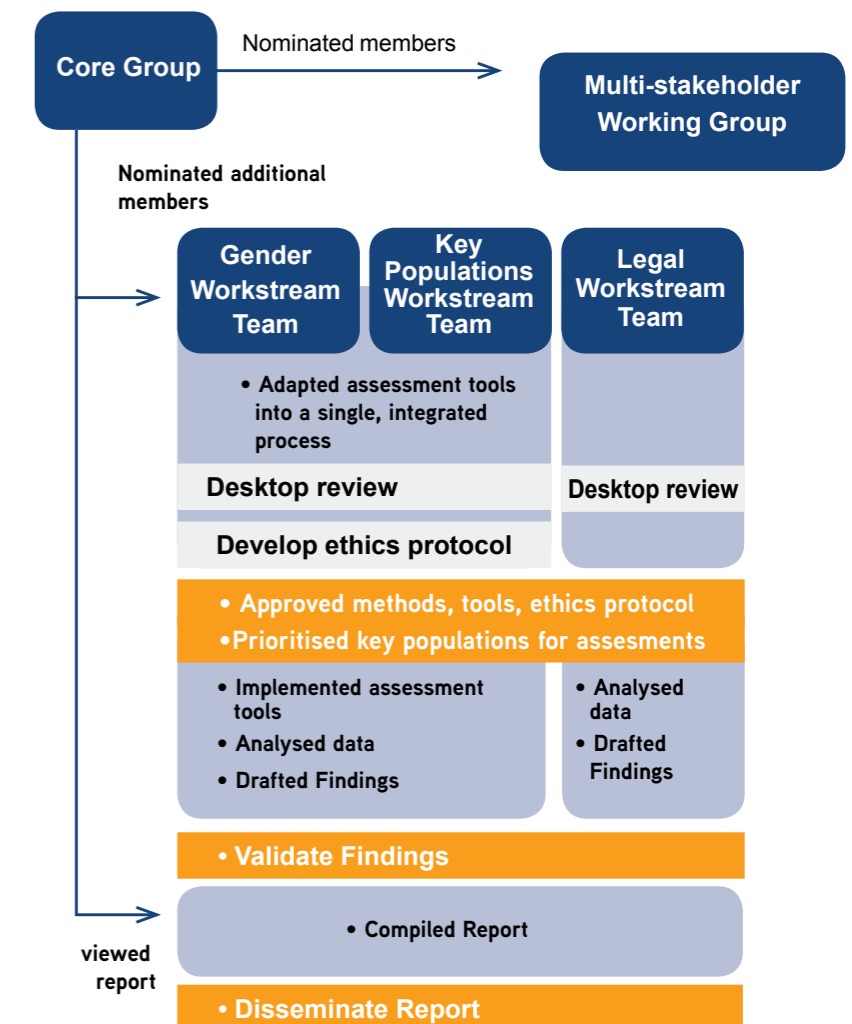


Figure 1: South African CRG Process



### 3. Qualitative Research Methodology

Rapid qualitative research processes were implemented in the Eastern Cape and Western Cape. These two provinces were selected in the first multi-stakeholder meetings because they have high TB burdens, had representations of the key populations included in the research, and had partner organisations that could assist with accessing the selected key populations.

#### 3.1 Research questions

The qualitative research asked the following key questions:

1. How do gender identity, belonging to one or more of the selected key populations, and the current legal and policy environment impact on TB vulnerability, care access and treatment outcomes?
2. What policy and programmatic changes could be made to improve the TB response to ensure service provision that is:
  - Inclusive of members of the selected TB key populations
  - Gender sensitive and responsive
  - Grounded in a human-rights based approach

#### 3.2 Research methods

The research used a combination of the following methods:

- **Observations in selected facilities or in-community with healthcare workers affiliated with the selected facilities.**
- **Key informant interviews with experts and advocates in the field.**
- **Interviews with TB-affected individuals.** These focused on “illness narratives” – the story from the moment of recognising illness.
- **Focus groups with healthcare providers and people affected by TB.** This includes focus groups with farm dwellers, people who use substances and healthcare workers. Issues related to vulnerability and care

for contacts of TB index patients have been integrated into all methods. Therefore, there were no separate research tools designed for this group in the research process.

- **Facilitated research activities with people affected by TB.** There were several methods designed, each capturing a different aspect of life. The activities included:

- ❖ **Life mapping, where people drew their lives as a journey**
- ❖ **Facility access mapping in which individuals drew their journey to and from their residence to the healthcare facility where they went for TB care.**
- ❖ **TB risk and service access assessment, which examined barriers and facilitators to care through brainstorming and ranking.**

The research tools were designed to broadly capture the dynamics and experiences of TB infection, diagnosis, care access and treatment completion from the perspectives of TB-affected individuals (patients and family members), healthcare providers and stakeholders (including civil society advocates and government representatives).

#### 3.3 Research sites

Key informant interviews were either conducted at a place suitable to the interviewee, telephonically, or over Skype. In the Western Cape, facility-based research was conducted at two facilities - one TB hospital, which provides inpatient treatment to people in the Boland towns and surrounding farm areas, and another urban facility in Cape Town. In the Eastern Cape, research was done in one healthcare facility on the outskirts of Port Elizabeth, which provides services to urban and rural populations. Sites for key population focus groups were selected by partner organisations based on the location accessibility to the key population in question.

#### 3.4 Study populations

The qualitative research included the following populations:

- Men, women and transgender people affected

#### QUALITATIVE RESEARCH METHODS & PARTICIPANTS

Method	Participants	# of method
<b>All included groups</b>		
Observation days	TB-affected individuals and healthcare providers	5
<b>Gender</b>		
Interviews	Key informants	4
Focus groups	TB-affected individuals	5
Focus groups	Healthcare providers	2
Facilitated activities	TB-affected individuals	19
<b>Key Populations</b>		
<b>Farm dwellers</b>		
Interviews	Key informants	3
	Healthcare providers	3
	TB-affected individuals	2
Focus groups	TB-affected individuals	4
Facilitated activities	TB-affected individuals	8
<b>People who use substances</b>		
Interviews	Key informants	2
	TB-affected individuals	1
Focus groups	TB-affected individuals	4
Facilitated activities	TB-affected individuals	8
<b>Healthcare workers</b>		
Interviews	Key informants	2
	TB-affected individuals	2
Focus groups	TB-affected individuals	4
<b>TB-index patient contacts</b>		
Interviews	Key informants	2

Table 1: Qualitative research methods and participants

by TB. In this case, ‘people affected by TB’ refers to people who are ill with TB and their family members, dependents, communities and healthcare workers who may be involved in caregiving or are otherwise affected by the illness.

- People who self-identified as belonging to one of the following three selected key populations, and have been affected by TB:



FARM DWELLERS

❖ **Farm dwellers.** We focused on people working and living on farms as a subset of the rural population that faces particular difficulties in relation to care access.

❖ **Healthcare workers.** This assessment focused primarily on CHWs as a subset of healthcare workers. This focus is based on the fact that CHWs are at the frontline of TB treatment and we found less information available in the literature about their experiences than facility-based healthcare workers. For the qualitative discussions, we included all the staff in research-based facilities and refer to healthcare workers (including students) as a broad category in our key informant interviews.

❖ **People who use substances.** In this category, we have included both individuals who use alcohol in ways that might disrupt treatment and those who use illicit drugs. This inclusion is premised on the fact that there are many overlapping concerns between these two groups of people who use these substances. We distinguish between people who use alcohol and people who use drugs only when the literature makes this distinction, or as far as it is important for the analysis.

- We also included an exploration into accessing contacts of TB index patients, but this was done through incorporating questions about contacts and contact tracing into the other research areas.
  - ❖ Healthcare providers involved in the TB response
  - ❖ TB response experts

All participants were required to be 18 years old and older (based on self-reports) and to provide informed consent for their data to be included in the research report. In addition, participants had to meet at least one of the below inclusion criteria:

- Affected by TB in the past five years
- Self-identifies as belonging to one of the selected key population groups
- Works with or has an interest in one of the selected key populations and the TB response
- Works or has an interest in human rights and/or legal environment-related aspects of the TB response
- Works or has an interest in gender-related aspects of the TB response

### 3.5 Data collection and analysis

Data was collected by two trained social scientists between September and November 2018. Research processes were guided by data collection tools set out in the approved research protocol. Data was recorded through a combination of audio recordings, written notes and participant-drawn images. Audio recordings were transcribed and, where necessary, translated. Data was analysed thematically in NVivo.



HEALTHCARE WORKERS



PEOPLE WHO USE SUBSTANCES

### 3.6 Ethical considerations

This research was designed and undertaken with numerous considerations for the fact that the work was being done with vulnerable populations. It was approved by the University of Cape Town Human Research Ethics Board, as well as by the Western Cape Provincial Department of Health and the Eastern Cape Provincial Department of Health. All participants were provided with comprehensive information sheets about the project and participation was entirely voluntary. People affected by TB received R120 for the research activities they participated in. Every effort was made to protect the privacy and confidentiality of the participants during the research process. This included the use of private spaces for research activities, the use of civil society selected sites for research with the key population groups to avoid identification by healthcare providers, and the protection of all hard and soft forms of data so that these were only accessed by researchers who had signed confidentiality agreements. This report uses pseudonyms for all participants and where it is deemed necessary, personal details have also been obscured to avoid the identification of respondents.

### 3.7 Limitations

**TB-affected individuals' perspective:** Though the qualitative research included some key informant interviews (see Table 1, p12), it focused predominantly on the voices and insights of people affected by TB. This means that our emphasis in this report is on the experiences and understandings of TB from the perspectives of the people affected by this disease. We therefore only make very cursory observations related to health systems, and do not emphasise issues relating to healthcare provision processes.

**Limited geographic coverage:** This assessment draws on available literature pertaining directly to TB in South Africa, as well as a rapid qualitative assessment, which was conducted in one area of each of the two selected provinces. The findings cannot be considered generalisable to the other seven provinces, or the country as a whole.

**Key population focus:** The qualitative research conducted only focuses on three key populations (four,

including contacts of TB patients). However, as is evident in the literature review, there are many other TB key populations worthy of focus in South Africa. Focusing on additional key populations was beyond the scope of this work.

**Limited exploration of gender minorities:** We included transgender women in this assessment. These women were all accessed through one social network. While we did find that their experiences resonated with those described elsewhere, caution should be taken in assuming their experiences are common across transgender women and the country. We were further unable to actively include other gender and sexual minorities, except through facility observation processes.

**Selection bias:** We accessed our research participants through non-profit organisations active in the sphere of TB and selected populations. This meant that we included people who were not entirely excluded from either TB care or NGO activities (sometimes these were combined). We are therefore not able to provide the views of people actively avoiding the healthcare system and non-profit involvement.

## 4. Context

South Africa has a progressive and extensive national public healthcare system, with approximately 3 500 clinics providing healthcare to the population (Pren Naidoo et al. 2017) meeting the goals of the End TB Strategy requires an invigorated programmatic response informed by accurate data. Enumerating the losses at each step in the care cascade enables appropriate targeting of interventions and resources. Methods. We estimated the tuberculosis burden; the number and proportion of individuals with tuberculosis who accessed tests, had tuberculosis diagnosed, initiated treatment, and successfully completed treatment for all tuberculosis cases, for those with drug-susceptible tuberculosis (including human immunodeficiency virus (HIV, including free access to TB diagnosis and treatment. In 2017, an estimated 68% of the 322 000 people with TB disease received treatment (World Health Organization 2018). While TB has declined compared to the levels seen at the beginning of the century (World Health Organization 2018) the rate of decline is insufficient to meet the Sustainable Develop-





ment Goals (South African National AIDS Council 2017). We outline three key drivers of TB in South Africa below, followed by an brief overview of some key national responses.

#### 4.1 Drivers of TB in South Africa

##### 4.1.1 Poverty

There is a strong link globally between poverty and tuberculosis. In resource-limited settings, living and working conditions are often dark and overcrowded with poor ventilation, heightening the likelihood of transmission of TB. Sub-optimal nutrition and limited access to adequate healthcare contribute to poor health and less robust immunity. According to a World Bank report, South Africa is one of the most (if not the most) unequal countries in the world (Sulla and Zikhali 2018), and poverty is again on the rise since 2011, after showing significant declines between 2001 and 2011. More than half of all South Africans (55.5%), over 30.4 million people, live below the upper bound poverty line - meaning that their monthly income per person in 2015 was less than R992.00 (Stats SA 2017). Those most affected include children under the age of 17, black Africans, females, people from rural areas, people living in the Eastern Cape or Limpopo and those with limited education.

Not only are the poor at higher risk of developing TB, but having TB can further worsen their economic state. Loss of income due to illness and the costs associated with accessing treatment result in less available funds to spend on food and housing, poorer nutrition and subsequent increased susceptibility to recurrent infection or relapse.

##### 4.1.2 HIV

TB and HIV are often referred to as a dual epidemic in South Africa because of the high rate of co-infection in the country. Living with HIV significantly increases the likelihood of developing TB because compromised immune function has a staggering effect on increasing the risk of developing TB disease following primary infection. However, even in the first year of HIV infection when the immune system is relatively intact, the risk of TB is elevated. South Africa has the biggest HIV epidemic worldwide, accounting for 19% of the total global HIV infections (UNAIDS 2018). Despite the significant strides that have been made towards addressing the epidemic, less than half (3.7 million) of all people infected with HIV (7.9 million) are on ART (Human Sciences Research Council 2018). This means that over four million people remain untreated. Of those on treatment, 87.5% of adults 15-64 years are virally suppressed, while this is considerably lower in children, who are already at higher risk of TB infection and disease. Data from the national TB register show that in 2017, almost two thirds (59.1%) of the 93.8% of TB cases whose HIV status was known, were HIV infected. Three quarters of these individuals (74.0%) were virally suppressed on ART. South Africa has the world's largest HIV programme, which has

recently undergone expansion with the implementation of the 'universal test and treat' programme, through which any individual who tests positive for HIV must be started on antiretroviral therapy (ART).

In addition to people living with HIV (PLHIV) being more susceptible to TB, TB is often more difficult to diagnose in PLHIV and treatment outcomes are poorer. For untreated HIV with progressive immune compromise, the clinical presentation of TB can change - resulting in a higher proportion of extra-pulmonary or disseminated TB, sputa that is often smear negative (even in pulmonary TB) and chest X-ray findings that are atypical or even normal. The presence of TB disease also accelerates the progression of HIV, resulting in a higher mortality rate for HIV-infected TB patients.

There is a vast body of literature and work related to HIV and TB/HIV co-infection in South Africa. Despite our noting that the majority of people with TB are also living with HIV and that people with HIV are a TB key population as listed in the South African National Strategic Plan, this assessment does not attempt a notable engagement with TB/HIV co-infection because limited scope and capacity disallowed thorough engagement with the topic.

We note, however, that the HIV epidemic has resulted in profoundly gendered, and age differentiated, health profiles. Adolescent girls and young women between the ages of 15-24 years are most at risk of contracting HIV in South Africa. In 2016, this cohort of young women acquired 30% of all new HIV infections, despite making up only 12% of the adult population in the country (UNAIDS 2017). HIV prevalence among 20 to 24-year-olds is three times higher among females (15.6%) than males (4.8%).

The peak prevalence of HIV occurs in 35 to 39-year-old females at a rate of 31.5 percent. The difference in prevalence between females (39.4%) and males (23.7%) in this age group is marked. The highest HIV prevalence rate in men (24.8%) occurs later in life, between the ages of 45 to 49 years (Human Sciences Research Council 2018)

##### 4.1.3 Drug-resistant TB

South Africa has among the world's highest number of people with drug-resistant TB (DR-TB). In 2017, there were approximately 14 000 incident cases of MDR-TB (WHO 2018). Cox et al. (2017) have provided a useful historical overview of DR-TB in South Africa: Over a third of diagnosed patients are recorded as not initiating treatment. At best, approximately half of all diagnosed patients are recorded as completing treatment, but a broader view (which includes all TB cases) suggests that only 13% of all incident cases are successfully treated. Resistance to first-line TB drugs was first identified in the 1980s, though it seems to have been present in South Africa since the 1960s. Rapid inclines in the number of people with TB in the 1990s accelerated the number of people with DR-TB, and the first decade of the 21<sup>st</sup> century saw marked inclines in the number of people recorded to have DR-TB - from an estimated 3 300 cases per year in 2000, to an estimated 8 000 cases per year in 2010. The year 2011 was an important year in terms of DR-TB policy and implementation - more sensitive (and rapid) GeneXpert testing was rolled out across the country, increasing the numbers of people identified as having MDR-TB. Standardised second-line treatment became available to lower level public health facilities, rather than only from specialist TB hospitals. The most recent and important policy initiative in relation to DR-TB has been the introduction of bedaquiline as a treatment option for all DR-TB patients. Bedaquiline allows for a shorter drug regimen and early indications are that it is improving treatment outcomes. This report includes both DS-TB and DR-TB, though research activities were largely focused on people with DS-TB.

#### 4.2 National health provision structure

Matters relating to TB policy, national strategy and treatment guidelines are the responsibility of the National Department of Health (NDoH). Within the NDoH, tuberculosis control is the responsibility of the National Tuberculosis Programme (NTP).



BETWEEN  
**64.4%**  
 AND  
**91.3%**

OF PEOPLE WERE  
 INITIATED INTO  
 TB TREATMENT  
 ACROSS THE  
 COUNTRY IN 2015



The NTP has four levels:

1. The National Department of Health sets policies and guidelines and co-ordinates, facilitates and evaluates TB services countrywide.
2. Provincial Departments of Health oversee implementation at the provincial level and budget for programme implementation
3. District level units manage primary health care administration
4. Health units (including rural hospitals, health centres, dispensaries and clinics) provide public healthcare.

As with other spheres of government, Implementation is the responsibilities of provinces, districts and municipalities and varies greatly between provinces, districts and facilities. The quality of public healthcare services for TB varies greatly by district, with treatment success rates being listed at between 64.4% and 91.3% of people being initiated into treatment across the country in 2015 (Vanleeuw and Loveday 2018). This report relates almost exclusively to the public healthcare system, where the majority of tuberculosis tests (93%) are done (Naidoo et al. 2017). Meeting the goals of the End TB Strategy requires an invigorated programmatic response informed by accurate data. Enumerating the losses at each step in the care cascade enables appropriate targeting of interventions and resources. Methods. We estimated the tuberculosis burden; the number and proportion of individuals with tuberculosis who accessed tests, had tuberculosis diagnosed, initiated treatment, and successfully completed treatment for all tuberculosis cases, for those with drug-susceptible tuberculosis (including human immunodeficiency virus (HIV and almost all treatment is provided free of charge.

### 4.3 Key responses to the TB epidemic

The South African TB response is supported by many structures and processes, including:

- **The TB Think Tank.** The NTP TB Think Tank was established in 2014 to evaluate evidence, conduct quantitative analysis and improve national TB data (White et al. 2018) typically against tight deadlines. OBJECTIVE: To describe lessons learned from establishing a dedicated tuberculosis (TB). Professionals from government, civil society, academia and NGOs work together to monitor and evaluate current TB programmes and policies; and conduct new TB research to generate and correlate data to provide insights into key gaps as far as interventions and local policies are concerned (White et al. 2018) typically against tight deadlines. OBJECTIVE: To describe lessons learned from establishing a dedicated tuberculosis (TB). These activities allow for recommendations to be made which aim to provide the NTP with information on where and how to improve TB programmes and interventions. TB-related policy recommendations are also provided in order to achieve the National Strategic

Plan's TB targets (White et al. 2018) typically against tight deadlines. OBJECTIVE: To describe lessons learned from establishing a dedicated tuberculosis (TB).

- **TB Innovations Consortium.** The South African TB Demonstration, Scale and Sustainability (SA-DSS) consortium was established in late 2017. It comprises academic institutions, civil society organisations and Departments of Health in Gauteng, KwaZulu-Natal and the Western Cape (three of the highest TB burden provinces in South Africa); together with the Bill and Melinda Gates Foundation (BMGF), the National Institute of Communicable Diseases (NICD), the National Department of Health, the South African Medical Research Council and implementing partners. The role of this consortium is to foster the engagement of key stakeholders that can inform or support demonstration research projects to provide robust evidence, scale process, ensure strong alignment with South African DOH programme priorities and leverage the expertise of multiple research and other groups to test innovative strategies to improve TB control in diverse settings in South Africa. Three initial projects have been designed to test strategies to improve case finding, increase linkage to treatment following diagnosis, and support adherence to treatment for DS-TB.
- **National Prevalence Survey.** A new National Tuberculosis Prevalence Survey is expected to report its first findings in 2019. The study is being conducted by the South African Medical Research Council (SAMRC), the Human Sciences Research Council (HSRC) and the National Institute for Communicable Diseases (NICD) collectively (Human Sciences Research Council 2018).
- **The South African TB Caucus.** The Global TB Caucus works to address the global TB epidemic through actions at a global, regional and national level; aiming to achieve a sustainable political response to TB in order to achieve a TB-free world (The Global TB Caucus 2017). The Global TB Caucus consists of over 2 300 parliamentarians from 130 countries around the world, and the South African TB Caucus is its local chapter. The SA TB Caucus was launched on the 4th September 2018 through a resolution passed by the National Assembly. It is led jointly by the Chair of the Health Committee in the National Assembly and the Chair of the Select Committee on Social Services in the National Council of Provinces, with the support of a Coordinating Body made up of the members of the aforementioned committees. The purpose of the SA TB Caucus is to raise awareness about the TB epidemic and support efforts towards the elimination of TB by 2030. The SA TB Caucus will encourage members of parliament to produce legislation that will create an enabling environment for access to healthcare and TB research and development.

## 5. TB Burden in South Africa

### 5.1 TB burden overview


















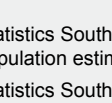
The 2018 Global Tuberculosis Report (World Health Organization 2018) estimates of the national TB incidence for 2017 are 320 000 (230 000-

The per-capita  
 TB incidence  
 is the second  
 highest in the  
 world.

WORLD HEALTH ORGANISATION 2018



## AVAILABLE DATA ON POPULATION SIZES RELEVANT TO INCLUDED POPULATIONS

	Research population	Specific population	Total	Males	Females	Comments
	<b>ALL</b>	National population [1]	<b>57,7 m</b> (49%)	28,23 million (51%)	29,5 million	
	<b>FARM DWELLERS</b>	Farm workers [2]	<b>843 000</b>	278 000 (33%)	565 000 (67%)	Data on all farm dwellers not found.
	<b>HEALTHCARE WORKERS</b>	HPCSA-registered HCWs	<b>165 371</b>	No data found	No data found	Data on HCWs, including CHWs not found.
	<b>PEOPLE WHO USE SUBSTANCES</b>	People who binge drink [3]				Where binge drinking is qualified as consumption of five or more standard drinks on an average drinking day.
		People who inject drugs [4]	<b>67,000</b>	No data found	No data found	Data not found on full population of people who use drugs. PWID data estimated.
	<b>CONTACTS OF TB INDEX PATIENTS</b>	Household contacts TB-index patients [5]	<b>1,62 m</b>	No data found	No data found	No data on all contacts, including contacts outside of the household.
	<b>ELDERLY PEOPLE</b>	Elderly people (60+ years) [6]	<b>4,6 m</b>	2,65 million (60%)	1,95 million	People over 60 years make up 8.1% of the total population.
	<b>MIGRANTS AND ASYLUM SEEKERS</b>	Foreign born people living in South Africa [7].	<b>1,6 m</b>	No data found	No data found	
		Asylum seekers [8]	<b>1,1 m</b>	No data found	No data found	
		Refugees [8]	<b>122 000</b>	No data found	No data found	
	<b>MINE WORKERS</b>	Mine workers [9]	<b>464 667</b>	53 179 (11%)	411 488 (89%)	
	<b>PEOPLE WITH DIABETES</b>	People with diabetes between aged 21-74 [10]	<b>3,85 m</b>	No data	No data	
	<b>PEOPLE WHO SMOKE</b>	People who smoke [10], [11] of the population [10]	<b>17.6%</b> population [11]	31.4% of the male population [11]	6.5% of the female	Available information only included percentages.
	<b>PEOPLE WITH SILICOSIS</b>	No data found	<b>No data found</b>	No data found	No data found	
	<b>PREGNANT WOMEN</b>	Live births in 2017 [12]	<b>897 750</b>	No data found	No data found	
	<b>INMATES/PRISONERS</b>	Inmates [13]	<b>161 054</b>	159 803 (99%)	4 326 (1%)	Johnstone-Robertson et al [14] estimate the number of people who cycle through the prison system annually to be between 360 000 – 368 000
	<b>SEX WORKERS</b>	Sex workers [15]	<b>131 000 – 182 000</b>	6883 (5%)	137641 (90%)	These are the moderate estimates provided. 5506 (4%) sex workers estimated to be transgender.
	<b>URBAN POOR/ PEOPLE LIVING IN INFORMAL SETTLEMENTS</b>	People living in informal dwellings (urban and rural) [16]	<b>13,6%</b> of the population	No data found	No data found	Actual numbers not provided.

## Data sources

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428 000), or 567 (406 – 754) per 100 000 people. This puts the per-capita incidence at the second highest in the world, behind Lesotho. The DR-TB (including RR and MDR-TB) incidence rate is estimated by the same report at 14,000 (8 900 – 20 000) or 25 (16 –36) per 100 000 people.

WHO statistics are an estimate of all people affected by TB. In contrast, figures provided by the National Department of Health report on new smear positive TB cases that have been recorded by the healthcare system, excluding cases where people have not accessed healthcare, but also those who have been previously infected and not treated to cure (Naidoo et al. 2017) meeting the goals of the End TB Strategy requires an invigorated programmatic response informed by accurate data. Enumerating the losses at each step in the care cascade enables appropriate targeting of interventions and resources. Methods. We estimated the tuberculosis burden; the number and proportion of individuals with tuberculosis who accessed tests, had tuberculosis diagnosed, initiated treatment, and successfully completed treatment for all tuberculosis cases, for those with drug-susceptible tuberculosis (including human immunodeficiency virus (HIV). Recorded national figures are, therefore, notably lower than those presented by the WHO. Nevertheless, national data can be useful to examine trends and for a more detailed view of TB-affected people and their treatment outcomes.

According to the NDoH, in 2017, there were 227 224 reported cases of TB, inclusive of new and previously treated cases. Of these, 95.3% (n=216 502) were drug-sensitive TB (DS-TB), with drug-resistant TB (DR-TB) making up 4.7% (n=10 722) of cases. Within the DS-TB cohort, 54.7% (n=124 288) were bacteriologically confirmed, with the remainder of diagnoses being made on clinical suspicion. 88.9% (n=192 509) of DS-TB cases were pulmonary TB (PTB) and 89.3% (n=193 399) were new TB cases with no prior history of treatment exposure. Within the DR-TB cohort 95.7% (10 257) of cases were MDR-TB (inclusive of RR-TB) and 4.3% (n=642) were pre-XDR-TB. 40.4% of all reported MDR-TB cases were lab confirmed and 0.4% (n=39) were not confirmed. Of the XDR cohort, 99.6% (n=463) were culture confirmed.

At the time of writing, treatment outcomes for DS-TB for 2017 were not available. Results for 2016 were as follows: of the full cohort (N=241 831), 61.9% (n=149 581) were documented to have completed treatment and 19.9% (n=48 084) were cured (i.e. smear or culture-negative in the last month of treatment and on at least one previous occasion). This equates to an 81.7% treatment success rate. Treatment failure was reported in 0.3% (n=796) of cases, 6.9% (n=16 630) of cases were lost to follow-up and 6.6% (n=15 850) died. No treatment outcome was available in 4.5% (n=10 890) of cases (including patients who were transferred out and those for whom the treatment outcome was not evaluable). (Table 2)

The most recent treatment outcomes for DR-TB (RR and MDR-TB) and for XDR-TB are from 2015. 9.9% of the full DR-TB cohort (N=11 810) were recorded to have completed treatment and 43.9% (n=5 082) had documented cure. Treatment failure was reported in 4% (n=467) of cases, 18% (n=2 122) were lost to follow-up, 22.5% (n=2 656) died and 2.6% (n=308) had no known outcome. For XDR-TB (N=766), 7.7% (n=59) of the cohort were documented to have completed treatment and 40.2% (n=308) had documented cure, resulting in a total recorded 47.9% (n=367) treatment success. 28.2% (n=216) of cases resulted in death, 9.9% (n=76) of cases had recorded treatment failure, and 11.7% (n=90) were lost to follow-up and 2.2% (n=17) had no known outcome. (Table 3)

Naidoo et al (2017) have provided insight into where people affected by TB might be missed, or lost, in the national TB response (and therefore statistics) in the year 2013. In this analysis they estimate that for DS-TB in the year 2013, the treatment success for new, smear positive TB cases exceeded 80%, when the measure included all TB cases, one in four people who initiated treatment did not successfully complete treatment. Their assessment shows that a relatively low percentage (estimated at 5%) of people did not access care at all. This low number is attributed to the relatively large-scale public healthcare network in the country. Loss between testing and diagnosis was estimated at 13%. This loss is attributed largely to false negative tests due to the failure to follow diagnostic algorithms, including the use of smear-microscopy rather than more

Total cohort	N=241 831
Treatment completed	61.9% (n=149 581)
Cured	19.9% (n=48 084)
Treatment success	81.7% (n=197 665)
Treatment failure	0.3% (n=796)
LTFU	6.9% (n=16 630)
Died	6.6% (n=15 850)
Not evaluated	4.5% (n=10 890)

Table 2: DS-TB outcomes 2016

TB type	DR- TB (RR & pre-XDR)	XDR-TB
Total cohort	N=11 810	N=766
Treatment completed	9.9% (n=1175)	7.7% (n=59)
Cured	43% (n=5082)	40.2% (n=308)
Treatment success	53% (n=6257)	47.9% (n=367)
Treatment failure	4% (n=467)	9.9% (n=76)
LTFU	18% (n=2122)	11.7% (n=90)
Died	22.5% (n=2656)	28.2% (n=216)
Not evaluated	2.6% (n=308)	2.2% (n=17)

Table 3: DR-TB outcomes 2015

sensitive GeneXpert tests. The initial loss to follow-up (people diagnosed, but not treated) is estimated at 12%. This is attributed to a combination of diagnostic delays, fragmented data systems and health system failures such as poor record-keeping. A final 17% loss was estimated between starting and successful treatment completion. Drawing on the literature, they note that poor patient knowledge, lack of patient empowerment, and high costs of daily attendance of clinics (still required for Directly Observed Treatment, Short course (DOTS) at the time of the study) are all implicated in this final loss.



## 5.2 TB burden gender differences

The South African National Tuberculosis Programme does not request gender-disaggregated information from provinces (though this data is gathered by healthcare facilities). However, the Global Tuberculosis Report provides breakdown of TB incidence by age and sex. This estimates that in 2017, there were 135 000 incident cases in females, and 187 000 incident cases in males. This estimate female-to-male ration (of 0.72) is lower than the international average, where women are approximately half as likely to be infected with TB in comparison to men (World Health Organization 2018). It is, however, similar to the findings of the most detailed study on national gender differences in TB screening and diagnosis, which draws on data from the National Laboratory Services between 2009 and 2011 (McLaren et al. 2015). This study describes an average female-to-male prevalence ratio of 0.70 across all provinces, and a national female-to-male incidence ratio of 0.83. On average, 11 000 females were diagnosed with TB on a monthly basis compared to 13 000 males. The rate of females with TB in South Africa is proportionally higher than is common elsewhere (McLaren et al. 2015), likely due to the higher numbers of women with HIV. Furthermore, peak TB prevalence in women occurs approximately 5-7 years earlier than in men (Shisana et al. 2009; Racow 2013; McLaren et al. 2015), a difference which likely relates to a woman's childbearing years.

There is further evidence that women's risk of TB infection is locally increased by the nature of care work in the country, which has traditionally been (and continues to be) very gendered. Women do the majority of care work for people who are sick (Boffa et al. 2018), increasing their exposure to infectious bacilli. This exposure often takes place within the context of their roles as both care providers in the home and as healthcare workers. It has further been shown that 78% of all healthcare workers are female (O'Donnell et al. 2010). It may also be partly due to who enters into care and therefore into the statistics: females under 40 years of age are more likely to be on ART than their male counterparts, and therefore have more frequent access and medically driven encouragement to be screened and tested for TB (O'Donnell et al. 2011)

There are some indications that women might carry a greater burden of drug-resistant TB in KwaZulu- Natal. O'Donnell and colleagues found that women admitted to an inpatient TB hospital were 38% more likely to have XDR-TB than men, and that women with MDR or XDR-TB were on average younger than men (32 years for women compared to 36 years for their male counterparts). Women were also more likely to be HIV infected (65% of women and 47% of men) and receiving ART - 51% of women as opposed to 43% of men (O'Donnell et al. 2011).

There are no local statistics on TB in gender minorities. The first study measuring HIV prevalence in transgender women is currently underway (HSRC 2018). Internationally, transgender women are 49 times more likely to be living with HIV than someone from the general population (UNAIDS 2016) and it is likely that South Africa has similarly high levels of HIV among transgender women (Stevens 2012). This suggests that this cohort will experience higher than average levels of TB as well, given the increased incidence of TB in people with HIV.

### 5.2.1 Mortality

The WHO estimate the full TB mortality burden for South Africa in 2017 to have been 78 000 (39 people per 100 000). As with morbidity, national statistics provide notably lower figures, but these are useful to view in terms of category breakdowns.

The most recent national mortality statistics, from 2016, record TB deaths as accounting for 29 513/456 612 deaths, or 6.5% of all deaths (Statistics South Africa 2018a). TB-related deaths are nationally recorded as follows:

National mortality rates in the country for 2016 indicate that TB was the leading cause of death in men, accounting for 7.6% (18 153/240 001) of deaths. TB was only the fifth leading cause of death in women, accounting for 5.2% (11 246/214 988) of deaths, but it was still the leading cause of death overall. A total of 29 513 deaths (6.5% of all deaths) were recorded as having been caused by TB in 2016. The gender differences in the mortality statistics echo multiple studies in South Africa that have found that men have higher TB-attributable mortality than women (McLaren et al. 2015; Reniers et al. 2017; Mossong, Byass, and Herbst 2014).

This lower rate of mortality in women despite higher HIV prevalence rates for this group indicate the impact of healthcare service access and use (Treves-Kagan et al. 2017) most HIV-stigma research focuses on individuals; further the intersection of gender, testing and stigma is yet to be fully explored. We examined the relationship between anticipated stigma at individual and community levels and recent testing using a population-based sample (n = 1126).

Total Deaths			
Rank	Cause of Death (N=456 612)	No. of deaths	%
1	TB	29,513	6.5
2	Diabetes mellitus	25,255	5.5
3	'other' forms of heart disease	23,515	5.1
4	Cerebrovascular disease	23,137	5.1
5	HIV	21,830	4.8
Female Deaths			
1	Diabetes mellitus	15 506	7.2
2	Cerebrovascular disease	13 396	6.2
3	'other' forms of heart disease	12 485	5.8
4	Hypertensive disease	12 374	5.8
5	TB	11 246	5.2
Male Deaths			
1	TB	18 153	7.6
2	HIV	11 021	4.6
3	'Other' forms of heart disease	10 990	4.6
4	Influenza and pneumonia	10 160	4.2
5	Diabetes mellitus	9 723	4.0

Table 4: Causes of death as recorded by Statistics South Africa



For both sexes, the proportion of deaths due to TB has decreased - from 9.5% to 7.6% for men between 2014-2016, and from 7.0% to 5.2% over the same period for women (Statistics South Africa 2018a). This is likely due to improved coverage and uptake of ART.

### 5.3 TB burden in selected key populations

#### 5.3.1 Farm workers

TB, lung disease and silicosis are common in the farming sector of South Africa (Hazard 2002). The Western Cape province, which employs about a fifth of all farm dwellers nationally (Clarke, Dick & Bogg 2006), has a TB infection burden of almost three times the general population. An integrated biological and behavioural surveillance study conducted in 2010 in the provinces of Limpopo and Mpumalanga found a TB case-notification rate of 6 per cent per annum – about nine times the national average. The authors suggest that the TB burden was related to elevated levels (almost 40%) of HIV infection recorded among farm dwellers (from both migrant and non-migrant populations).

#### 5.3.2 Healthcare workers

As elsewhere in the world, South African HCWs carry a notably higher TB burden than the general population (Grobler et al. 2016; Kranzer et al. 2010). Their risk of TB acquisition has been measured to be approximately twice that of the general population (M. M. Claassens et al. 2013; Tudor et al. 2014), but this risk may well be higher than measured due to under-reporting (Ehrlich 2018). The admission rate at TB hospitals for MDR and XDR-TB among healthcare workers is 5-6 times higher than in the general population (Grobler et al. 2016; O'Donnell et al. 2011). This increased burden is experienced by all HCWs, including medical students (van der Westhuizen and Dramowski 2017) and all staff working in non-TB-specific areas of healthcare such as paediatric wards, outpatient departments and storerooms (Tudor et al. 2014). HCWs in community-based settings are equally (if not more) at risk of contracting TB compared to HCWs who are facility based (Kranzer et al. 2010).

#### 5.3.3 People who use substances

A number of studies record the overlap of TB and hazardous or harmful drinking in South Africa. Comparisons using these results are difficult due to the varying measures used for defining alcohol use as problematic. Nevertheless, overall the data illustrates a notable overlap between TB and alcohol use: A current TB rate of 2.1% (double the population average) was found in people who self-reported hazardous drinking (Mertens et al. 2010). In people with current TB, 24.6% were found to have hazardous or harmful drinking results on the Alcohol Use Disorder Identification Test (Peltzer et al. 2013). In a retrospective cohort study of MDR patients, Kendall et al. (2013) found that 63% of their participants were using alco-

hol (Kendall et al. 2013b), compared to 41.5% of the men and 17.1% of women reporting alcohol use in a national study (K Peltzer, Davids, and Njuho 2011).

Alcohol use is thought to be responsible for an estimated 939 000 disability-adjusted life-years lost in South Africa from TB (Rehm & Parry 2009). Data on the burden of TB among drug users is lacking, though Mertens et al. (2010) showed that hazardous drug use increased the lifetime odds of contracting TB (OR=2.31). Furthermore, a chart review of patients in a TB hospital found that 26% (44/167) of patients were using methaqualone, heroin or methamphetamines at the onset of TB symptoms (Versfeld 2017). Overall, efforts to quantify the burden of TB in people who use substances are undermined by insufficient data on the real rates of drug use in the country and routinised stigma towards people who use substances in healthcare facilities (Myers, Fakier, and Louw 2009)

#### 5.3.4 Contacts of TB index patients

In the North West province, a study found that 19% of the households of TB index patients were found to have at least one person with undiagnosed TB (Shapiro et al. 2012). At 6 705 per 100 000, prevalence in TB index patient households was nine times more than that of randomly selected households in the same area. In the same district, a baseline prevalence of 9.2% for active TB was found in household contacts (Van Schalkwyk et al. 2014). Another study found that contact slips given to TB index patients to give to their contacts (many of whom were not household contacts) resulted in a 26% contact tracing rate, with a 12% TB detection rate (Mwansa-Kambafwile et al. 2013).

### 5.4 TB burden in other key populations

#### 5.4.1 Children under five

Estimates of the national TB burden in children under five were not found, but studies have estimated that children up to the age of 13 probably carry between 15 and 30% of the South African TB burden (Martinez et al. 2018). Ncayiyana et al. (2016) found a 3.1% (14/446) annual risk of infection among children in an informal settlement in Johannesburg and a birth cohort study in a TB hyperendemic region found that for

every 100 child-years, the incidence in children was 11.8 (95% CI 10.0–13.8) for tuberculin skin test conversion, 2.9 (2.4–3.7) for all diagnosed tuberculosis, and 0.7 (0.4–1.0) for microbiologically confirmed tuberculosis in children who had received a BCG vaccination (Martinez et al. 2018). Risk of infection and disease was found to be particularly high during the first two years of life, after which it drops substantially (Martinez et al. 2018).

#### 5.4.2 The elderly

Currently, there is limited research on TB infection among the elderly population in South Africa. National TB data is not disaggregated by age in adults, and most South African models of TB dynamics do not include age, or only include age for HIV incidences (Blaser et al. 2016).

While TB does affect the elderly, the burden is lower than it is in the younger population. The HIV epidemic is also notably higher in the younger population. A study conducted in Soweto, Gauteng found that the TB burden decreases after the age of 35, and is at its lowest among the elderly (Karstaedt and Bolhaar 2014). The study found a TB prevalence of 262/100 000 in elderly persons between the ages of 65 and 97 (Karstaedt and Bolhaar 2014).

TB risk among the elderly is increased by frailty, comorbidities, high-risk social behaviour such as smoking and substance use, as well as poor quality of life - which is often associated with low socioeconomic status (Karstaedt and Bolhaar 2014; B. Clark, Kahn, and Tollman 2013).

#### 5.4.3 Refugees and asylum seekers

No TB burden data found.

#### 5.4.4 Mineworkers

TB prevalence rates in mineworkers range between 3 000 –7 000 per 10 000 people, between 4–7 times higher than the prevalence rate of the general population (Lebina et al. 2016). The increased risk of tuberculosis in South African miners is related to silica exposure and the development of silicosis, which predisposes people to TB (Marks 2006; Rees and Mur-



FARM DWELLERS



HEALTHCARE WORKERS



PEOPLE WHO USE SUBSTANCES



ray 2009; TeWaterNaude et al. 2006). Further risks include poorly ventilated mine shafts, high rates of HIV, as well as hostel-style accommodation on mine premises which is often overcrowded and inadequately ventilated - providing ideal conditions for the spread of TB (Packard 1989; Macdonald and Mutendi 2017). The abundance of people seeking work means that sick miners can easily be replaced by healthy individuals. This means that mining companies often lack incentives to implement occupational health and safety measures and healthcare benefits for workers (Stuckler et al. 2011).

#### 5.4.5 People with diabetes

A study conducted in Khayelitsha, an informal township near Cape Town, found that HIV-negative people with diabetes have a threefold risk of developing TB (Oni et al. 2017) and have a fivefold chance of dying during TB treatment (Baker et al. 2011). Another study found a prevalence of TB disease of 4 242/100 000 in children aged 0–14 years in the Western Cape, based on Tuberculin Skin Test (TST) positivity – a rate seven times higher than the general, non-diabetic population of the same age living in the Western Province (Webb et al. 2009). This latter study found 3,48% (9/258) prevalence of current TB disease in this group. In a Cape Town study, 13% of tuberculosis patients were found to have diabetes (Oni et al. 2017). Furthermore, there are indications that the diabetes-tuberculosis relationship may be bi-directional: in one local study the onset of tuberculosis has been linked to increased risk of developing insulin-resistance, though the reasons for this remain unclear (Philips et al. 2017).

#### 5.4.6 People who smoke

A Cape Town-based study found that having ever smoked doubled the likelihood of a positive TST test (den Boon 2005). Another study found that previous smoking doubled the odds of active pulmonary tuberculosis, and current smoking tripled the odds (Murrison et al. 2016). A further study in the same city found that 72.2% (306/424) of people symptomatic for TB had ever smoked (Brunet et al. 2011).

People who smoke are also more likely to drink alcohol (Murrison et al. 2016), and heavy drinking is inde-

pendently associated with the risk of TB acquisition (K Peltzer et al. 2013). Additionally, the environments in which smoking and drinking occur are often crowded and lack ventilation, further increasing tuberculosis risk (Murrison et al. 2016).

#### 5.4.7 People with silicosis

Silicosis is associated with a threefold increase in tuberculosis infection risk (Corbett et al. 2000) with consent, at primary health clinics during 1991–1996, predominantly because of a symptomatic sexually transmitted disease. Results Tuberculosis (TB. Between 22% and 32% of South African mineworkers develop silicosis (Lebina et al. 2016), though it is most common in gold miners (Sonnenberg et al. 2005; Rees and Murray 2009). A 2008 study that included 700 mineworkers found that 24% had silicosis. And of the miners with silicosis, 44% had a history of tuberculosis, as compared to 26% among those without silicosis (Girdler-Brown et al. 2008). The high silicosis and tuberculosis mortality rates among miners may be attributed to mining companies' failure to control occupational dust exposure (Cowie 1994; Packard 1989), as well as the lack of occupational health services for miners (Lebina et al. 2016).

#### 5.4.8 Pregnant women

In high TB burden countries such as South Africa, TB rates of between 0.07% and 0.5% have been found among HIV-negative pregnant women, and between 0.7% and 11% among HIV-positive pregnant women (Bates et al. 2015). The burden of tuberculosis in pregnant women has increased with the HIV epidemic (Pillay et al. 2001; Soul City Research Unit 2015). Between 1996 and 1998 in Durban, TB in pregnant women increased from 0.1% to 0.6% (Pillay et al. 2001) and TB rates in HIV-infected maternities were 774.2/105 (Pillay et al. 2001). More recent findings indicate an estimated 3.3% tuberculosis prevalence among HIV-infected pregnant women in South Africa (Hoffmann et al. 2013). Very little information exists about TB in pregnant women who do not have HIV.

Inadequate integration of tuberculosis and prevention of mother-to-child transmission of HIV programmes in South Africa further increases the TB burden among

pregnant women (Uwimana et al. 2012; Uwimana & Jackson 2013; Searle & Coovadia 2013). This is due to the lack of skilled providers and their supervision (Uwimana & Jackson 2013), the physical layout of the TB-PMTCT services and the service delivery mechanisms currently in place (Searle & Coovadia 2013; Uwimana et al. 2012). Locally, MDR-TB has been linked to pregnancy complications such as spontaneous pre-term birth, infant deaths (Khan et al. 2007) and higher maternal mortality (Karim et al. 2009) compared to drug-sensitive TB.

#### 5.4.9 Prisoners/inmates

Studies have found notably higher levels of tuberculosis in inmate populations compared to the general population. One study found a 2.7% (2017/426) prevalence across four facilities, fuelled by high levels of HIV, overcrowding, prolonged confinement, poor ventilation, and poor diets (Zishiri et al. 2015).

According to the Department of Correctional Services, 1 250 inmates were diagnosed with TB in 2016/2017 out of a total prison population that year of 161 054. Of these, 1 034 (83%) were treated to cure. At 0.77% of the prison population, this is markedly lower than found in prior studies and notably also lower than in the general population. The TB burden in prisons is likely to be positively influenced by improvements in the HIV response which have been reported by the Department of Correctional Services, including the implementation of universal test and treat for HIV in 2016. The Department further reports that 98% (24 506/25 042) of those who tested positive for HIV were put on treatment in the 2016/2017 financial year (Republic of South Africa 2017). A 2011 study reported 230% overcrowding in communal cells. The Department of Correctional Services acknowledges that overcrowding is a persistent problem, reporting an overall overcrowding rate of 35%, with occupancy at 150% in some prisons (Republic of South Africa Department of Correctional Services 2017)..

#### 5.4.10 Sex workers

There is currently very little data available on TB prevalence and burden among sex workers in South Africa. Neither is there any information on treatment access and care. Estimates of HIV prevalence are high in Johannesburg at 71.8%, 39.7% in Cape Town and 53.5% in eThekweni (UCSF, Anova Health Institute, and WHRI 2015). This, combined with the characteristic work conditions of high levels of migration, substance use, incarceration and economic vulnerability (Desmond Tutu HIV Foundation 2017) would imply high rates of tuberculosis. However, tuberculosis does not seem to reflect as a notable problem in programmatic data from organisations providing services to sex workers. TB HIV Care data from October 2017 - August 2018 indicates a 0,05% TB burden in sex workers accessing TB treatment.



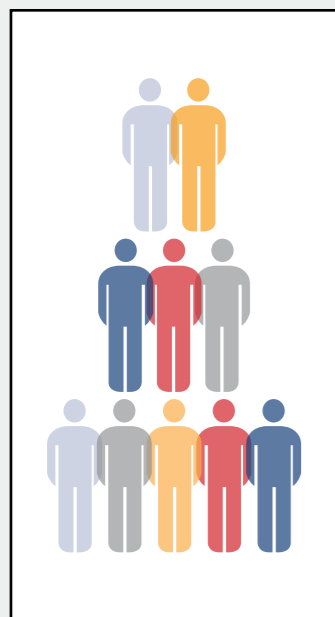
PRISONERS



SEX WORKERS



URBAN POOR



#### 5.4.11 Urban poor/informal settlements

Recent data on TB prevalence in informal settlements is lacking (Soul City Research Unit 2015). A decade ago, the prevalence of TB disease among people living in informal settlements was estimated at 2.6% (Mzolo 2009).

TB risk in informal settlements is increased by overcrowding in small shacks that are poorly ventilated - conditions that provide fertile ground for the spread of TB (Claassens et al. 2014). The burden of TB in informal communities may also be due to high social mixing in places such as shebeens, churches, transportation hubs (such as taxi ranks) and crèches (Johnstone-Robertson, et al. 2011; Ncayiyana et al. 2016) influenza. Indoor contact between individuals has been found to be the most common type of contact, particularly due to the high rates of social mixing events in townships. Indoor contact accounts for 86.2% of contact (with any other people), of which 58.4% occurs within the township community among community members (Johnstone-Robertson, et al. 2011) influenza.

Children living in informal settlements have a particularly high risk of contracting TB. A study done in a Cape Town township found that between the ages of five and 15 years, the mean annual risk of TB infection ranged from 3.9% to 4.8%; while the risk of infection in the study population of uninfected individuals was maximal at 7.8% at the age of 15 (Wood et al. 2010).

A study done in Cape Town townships aimed at determining age-specific prevalence rates of latent tuberculosis infection (LTBI) among HIV-negative individuals found that by the age of school entry almost a fifth of children were already infected with TB (Wood et al. 2010). By the age 15 years, 50% of adolescents in study communities were infected with TB. At the age of 25, when HIV prevalence peaks, the study found that approximately 75% of individuals had evidence of latent TB infection. Latent TB prevalence in males peaked at 85% at the age of 33, and 78% in women at the age of 29 (Wood et al. 2010).

## 6. International, regional and national laws and standards

This section contains information regarding the overarching legal and regulatory framework that protects and promotes the rights of all people, including vulnerable and key populations, in the context of health – including TB – in South Africa.<sup>3</sup>

<sup>3</sup> Note that for this section only we use the Oxford legal referencing system, rather than the Chicago manual style used elsewhere in the document.

Section 6.1 discusses those provisions relevant to all persons and that apply broadly to protect and promote the right to health in South Africa. Section 6.2 looks at specific international and regional commitments as well as national laws and policies particularly relevant in the context of gender. Section 6.3 sets out similar information for the four key populations selected for priority focus in this research.

Legal, regulatory and policy issues are raised and dealt with in further detail again, in the Section 9 discussion on the human rights and gender-related barriers experienced by key populations, in order to identify key gaps and challenges and make recommendations for strengthened laws, policies and access to justice.

### 6.1 Laws, regulations and policies relevant for the health rights of all affected populations

South Africa has ratified a number of international and regional human rights treaties that protect rights relevant to all persons, including the rights of vulnerable and key populations in the context of TB. South Africa has a dualist legal system in terms of which international and regional treaties are required to be enacted in domestic law before they can be invoked. However, the South Africa Constitution provides that when interpreting national laws, international and regional human rights commitments should be taken into account, and these international and regional commitments play an important part in South African jurisprudence.

Various treaties set out below are of importance; although they do not make specific reference to TB, they require states to respect, protect, promote and fulfil fundamental human rights important for all persons in the context of TB, including health rights.

South Africa has ratified or acceded to the following international and regional human rights conventions, among others, which - although not TB-specific - protect important human rights for vulnerable and key populations in the context of TB and provide a framework for TB interventions:

**The International Covenant on Civil and Political Rights, 1966** and its optional protocols (monitored by the Human Rights Committee) sets out the civil and

political rights of all persons, including the rights of all persons to equality and non-discrimination, privacy, freedom of movement, freedom of expression, freedom from arbitrary arrest and detention and right to a fair trial, among others. These rights protect people with TB in various ways, set out in the table, below.

**The International Covenant on Economic, Social and Cultural Rights (ICESCR), 1966** (monitored by the Committee on Economic, Social and Cultural Rights (CESCR)) protects the socioeconomic rights of all persons including the right to the highest attainable standard of physical and mental health, the right to education and the right to social assistance, among others.<sup>4</sup> General Comment 14 regarding the right to health recognises that the right to health is closely related to, and dependent upon, the realisation of other human rights - including the right to food, housing, work, education, participation, enjoyment of the benefit of scientific progress and its applications, life, non-discrimination, equality, the prohibition against torture, privacy, access to information and the freedom of association, assembly and movement. It also sets out four important elements of the right to health - healthcare should be available, accessible to all without discrimination, acceptable (in terms of respect for ethics, culture and gender diversity) and of high quality.<sup>5</sup> In the context of TB, this suggests that:

- **Availability:** There should be a sufficient quantity of functioning health care facilities, goods and services for the diagnosis and treatment of TB, appropriately trained health care providers, as well as adequately developed and updated TB programmes.
- **Accessibility:** Health facilities, goods and services for TB must be accessible to everyone. Accessibility has four overlapping dimensions: (i) non-discrimination, (ii) physical accessibility, (iii) economic accessibility (affordability), (iv) information accessibility.
- **Acceptability:** Health facilities, goods and services for TB must be respectful of medical ethics and

<sup>4</sup> South Africa has not, however, accepted the individual complaints procedures and inquiries established under the CESCR and CRC.

<sup>5</sup> UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), 11 August 2000, E/C.12/2000/4, available at: <https://www.refworld.org/docid/4538838d0.html> [accessed 16 February 2019]





culturally appropriate, as well as sensitive to gender and life-cycle requirements, and the special needs of key populations most at risk for TB. People with TB shall have the right to informed consent prior to treatment for TB and the right to be free from non-consensual, compulsory treatment.<sup>6</sup>

- Quality: Health facilities, goods and services for TB must be scientifically and medically appropriate and of good quality.

**The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment, 1984** (monitored by the Committee Against Torture) protects all persons and has been applied particularly to protect persons in detention, among others, from cruel, inhuman or degrading treatment or punishment committed by a public official or other person acting in an official capacity. This provides prisoners and those hospitalised with TB with the right to appropriate TB-related healthcare, as set out in the table below.

At a regional level, the **African Charter on Human and Peoples' Rights** (monitored by the African Commission on Human and Peoples' Rights) provides for the rights of all persons in Africa. It contains several provisions that protect the equality rights of all persons, including gender equality, and prohibit discrimination including on the basis of race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or any status.<sup>7</sup> These provisions apply to all persons and should apply equally to transgender persons. It also includes many of the key rights that are important for people in the context of TB as in the ICCPR, ICESCR and other core international treaties, including rights to liberty and security, freedom of movement, health and fair labour practices, among others. The relevance of these rights in the context of TB is set out below:

<sup>6</sup> Note that this is also closely related to the concept of accessibility of health information.

<sup>7</sup> South Africa ratified the ACHPR on 09 July 1996. See: African Commission on Human and Peoples' Rights: <http://www.achpr.org/instruments/achpr/ratification/>. The several provisions directly relevant for equality and non-discrimination include Article 2 which requires that 'every individual shall be entitled to the enjoyment of rights and freedoms... without distinction of any kind', and Article 3(1) which states that 'every individual shall be equal before the law'. Article 13(2) provides for equal access of citizens to public services, while Article 13(3) states that 'every individual shall have the right of access to public property in strict equality of all persons before the law'. The duties set out in the Charter include the duty of individuals to 'respect and consider his [sic] fellow beings without discrimination'. The equality of peoples is further recognised in Article 22 that guarantees the right to economic, social and cultural development of all peoples with due regard to their freedom and identity to 'equal enjoyment of the common heritage of mankind'. See: South African Human Rights Commission, Research Brief on Gender And Equality In South Africa 2013 – 2017, p8

RIGHT<sup>8</sup>

## INTERNATIONAL &amp; REGIONAL TREATIES

## MEANING OF RIGHT IN CONTEXT OF TB

## RIGHT TO LIFE

ICCPR 6(1): Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

ACHPR (4) Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right.

People with TB have the right to be protected from ill-health and to access life-saving diagnostics and treatment. Key populations - such as prisoners, health workers, people who use drugs, should be provided with diagnostics and treatment and not denied treatment.

## RIGHT TO HIGHEST ATTAINABLE STANDARD OF PHYSICAL AND MENTAL HEALTH

ICESCR 12(1): Everyone has the right to enjoyment of the highest attainable standard of physical and mental health including state obligations to: • improve environmental and industrial hygiene; • prevent, treat and control epidemic, endemic, occupational and other diseases; • create conditions which would assure to all medical service and medical attention in the event of sickness.

ACHPR 16(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health.

16(2) State parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.

People with TB have the right to available, accessible and acceptable good-quality diagnostics and treatment on a non-discriminatory basis. Denial of access to non-discriminatory quality TB treatment – e.g. in prison, for people with MDR-TB, for marginalised populations – violates this right.

## RIGHT TO ENJOY THE BENEFITS OF SCIENTIFIC PROGRESS

ICESCR 15(1)(b): Everyone has the right to enjoy the benefits of scientific progress and its applications.

People with TB have the right to be able to access the most effective diagnosis and treatment measures. In

resource-constrained settings, some people may have limited access to high-quality diagnostic services and first- and second-line medicines for treatment; restrictive intellectual property regimes may also limit access to quality, affordable anti-TB medicines.

## RIGHT TO NON-DISCRIMINATION AND EQUALITY

ICCPR (26): All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

ACHPR (2): Every individual shall be entitled to the enjoyment of the rights and freedoms recognised and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex,

language, religion, political or any other opinion, national and social origin, fortune, birth or other status. Legal frameworks should prohibit discrimination against people with TB in both public and private settings, including, but not limited to, health care, employment, education, and access to social services.

People with TB should not be refused medical treatment on or denied and fired from jobs on the basis of their TB status.



RIGHT	INTERNATIONAL & REGIONAL TREATIES	MEANING OF RIGHT IN CONTEXT OF TB
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RIGHT TO PRIVACY	ICCPR 17(1):	
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No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

Information related to an individual's TB status and treatment must be kept private and shall not be disclosed to any party, unless approved by appropriate medical professionals under narrowly and expressly

tailored circumstances enumerated in law, including to protect third parties who are at serious and imminent risk of infection and to share essential health information with medical professionals providing care to the patient.

Information about a patient's migrant, HIV drug use or other status should also be kept confidential.

RIGHT TO WORK		
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ICESCR 7(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of just and favourable conditions of work which ensure, in particular... (a)(i) Fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work; (ii) A decent living for themselves and their families in accordance with the provisions of the present Covenant; (b) Safe and healthy working conditions; (c) Equal opportunity for everyone to be promoted in his employment to an appropriate higher level, subject to no considerations other than

those of seniority and competence; (d ) Rest, leisure and reasonable limitation of working hours and periodic holidays with pay, as well as remuneration for public holidays

ACHPR (15) Every individual shall have the right to work under equitable and satisfactory conditions and shall receive equal pay for equal work.

Employees have the right to safe working conditions that protect them from TB exposure; employees with TB also have the right to fair treatment at work, not to be dismissed or denied employment simply on the basis of their TB status or history.

RIGHT TO BE FREE FROM TORTURE OR CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT		
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CAT 16(1): ...prevent ...other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article I [of CAT], when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.

Prisoners with TB and those at risk of contracting the disease in prison should be provided with appropriate

TB testing and treatment during detention and appropriate prison conditions to avoid transmission of the disease.

People with TB who use drugs should have access to substitution treatment or other form of drug treatment if hospitalized for TB treatment, so as not to be forced into withdrawal.

RIGHT TO INFORMED CONSENT		
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The right to informed consent is defined by the Special Rapporteur as the right of everyone to the enjoyment of the highest attainable standard of physical and mental health as an essential part of the national obligation to respect, protect and fulfil an individual's right to health.

People with TB shall have the right to informed consent prior to testing and treatment for TB and the right to be free from non-consensual, compulsory testing and/or treatment, including treatment with unapproved medication regimens, under all circumstances.

RIGHT	INTERNATIONAL & REGIONAL TREATIES	MEANING OF RIGHT IN CONTEXT OF TB
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RIGHT TO FREEDOM OF MOVEMENT		
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ICCPR 12(1): Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence; 12(2): Everyone shall be free to leave any country, including his own; 12(4): No one shall be arbitrarily deprived of the right to enter his own country.

ACHPR 12(1) Every individual shall have the right to freedom of movement and residence within the borders of a State provided he abides by the law. 12(2)

Every individual shall have the right to leave any country including his own, and to return to his country.

People with TB shall be free to move within and outside the country and able to receive free treatment in the location where they reside. They should not be unnecessarily isolated, quarantined or detained, refused treatment because they are not in a specific location or because they lack identity documents in a country.

RIGHT TO INFORMATION		
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ICCPR 19(2): Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.

ACHPR (9) Every individual shall have the right to receive information. Every individual shall have the right to express and disseminate his opinions within the law.

Individuals who undergo TB testing should receive basic information about the nature of TB and why they are being tested. Individuals who are offered TB treatment should be given information about the risks and benefits of the proposed interventions (for both the patient and others in the community), the importance of completing the full course of treatment and of infection control measures, and available support to help patients complete the full course of treatment.

RIGHT TO FREEDOM FROM ARBITRARY ARREST AND DETENTION		
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ICCPR 9(1): Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.

ACHPR (6) Every individual shall have the right to liberty and to the security of his person. No one may be deprived of his freedom except for reasons and conditions previously laid down by law. In particular, no one may be arbitrarily arrested or detained.

People with TB shall have the right to liberty and to freedom from arbitrary detention, including involuntary detention or isolation of contagious persons, except in exceptional circumstances enumerated in law and proportional to what is strictly necessary, using the least restrictive and intrusive means available to achieve legitimate public health aims. People with TB should not be detained or imprisoned in nonmedical facilities for failure to adhere to treatment

RIGHT TO A FAIR TRIAL, DUE PROCESS	ICCPR 14(1):	
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All persons shall be equal before the courts and tribunals. In the determination of any criminal charge against him, or of his rights and obligations in a suit at law, everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law.

ICCPR 14(3): In the determination of any criminal charge against him, everyone shall be entitled to... minimum guarantees, in full equality.

People with TB who have had their right to liberty restricted through involuntary detention or isolation shall have the right to due process, including the right to be heard by an independent authority, the right to appeal the decision to detain or isolate, and the right to have counsel during the proceedings.



RIGHT <sup>8</sup>	INTERNATIONAL & REGIONAL TREATIES	MEANING OF RIGHT IN CONTEXT OF TB
<b>RIGHT TO PARTICIPATION</b>		
Participation is a key principle of human rights-based approaches to health		People with TB and former TB patients have the right to participate in decision-making processes affecting their health, including the design, development and implementation of health services.
<b>RIGHT TO ACCESS TO AN ADEQUATE, EFFECTIVE AND PROMPT REMEDY</b>		
This right is instrumental in providing redress for individuals whose rights have been violated; it is an integral part of the respect, protect and fulfil obligations.		People with TB shall have access to an adequate, effective and prompt remedy under the law for the infringements and violations of their rights. This is especially important for marginalized populations who may not be able to afford legal support services.

Table 5: Rights and TB in South Africa

**The Trade-Related Aspects of Intellectual Property Rights (TRIPS) Agreement** protects and enforces intellectual property rights, including rights to patented medicines such as those for TB, across the world. All World Trade Organization members, with the exception of least developed countries, are required to provide a minimum of 20 years' patent protection. This results in limited competition and higher costs for medicines, with particularly onerous consequences for poorer, high-burden TB countries. The 2001 Doha Declaration on TRIPS and Public Health provided for the rights of member countries to use "flexibilities" in the application of TRIPS, to "promote access to medicines for all" for e.g. through defining standards of patentability for medicines, allowing for the production of generic medicines and the issuing of compulsory licences. South Africa has effectively used competition law to reduce the price of medicines for HIV and is able to use these flexibilities to increase access to diagnostics and medicines for TB, including the production of domestic generic medicines.

Other international and regional conventions protect the rights of specific populations, including populations who are vulnerable and at risk of TB infection. These

conventions elaborate the equality, health, employment and other rights of vulnerable populations:

**The International Convention on the Rights of Persons with Disabilities, 2006** (monitored by the Committee on the Rights of Persons with Disabilities) aims to promote the equality rights of persons with disabilities to ensure their meaningful participation in society and their development as persons. It provides, among other things, for the health rights of persons with disabilities. Article 5(2) prohibits all discrimination on the basis of disability and guarantees to persons with disabilities equal and effective legal protection against discrimination on all grounds, providing for the equality rights in health care, education and employment, among others, of all persons with TB who may experience temporary or permanent disability as a result of TB.

**The Convention on the Rights of the Child, 1989** and its optional protocols (monitored by the Committee on the Rights of the Child (CRC)) protects the rights of all children to non-discrimination, participation and development to ensure that the best interests of the child are paramount in all matters affecting children. A child's right to equality, including gender equality, and non-discrimination is a central tenet of the CRC and is

key for the full realisation of children's rights.<sup>8</sup> The right applies to all young people below the age of 18 years.

**The International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, 1990** (monitored by the Committee on Migrant Workers) protects the rights of migrant workers. Article 7 protects their rights to non-discrimination, Article 10 protects them from cruel, inhuman or degrading treatment or punishment; Article 14 protects their privacy rights and Article 28 protects their right to receive any medical care that is urgently required for the preservation of their life or the avoidance of irreparable harm to their health, on the basis of equality of treatment with nationals. These rights protect migrant workers in the context of TB in the same way as those set out in the table, above.

**The Convention on the Elimination of All Forms of Discrimination against Women, 1979** and its optional protocol, 1999 (monitored by the Committee on the Elimination of Discrimination against Women) commits states to take various measures to end gender inequality, including in access to healthcare, supporting gender-sensitive responses to TB that recognise the ways in which gender, and gender inequality, impact on health care needs of women in the context of TB.

**The United Nations Standard Minimum Rules for the Treatment of Prisoners (the Mandela Rules)** provide for the rights of prisoners to be treated with respect and dignity, to be protected from torture and other cruel, inhuman or degrading treatment or punishment and to conditions of dignity, including reasonable accommodation that meets the requirements of health (Rule 12), access to health care services at the same standards that are available in the community (Rule 24), transfer to specialised medical services where necessary (Rule 27) and the right to medical confidentiality (Rule 26), among other things. These Standards protect the health and related rights of prisoners, including their right to be protected from TB infection and to receive treatment for TB.

**The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (the Maputo Protocol):** The Maputo Protocol provides for the protection of women and girl children, as well as for the eradication of discrimination against women. Significantly, the Women's Protocol includes commitments towards the elimination of harmful cultural practices and specifically recognises the sexual and reproductive health rights of women,<sup>9</sup> hereby protecting women from HIV and its co-infections, including TB.

<sup>8</sup> Adapted from Stop TB Partnership & UNDP (2017) Legal Environment Assessments for Tuberculosis: An Operational Guide.

<sup>9</sup> South Africa ratified the CRC on 16 Jun 1995. The CRC is built around key general principles including 'non-discrimination' which is stated in Article 2. See also Save the Children, Resource centre, Gender Equality, <https://resourcecentre.savethechildren.net/our-thematic-areas/cross-thematic-areas/gender-equality> accessed 18 October 2018



EQUALITY



**The African Charter on the Rights and Welfare of the Child** (monitored by the Committee of Experts on the Rights and Welfare of the Child) sets out the rights of the African child, including the rights to equality, non-discrimination, education and health, among others.<sup>10</sup>

At national level, the Constitution and national laws, including anti-discrimination laws, health laws, employment laws and criminal laws, among others, also contain important provisions in the context of TB-related healthcare for vulnerable and key populations.

### 6.1.1 Domestic Legal and Policy Framework

**The Constitution:** The Constitution of the Republic of South Africa is supreme law and forms the ‘bedrock’ upon which the national TB response is based. It binds all parties (public and private) and places an obligation on them to respect, promote, protect and fulfil the rights enshrined in the Bill of Rights. It also sets out the standards that all laws, policies and conduct must comply with. Below we set out some of the relevant provisions of the Constitution.

**Equality and human dignity:** These rights are enshrined in section 9 and section 10 respectively. While TB is not specifically mentioned as a protected ground for non-discrimination, there is ample evidence of the protection of the rights of persons to non-discrimination on the basis of their health status in South African jurisprudence.<sup>11</sup> The Constitution furthermore specifically prohibits discrimination on the basis of sexual orientation, which protects the rights of sexual minorities.

**Health:** Section 27 of the Constitution provides all persons with the right to access to healthcare services. This right has been interpreted to include the right to treatment and medicines, the right to healthcare services, the right to emergency medical treatment and the right to be free from stigma and discrimination on

the basis of health status.<sup>12</sup> It applies equally to people in the context of TB, guaranteeing the right to healthcare services for TB without discrimination.

**Fair labour practices:** Section 23(1) of the Constitution also provides that “everyone has the right to fair labour practices”. These rights are the basis for protecting all people – including employees such as farm workers, healthcare workers and miners, among others - against unfair discrimination, including within the workplace. This is important for employees with TB who experience discriminatory treatment – including denial of jobs or dismissals – based on their TB status or TB history. In addition, section 24 of the Constitution states that “everyone has the right to an environment that is not harmful to their health or well-being”. This strengthens the right to a safe working environment, necessary to prevent accidents and injuries and to protect workers from contracting occupational diseases (Hassim, Heywood, and Berger 2007). All employees have the right to be protected from exposure to TB within the working environment.

**Right to legal remedy:** Section 34 guarantees the right of every person to access to courts.<sup>13</sup> This guarantees access to justice for people living with TB, as well as vulnerable and key populations, whose rights have been violated.

**Values governing public administration:** Section 195 of the Constitution sets out the basic values and principles governing public administration, which must be governed by the democratic values and principles enshrined in the Constitution, including professional ethics, effective use of resources, fair and equitable services, accountability and transparency, among other things. This guarantees all persons, including those with TB, access to fair and equitable public services.

The Constitution furthermore protects other important human rights that protect people with TB, vulnerable

and key populations from discriminatory and punitive laws, policies and practices in the context of TB, including the rights to privacy, liberty and security of the person, protection from cruel, inhuman and degrading treatment of punishment, freedom of expression and freedom of movement. The relevance of these rights in the context of TB has been detailed in the table, above.

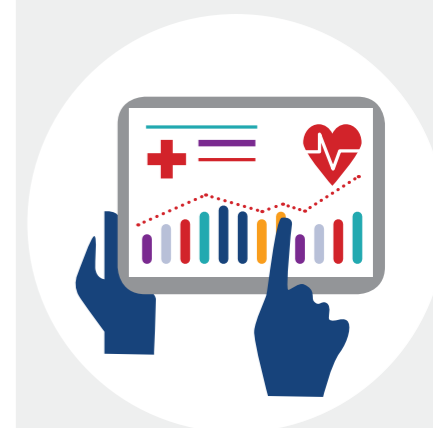
Human rights are interconnected, interdependent and indivisible,<sup>14</sup> and the failure to realise a basic right – such as the right to information, e.g. health information or information regarding legal rights and redress mechanisms – may impact on the realisation of other rights, such as the right to health or the right to access remedies for violations. An enabling legal and regulatory framework for the rights of people in the context of TB requires recognition of the need to respect, protect, promote and fulfil civil, political, socioeconomic and cultural rights, in order to protect and promote the health and well-being of all persons.

Several laws have been enacted in order to give effect to these constitutional rights. The section below sets out some of the main pieces of legislation and important policies as they relate to health. However, since several rights are invoked, we also provide an outline of non-health, but relevant legislation and policies. Laws, regulations and policies relevant to gender and to specific key populations are dealt with in separate sections, below.

### 6.1.2 Health laws, plans, policies, guidelines and structures

**The National Health Act 61 of 2003** regulates the provision of health care in South Africa. It also sets out the rights of health users, such as the right to equality in access to healthcare,<sup>15</sup> the right to have full knowledge of one’s condition, to participate in decisions regarding one’s health, to consent to healthcare services<sup>16</sup> and the right to medical confidentiality,<sup>17</sup> among other things. It also provides for the right to lay complaints about unprofessional healthcare services.<sup>18</sup>

The **Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions 2017**, published in terms of the National Health Act, 2003 include TB (including MDR-TB) as a Schedule 2 notifiable condition. This means that full nominal reporting is required to provincial and national public health authorities. It also provides that persons with TB may be subject to mandatory medical examinations and treatment or confinement in a medical facility, un-



## HEALTHCARE PLANS & POLICIES

<sup>10</sup> South Africa ratified the Maputo Protocol on 17 December 2004. See Article 5 of the Maputo Protocol

<sup>11</sup> See *Hoffmann v South African Airways* (CCT 17/00) [2000] ZACC 17 in terms of which the court determined that discrimination on the basis of a person’s HIV status within the working environment amounted to unfair discrimination.

<sup>12</sup> Health Rights, Issues and Recommendations, Joint Submission of Health Stakeholders in South Africa to the United Nations Committee on Economic, Social and Cultural Rights, 64th Session, 24 September 12 October 2018, [https://tbinternet.ohchr.org/Treaties/CESCR/Shared%20Documents/ZAF/INT\\_CESCR\\_CSS\\_ZAF\\_32292\\_E.pdf](https://tbinternet.ohchr.org/Treaties/CESCR/Shared%20Documents/ZAF/INT_CESCR_CSS_ZAF_32292_E.pdf)

<sup>13</sup> Section 34 SA Constitution: Everyone has the right to have any legal problem or case decided by a court or an independent body.

<sup>14</sup> See *Government of the Republic of South Africa and Others v Grootboom and Others* [2000] ZACC 19, 2001 (1) SA 46 (CC).

<sup>15</sup> Section 2

<sup>16</sup> Sections 6 and 7.

<sup>17</sup> Section 14.

<sup>18</sup> Section 18.



## EQUALITY & ANTI-DISCRIMINATION

der exceptional circumstances, only as a measure of last resort and in terms of a court order. Since these regulations have only recently been gazetted, it is unclear how they will be implemented, how they may impact on contact tracing for TB and on encouraging access to healthcare more broadly.

**The Medicines and Related Substances Act 101 of 1965** regulates the registration and control of medicines and related substances in South Africa, including medicines for HIV and TB. The Act also identifies many commonly used addictive substances (like heroin and crystal methamphetamine) as illegal, criminalising their use. Laws criminalising drug use impact on people who inject drugs - who are at high risk of HIV and its co-infections, including TB - and create barriers to their access to healthcare services, detailed further below.

The Act, as amended by Act 72 of 2008 and Act 14 of 2015, establishes the **South African Health Products Regulatory Authority (SAHPRA)**, which replaced the Medicines Control Council in February 2018. SAHPRA will be responsible for monitoring, evaluation, regulation, investigation, inspection, registration and control of medicines, scheduled substances, clinical trials, medical devices and related matters, to ensure access to safe, effective, good quality medicines and medical devices. It aims for improved transparency, accountability and communication. It has also committed to reviewing its procedures and processes to streamline applications for unregistered medicines, to deal with the backlogs in applications for new and generic medicines within 2 years and to prioritise the review of applications of products that address public health needs and emergencies, unmet medical needs as well as shortages of medicines in the marketplace. It is hoped that this will help to increase access to medicines, including generic medicines, for TB.

**The National Strategic Plan 2017 – 2022** outlines South Africa's response to HIV and TB. It includes a comprehensive response to TB, including providing for information and social behaviour change communication around TB. It also commits to taking steps to promoting the rights to equality of all people with HIV, TB and vulnerable and key populations and to reduce TB-related stigma and discrimination within society (including within the healthcare setting and the working environment).

**The National TB Management Guidelines 2014** developed by the National Department of Health aim to support and guide clinicians and healthcare workers in the management of tuberculosis, including cases of TB and HIV co-infection. They provide for the various key interventions, not all of which are discussed here; importantly in terms of this research findings, the Guidelines make provision for counselling of TB patients at defined intervals during the treatment period as well as for training of healthcare workers, including counselling training for community health workers.

Furthermore, the Guidelines acknowledge the needs of and provide for key populations, including healthcare workers, TB index patient household contacts and people who use substances or alcohol. The Guidelines provide for specific measures to protect healthcare workers from occupational infection, including regular screening and infection control at all levels as well as provisions for time off for healthcare workers with TB. Notably, the Guidelines provide all patients with the right to confidentiality with regard to TB and its management, although they stress the importance of disclosing to "contacts" that have been exposed to TB.

The guidelines for the **Management of Tuberculosis, Human Immunodeficiency Virus and Sexually-transmitted Infections in Correctional Facilities 2013** set out screening, treatment and prevention requirements in correctional facilities and for TB-affected inmates being released from correctional facilities.

**The Multidrug-Resistant Tuberculosis Policy Framework on Decentralised and Deinstitutionalised Management for South Africa 2011** provides a framework for improving drug-resistant TB care by decentralising and deinstitutionalising care and treatment for drug-resistant TB, in order to reduce the length of time that patients are required to stay in centralised drug-resistant TB hospitals and to allow health facilities and communities to manage MDR-TB patients closer to their homes. It describes the framework, organisational structures and human resources required and the expected functions of each level of operations and includes provision for centralised DR-TB units at provincial level, decentralised DR-TB units, satellite MDR-TB units and community support through mobile teams and community caregivers.

The **Operational Guidelines for HIV, STIs and TB Programmes for Key Populations in South Africa 2012** set out a human rights-based approach to service delivery for HIV key populations. This document was designed to provide guidance to the 2012-2016 NSP. While the document includes TB in its title, TB is dealt with in terms of the way it relates to HIV. Thus, while important issues are raised – including gaps in service provision and considerations for working with the listed HIV key populations – attention to the specifics of TB in key populations is missing.

**The Management of Drug-Resistant Tuberculosis: Policy Guidelines (2013)** provide guidance on the management of DR-TB, including special measures for key populations such as patients who abuse alcohol or drugs, women, TB index patients and healthcare workers. The Guidelines also include protection for the employment rights of healthcare workers who contract drug-resistant TB at work (dealt with in further detail, below).

The 2013 Policy Guidelines furthermore detail infection control measures specifically for TB, supplementing the various **infection control policies** that have been developed in the healthcare sector to promote occupational health and safety (dealt with in further detail, below).<sup>19</sup>

The **Office of Health Standards Compliance (OHSC)** is an independent body established in terms of the National Health Amendment Act of 2013 to ensure that both public and private health establishments in South Africa comply with the required health standards. It aims to protect and promote the health and safety of users of health services by monitoring and enforcing compliance by health establishments with norms and standards and investigating complaints relating to non-compliance. The **Office of Health Ombud** is located within the OHSC and responsible for considering, investigating and disposing of complaints from the public relating to breaches of norms and standards, reporting findings to the complainant and health establishment and making recommendations for action. The OHSC and Health Ombud therefore have a critical role in promoting compliance with the various norms and standards set out for the management of TB, including complaints regarding non-compliance in all facilities, and recommendations for the review of these standards.

<sup>19</sup> E.g. South African National Tuberculosis Infection Control Guideline (2007); National Core Standards for Health Establishments in South Africa (2011); National Strategic Plan on HIV, STIs and TB (2012-2016); Management of Drug-Resistant Tuberculosis. Policy Guidelines (2013); National Tuberculosis Management Guidelines (2014); National Infection Prevention and Control Guidelines for TB, MDR-TB and XDR-TB (2015).



### 6.1.3 Equality and Anti-discrimination

**The Promotion of Equality and Prevention of Unfair Discrimination Act, 4 of 2000 (PEPUDA):** This Act is the national legislation mandated by section 9(4) of the Constitution, and thus enjoys special constitutional status. It elaborates on the constitutional guarantee of equality, providing detailed protection for the rights of all persons. Significantly, it recognises the need to address systemic discrimination and specifically aims at the 'eradication of social and economic inequalities'.

### 6.1.4 Labour laws

**The Labour Relations Act 66 of 1995 (LRA)** regulates the employment relationship, providing for an employee's right to fair labour practices, prohibiting discriminatory acts in the workplace and protecting workers from unfair dismissals – such as dismissals based on unfair discrimination. Section 185 of the Act provides every employee – including employees with TB – with the right not to be unfairly dismissed or subjected to an unfair labour practice. Dismissals based on an arbitrary ground are automatically unfair dismissals; other unfair dismissals are dismissals that do not relate to a person's conduct, capacity to work or the operational requirements of the employer, in terms of s187 and s188. Unfair labour practices include unfair conduct relating to promotions and demotions, unfair suspensions and unfairly failing to reinstate an employee. These provisions protect employees with TB from being treated unfairly or dismissed in the workplace simply on the basis of their TB status or TB history, without regard to their capacity to work. The **Public Service Act 103 of 1994** and regulations to the Act regulate the employment conditions of employees within the public service, ensuring their rights to fair labour practices.

**The Basic Conditions of Employment Act 75 of 1997** provides for the minimum conditions of employment to which all employees are entitled. It regulates matters such as sick leave and termination of employment, among other things, to protect the labour rights of all employees, including those with ill health. These provisions protect employees with TB by providing them with the right to paid sick leave during periods of illness.

**The Employment Equity Act 55 of 1998 (EEA)** aims to promote equal opportunity and fair treatment in employment through the elimination of unfair discrimination. Section 6 of the Act provides that no person may unfairly discriminate against an employee or job applicant in any employment policy or practice on the basis of various listed 'grounds', unless meeting that criteria is an inherent requirement of the position. While TB status is not specifically listed as a ground for non-discrimination (HIV status is), it is not a closed list. This provision could arguably protect a person from unfair discrimination on the basis of his or her TB status.

**The Occupational Health and Safety Act 85 of 1993 (OHSA):** The Act places a general obligation on employers to provide and maintain a working environment that is safe and without risk to the health of their employees. OHSA sets out the rights of employees (which would include farm workers and healthcare workers) to a safe working environment and to receive information and training on health and safety measures. Employers have a duty to provide a safe environment, including organising work, equipment and machinery in such a way that they are safe, providing information and training and enforcing the necessary health and safety measures.<sup>20</sup> In the context of TB, this means that employers have a duty to take steps to ensure conditions at work do not place employees at higher risk of TB infection - e.g. by reducing risks such as poor ventilation and by providing equipment and training to support employees to use infection control measures in the health care environment, for instance (detailed further below in the section on healthcare workers). **The Hazardous Biological Substances Regulations** promulgated in terms of OHSA provide further detail on workplace safety and controls for workers exposed to biological agents.

**The Mines and Works Act 27 of 1956** and the **Mine Health and Safety Act 29 of 1996** protect the occupational health and safety of mineworkers. In the case of *Nkala and Others v Harmony Gold Mining Company Limited and Others* the court found that mining companies were obliged to take reasonable measures to provide a safe and healthy work environment and to take rea-

<sup>20</sup> Section 8, Occupational Health and Safety Act 83 of 1995.

sonable care for the safety of persons entering the mines, in terms of the constitutional rights of all persons to equality, dignity, bodily integrity and the right to an environment not harmful to their health; the common law duty of care and their statutory obligations in terms of the Mines and Works Act 12 of 1911, the Mine Health and Safety Act 29 of 1996 and accompanying regulations.<sup>21</sup>

**The Compensation for Occupational Injuries and Diseases Act 130 of 1993 (COIDA)** provides employees with compensation for disability or death caused by occupational injuries or diseases. In terms of the Act, the Compensation Commissioner is held liable for any occupational injuries or diseases instead of the employer. Workers who are injured on duty or who contract an occupational disease can claim compensation for temporary or permanent disablement in terms of the COIDA. If workers die as a result of injury on duty, their dependants will also be entitled to claim compensation.

**The Occupational Diseases in Mines and Works Act, 1973 and Occupational Diseases in Mines and Works Amendment Act 1993** regulates the payment of compensation in respect of particular diseases contracted by persons who work in mines. The Act identifies TB as one of the compensable diseases and sets out the circumstances under which compensation may be awarded. This is important due to the high risk of exposure to TB in the mining sector. Miners who develop TB at work or within a period of time after leaving work can claim compensation when they lose earnings and have impaired lung function.<sup>22</sup> The gold mining sector's collective bargaining agreement (2007) further provides for additional paid sick leave (up to six months) for employees undergoing treatment for TB.<sup>23</sup>

### 6.1.5 Prisons

**The Correctional Services Act No 111 of 1998, as amended by the Correctional Services Amendment Act 32 of 2001** gives effect to the Bill of Rights in the Constitution of 1996, and in particular its provisions with regards to the inmates of correctional facilities. It regulates among other aspects, the custody of all inmates under conditions of human dignity and the access to healthcare for inmates. This is critical due to the fact that the prison environment and conditions - overcrowding, congestion, poor ventilation, poor nutrition - may place prisoners at high risk of TB exposure and infection; prisoners have a right to be protected from ill health within the prison environment. Section 6 of the Correctional Services Act requires

<sup>21</sup> *Nkala and Others v Harmony Gold Mining Company Limited and Others* (48226/12, 31324/12, 31326/12, 31327/12, 48226/12, 08108/13) [2016] ZAGPJHC 97; [2016] 3 All SA 233 (GJ); 2016 (7) BCLR 881 (GJ); 2016 (5) SA 240 (GJ) (13 May 2016) <http://www.saflii.org/cgi-bin/disp.pl?file=za/cases/ZAGPJHC/2016/97.html&query=%20sonke%20gender%20justice>

<sup>22</sup> <https://www.soulcity.org.za/projects/tuberculosis/research/literature-review-on-tuberculosis-in-south-africa.pdf>

<sup>23</sup> Chamber of Mines of South Africa, 2017



GENDER EQUALITY



# GENDER INEQUALITY AND GENDER BASED VIOLENCE

INCREASE  
VULNERABILITY TO  
HIV, TB AND STIS.

that all inmates must be medically assessed on admission, and section 7(1) provides for conditions of human dignity: “prisoners must be held in cells which meet the requirements prescribed by regulation in respect of floor space, cubic capacity, lighting, ventilation, sanitary installations and general health conditions. These requirements must be adequate for detention under conditions of human dignity.” The implementation of these provisions is critical to protect the health of inmates and to decrease their risk of exposure to TB.<sup>24</sup> These provisions protect the health of inmates.

In the unreported case of *Sonke Gender Justice v. The Government of the Republic of South Africa* of 2016,<sup>25</sup> the court declared the conditions of detention in Pollsmoor prison to be a violation of detainees’ constitutional rights to health and conditions of detention consistent with human dignity. The court ordered the government to reduce overcrowding to no more than 150% of its approved capacity within six months and ordered the Department of Correctional Services to develop a plan for rectifying detention conditions and to report to the court regularly on inspections of cell accommodation.

## 6.1.6 Social Assistance

The **Social Assistance Act 13 of 2004 and Regulations** give effect to the section 27 (1)(c) of the South African Constitution by providing for the rendering of social assistance to persons, and mechanisms for the rendering of such assistance. People who are unable to work are entitled to disability grants and this would apply equally to persons unable to work due to TB.

## 6.2 Laws, regulations and policies impacting on gender equality, harmful gender norms and gender-based violence

At international and regional levels, South Africa has ratified several binding conventions relevant to protecting gender equality, many of which have been set out above. South Africa has also signed the **Southern African Development Community’s Protocol on Gender and Development in 2008**. While it is not binding, this Protocol nevertheless recognises the importance of gender equality for the development of persons, highlights a regional commitment to achieving gender equality and encourages states to take measures to fulfil this commitment.<sup>26</sup>

At national level, various laws protect the right to gender equality and work towards prohibiting harmful gender norms and gender-based violence.

<sup>24</sup> The Judicial Inspectorate for Correctional Services Annual Report for The Period 01 April 2015 To 31 March 2016 <https://africacheck.org/wp-content/uploads/2017/05/JICS-Annual-Report-2015-2016-as-at-4-October-2016-v-12.pdf>

<sup>25</sup> *Sonke Gender Justice vs RSA*, [http://www.southernafricalitigationcentre.org/wp-content/uploads/2017/03/Sonke-Gender-Justice-v-the-Government\\_SA\\_2017.pdf](http://www.southernafricalitigationcentre.org/wp-content/uploads/2017/03/Sonke-Gender-Justice-v-the-Government_SA_2017.pdf)

<sup>26</sup> South African Human Rights Commission, *Research Brief on Gender And Equality In South Africa 2013 – 2017*, p. 8

**The Promotion of Equality and Prevention of Unfair Discrimination Act, 4 of 2000**, as set out above, protects the rights of all persons to equality and non-discrimination. Section 13 stipulates that discrimination based on the prohibited ground of gender is presumed to be unfair discrimination unless established to be fair. Section 8 stipulates that no person may unfairly discriminate against any person on the ground of gender, with specific reference to (i) gender-based violence;<sup>27</sup> (ii) any practice, including traditional, customary or religious practice, which impairs the dignity of women and undermines equality between women and men, including the undermining of the dignity and well-being of the girl child;<sup>28</sup> and (iii) limiting women’s access to social services or benefits, such as health, education and social security.<sup>29</sup>

**The Domestic Violence Act 116 of 1998** protects women from domestic violence, providing victims with accessible legal remedies to prevent abuse and claim redress and obliging law enforcers to take measures to protect women. The Act extends the definition of domestic violence to include not only married women and their children, but also unmarried women who are involved in relationships or living with their partners, people in same-sex relationships, mothers and their sons, and other people who co-habit. It should apply equally to transgender women.

**The Gender Equality and Women’s Empowerment Bill, 2013** aims to strengthen gender equality and the participation of women in society. It calls for the progressive realisation of at least 50% representation of women in decision-making structures and the improvement of access to education, training and skills development. It also aims to promote and protect women’s reproductive health, and eliminate discrimination and harmful practices, including gender-based violence. Once more, this should also include protection for transgender women.

Sex work is criminalised in South Africa in terms of the **Sexual Offences Act 23, 1957** which provides that any individual who has “unlawful carnal intercourse or

<sup>27</sup> Section 8(a)

<sup>28</sup> Section 8(d)

<sup>29</sup> Section 8(g).

an act of indecency with any other person for reward commits an offence”. The various provisions of the Act make selling sex, brothel keeping, solicitation, indecent exposure, and knowingly living from the proceeds of sex work illegal. Furthermore, the provisions of the **Sexual Offences and Related Matters Amendment Act, 2007** also criminalise clients who engage the services of sex workers. Sex workers are at high risk of HIV exposure and its co-infections, including TB; however, laws criminalising sex work impact on their ability to access services - including health care services.

The **NSP 2017-2022** has a strong gender focus, recognising that gender inequality and gender-based violence increase vulnerability to HIV, TB and STIs. In particular, it focuses on the impact of gender-based violence on HIV transmission and envisions an extended response through the development of safe spaces and referral networks for affected women. It further aims to develop screening tools for specific health challenges characteristic of gender-based violence. The plan recognises that there is a lack of available information about gender and envisions routine general population surveillance through which data is collected and disaggregated by age and gender. Notably, it refers to the need for gender equality and gender sensitivity within national health responses; however, the emphasis on gender is largely concentrated in the aspects of the plan that deal with HIV, with limited attention paid to the impact of gender on TB vulnerability, diagnosis and care.

The **2014 National TB Treatment Guidelines** do not specifically refer to gender, other than providing guidance on the diagnosis and treatment of pregnant and breastfeeding women. The policy guidelines for the treatment of DR-TB only refer specifically to females when warning to provide contraception to women of childbearing age, due to the damage that treatment can cause to the foetus. No specific mention is made of gender minorities. The MDR-TB guidelines do, however, include a whole chapter on responding to healthcare workers affected by MDR-TB - the majority of whom are women (see Section 5).



## 6.3 Legal and policy frameworks for selected key populations

### 6.3.1 Farm dwellers

People who live on farms are not subject to any specific protective legislation. However, farm workers are protected by the broad rights set out in the Constitution, which apply to all persons, as well as a range of general labour-related legislation and health laws set out above. In terms of the Constitution and as further detailed in these national laws, farm workers have the rights to, among others, equality and non-discrimination, fair labour practices, occupational health and safety and compensation for occupational injuries and diseases as well as the rights of all persons to access to healthcare services.

In terms of national law, OHS Act applies to the agricultural sector, as set out above. Specifically, it obliges farmers employing more than 20 employees to appoint health and safety representatives. According to Section 7 of OHS Act, each farming enterprise/business has to prepare a written health and safety policy, signed by the owner/executive officer concerning the protection of the health and safety of his employees at work, which must be prominently displayed in the workplace where farm workers normally report for service.

### 6.3.2 Healthcare workers

HCWs are, like farmworkers protected by the broad rights set out in the Constitution as well as by the range of general labour-related legislation and health laws, as set out above. These protect the rights of HCWs to fair labour practices, non-discrimination in the workplace as well as protection from occupational injury and disease.

The **National Health Act 61 of 2003** also deals with occupational health and safety specifically within the healthcare sector. These provisions should be read with the OHS Act to govern safety at work. It provides that health establishments must implement measures that minimise injury or damage to the person or property of HCWs. This means that HCWs must be protected from physical harm and their working environment

made safe and free from any hazardous incidents.<sup>30</sup> The National Health Act establishes an Inspectorate for Health Establishments to ensure compliance with these standards.

Various infection control policies have been developed in the healthcare sector to give effect to these legal provisions.<sup>31</sup> Specifically in relation to TB, the **Management of Drug-Resistant Tuberculosis: Policy Guidelines** focus on the clinical management, referral mechanisms and models of care and cover psychosocial support to ensure comprehensive management of patients, strategies for infection prevention and control, and occupational health services for healthcare workers (HCWs).<sup>32</sup> These guidelines provide, among others, that the management of MDR-TB will be conducted in dedicated MDR-TB units, in other health care facilities and in the community by trained healthcare workers in an environment with appropriate infection control measures to prevent nosocomial transmission of DR-TB.<sup>33</sup> The newly released **Policy Framework and Strategy for Ward-Based Primary Health Care Outreach Teams (2018)** aims to support community health workers, working with health professionals, to form the bridge between communities and health service provision within health facilities, to bring healthcare closer to communities. It contains important guidelines for strengthening the management and training of community health workers in various ways, including in terms of improved occupational health and safety processes.<sup>34</sup>

These Guidelines also provide additional protection for the labour rights of healthcare workers who contract drug-resistant TB through work: they note that “as a

<sup>30</sup> Hassim, Adila., Heywood, Mark., Berger, Jonathan (2007) Health & democracy: a guide to human rights, health law and policy in post-apartheid South Africa.

<sup>31</sup> These include the following: South African National Tuberculosis Infection Control Guideline (2007); National Core Standards for Health Establishments in South Africa (2011); National Strategic Plan on HIV, STIs and TB (2012-2016); Management of Drug-Resistant Tuberculosis. Policy Guidelines (2013); National Tuberculosis Management Guidelines (2014); National Infection Prevention and Control Guidelines for TB, MDR-TB and XDR-TB (2015).

<sup>32</sup> Management of Drug-Resistant Tuberculosis: Policy Guidelines (2011), p. vi

<sup>33</sup> Management of Drug-Resistant Tuberculosis: Policy Guidelines (2011), p. vi

<sup>34</sup> Goal 2, Objective 8.

general rule, HCWs who contract DR-TB through work should not be dismissed on the basis of incapacity at the expiry of their paid sick leave. A fair procedure should be followed, including an investigation into the nature and extent of the incapacity, the effects of treatment, and alternatives to dismissal. This would usually result in extended sick leave being granted. The provision of extended sick leave to an employee, at least on an unpaid basis or at less than full pay, in order to undergo treatment for MDR-TB would be regarded as fair. Fairness can only be tested in the circumstances of each particular case, and factors such as disability insurance and ill-health retirement benefits as alternatives would be relevant.”

There is currently a **Draft Policy on Occupational Health for Health Workers in respect of HIV and Tuberculosis**, developed to ensure a nationwide standard for the provision of occupational protection and occupational health services for health workers. The policy stresses information and procedures to manage the risk of occupational TB infection. Unlike labour laws, it includes protection for not only formal employees but also where appropriate, independent contractors, students and volunteers. The policy aims to set out minimum practicable standards in prevention and service provision and is restricted to activities relevant to occupational TB and HIV risk and the management of these conditions among health workers. This policy should contribute to the reduction of occupational TB beside the HIV infection risk and promote non-discriminatory care for health workers diagnosed with TB or HIV, including treatment and compensation.

Importantly for the healthcare sector, Schedule 3 of **COIDA** lists diseases that are occupational diseases (and thus presumed to have arisen during the course of work), and includes pulmonary TB acquired by healthcare workers.<sup>35</sup> Circular Instruction No. 178 of the Office of the Compensation Commissioner specifically defines compensation for occupationally acquired TB in HCWs: “Pulmonary Tuberculosis will be presumed to be work-related if Pulmonary Tuberculosis is transmitted to an employee during the performance of health care work from a patient suffering from active open tuberculosis or analysis or testing of infected body tissues or fluids”.<sup>36</sup> Extra-pulmonary TB, however, is not included. Additionally, the Hazardous Biological Agent Regulations recognise that TB acquired through occupational exposure in the healthcare setting is a compensable disease under COIDA, in the event of “transmission to an employee during the performance of health care work from a patient suffering from active open TB”.

When it comes to the specific duties of healthcare providers, such as their duties to their respective professions, to users of the health system and to the general public, various laws and policies regulate the professional

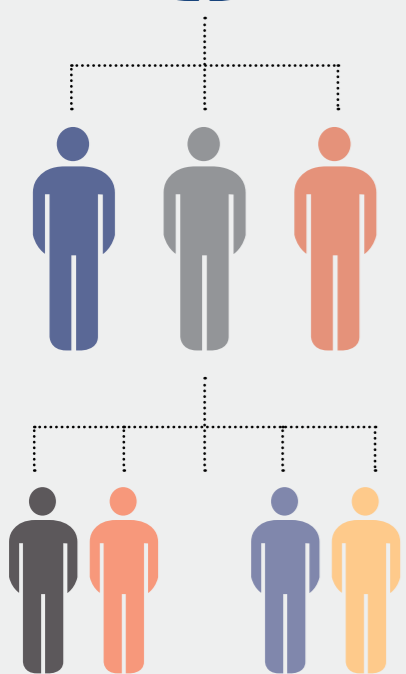
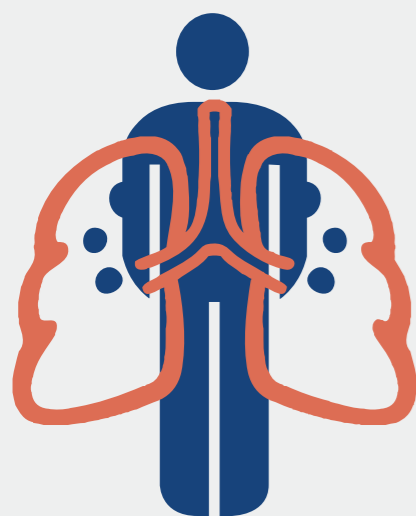
<sup>35</sup> Government Gazette Vol 469 of 16 July 2004, N 26585 See <http://www.labour.gov.za/DOL/legislation/regulations/compensation-for-occupational-injuries-and-diseases/regulations-and-notices>

<sup>36</sup> Saloshni Naidoo, Compensation reporting of occupationally acquired TB in health care workers in public sector hospitals, eThekweni Municipality, KwaZulu-Natal, 2006



PEOPLE WHO USE SUBSTANCES





CONTACTS OF TB-INDEX PATIENTS

conduct of healthcare providers, including the **Health Professions Act 56 of 1974**, the **Nursing Act 50 of 1978** and the **Batho Pele Principles, 1997**. HCWs are required to respect the rights of patients and may be disciplined for misconduct. This should, in principle, protect patients from unprofessional conduct by HCWs, including stigma, discrimination, coercive treatment and breaches of confidentiality, among others.

### 6.3.3 People who use substances

WHO have produced consolidated guidelines for an integrated package of HIV and TB care for people who use drugs,<sup>37</sup> guiding national health responses for people who use drugs. People who use drugs have the same rights as all persons, including the right to equality and non-discrimination and the right to access healthcare services. However, national drug laws and policies in South Africa are prohibitionist and punitive, supporting abstinence and justifying negative attitudes towards drug use and people who use drugs in the public healthcare sector. Newer policies and guidelines have started to move towards aligning with international standards for harm reduction for people who use drugs.

**The Medicines and Related Substances Act (Act 101 of 1965)** regulates medicines in the country. In terms of drugs, the Act draws on the UNODC 1961 Single Convention on Narcotic Drugs and the 1971 Convention on Psychotropic Substances, determining which substances are classified as illicit drugs and under what circumstances they are scheduled medicines. **The Drugs and Drug Trafficking Act No. 140 of 1992** criminalises the use of certain drugs scheduled in terms of the UN Conventions in South Africa. It provides for the prohibition of the use or possession of, or the dealing in, drugs, defining illegal acts, the roles and processes of law enforcement and penalties for drug use or possession. This Act predominantly guides law enforcement and sets up an overarching legislative framework in which all drug use and people who use drugs are criminalised. Laws criminalising drug use have been shown to create barriers to healthcare services for people who use drugs;<sup>38</sup> this would also impact on their access to TB-related healthcare services.

**The Prevention of and Treatment for Substance Abuse Act 70 of 2008** outlines the broader social and legislative response to substance use in South Africa, including the establishment, management and monitoring of inpatient treatment centres to rehabilitate people who use drugs, and the establishment of a Central Drug Authority (CDA) to act as an advisory body in relation to the management of substance abuse. The **Minimum Norms and Standards for Inpatient Treatment Centres** have been developed to support centres to standardise services, facilitate transfor-

mation and improve service quality,<sup>39</sup> and provide for informed consent for procedures and protection of patient confidentiality, unless disclosure is required in the case of sexual partners and parents.

Section 70 mandates the development of the National Drug Master Plan (NDMP) as a guiding national policy document, which should be renewed every five years. Section 70 mandates the development of the National Drug Master Plan (NDMP) as a guiding national policy document, which should be renewed every five years. Notably, the draft of the **NDMP (2018-2022)** provides for the national adoption of harm reduction programmes in line with international standards; however, it has yet to be finalised. The previous NDMP included the term 'harm reduction' but the definition of the term was not aligned with international standards (Versfeld 2018).

**The NSP (2017 – 2022)** provides for the needs of people who use drugs in terms of the scale up of harm reduction services in all districts. It also uses human rights-based terminology in relation to drug use and includes people who use drugs as a target population for stigma and discrimination reduction measures.

**The Management of Drug-Resistant TB: Policy Guidelines 2013** provide TB healthcare services for people who use drugs but require "rehabilitation" for those who fail to adhere to treatment, in order to continue treatment. However, drug treatment centres are unable to accept patients with MDR-TB, so the policy is, in effect, exclusionary (Versfeld 2018).

### 6.3.4 Contacts of TB index patients

People affected by TB and their contacts (people they come into contact with) have the same rights as all persons. The South African Constitution provides all persons with the right to access to healthcare services (which includes health information), as set out above. South African jurisprudence furthermore recognises that a rights-based approach to healthcare requires that particularly vulnerable populations should

be prioritised in access to services.<sup>40</sup> The Constitution and National Health Act also protect the rights of all persons to privacy, including medical confidentiality. However, in the context of TB, contacts of TB index patients are vulnerable to infection and special measures should be taken to ensure they are contacted and receive necessary information, diagnosis, prevention, treatment and care, where necessary.

National health plans and guidelines provide in various ways for TB index contact patients (although they are defined differently in various guidelines), including measures to ensure they are identified and linked to care, as well as measures to promote confidentiality and appropriate disclosure throughout the process.

The **South African National Tuberculosis Guidelines (2014)** defines 'contacts' as "people who share the same air for prolonged periods of time with people who are coughing up the MTB into the air (smear or culture positive PTB) and are therefore at risk of getting infected"; there is no reference in the definition to persons living in the same household. Healthcare workers are required to interview newly diagnosed TB patients about their contacts and to prioritise follow-up for those contacts at risk. The Guidelines are not prescriptive about whether follow-up is then active (through home visits to at-risk contacts) or passive (through contact slips, provided to the TB index patient to give to their contacts).

The **2017–2022 NSP** lists 'household contacts' as a key population, but also refers to 'close contacts'. It provides for a master patient index to track patients between health facilities, providers and districts as well as community education and mobilisation programmes to improve acceptance of contact investigations and to create awareness of the benefits of preventive therapy.

The **National Tuberculosis Management Guidelines (2014)** recognise the challenge of maintaining confidentiality during contact investigations and note that constant attention to maintaining confidentiality is required. They encourage ongoing discussions with the index patient and contacts to find solutions, including obtaining written consent from the patient to disclose

37 Available at <http://www.sahivsoc.org/Files/WHO%20Feb%202016.pdf>

38 GCHL (2012) *Risks, Rights & Health* available at [www.hivlawcommission.org](http://www.hivlawcommission.org)

39 National Department of Social Development, *Minimum Norms and Standards for Inpatient Treatment Centres*, Available at <https://docplayer.net/479010-National-department-of-social-development-minimum-norms-and-standards-for-inpatient-treatment-centres.html>

40 *Minister of Health v Treatment Action Campaign (TAC)* (2002) 5 SA 721 (CC)



information to specified persons. They note that refusal to grant consent requires documentation and, where necessary, legal consultation for determining acceptable interventions.

## 7. Literature findings – Vulnerability to infection, access to care, quality of services and impact of infection

This section builds on section 5, which outlines TB burden. Here we provide a brief overview of the key findings available in the literature related to vulnerabilities to infection and disease, care access (noting documented barriers and facilitators), quality of services, and any documented social, psychological and economic impacts of TB disease.

### 7.1 Gender and TB

#### 7.1.1 Men

There are several reasons why men are at higher risk of TB infection and disease than women in South Africa (see Section 5). Men are more likely to have occupations with a high risk of TB infection, particularly mine work and taxi driving. In 2017, there were an estimated 464 667 people employed in the mining sector of South Africa. This equates to one in every 40 working individuals or 2,5% of all employed people in South Africa (Statistics South Africa 2017b).<sup>41</sup> Eighty-eight percent of people working in the mining sector are male (South African Chamber of Mines 2016; Minerals Council South Africa 2018). Mine workers in turn have a higher TB burden (4-7 times higher) than the general population (Lebina et al. 2016). Although there has been very little work done on the taxi industry, the industry employs between 400 000-600 000 people, more than 98% of them being male (Transaction Capital 2015; Peters 2014). While there are no clear statistics on TB prevalence among taxi drivers, taxis tend to be overcrowded and poorly ventilated - creating the ideal conditions for the spread of TB. These conditions

are estimated to carry an annual 5% risk of infection for the average commuter (Andrews, Morrow, and Wood 2013).

Men are also at increased risk of TB infection due to higher rates of cigarette smoking compared to women (Brunet et al. 2011; Karstaedt & Bolhaar 2014). Men are also more likely to have higher levels of substance use, including alcohol (Vellios and van Walbeek 2018) and drugs (Peltzer, Ramlagan, Bruce, & Phaswana-Mafuya 2010) than women. The links between substance use and TB infection are further elaborated in the section on people who use substances below.

A key barrier to care and treatment lies in the ways in which cultural expressions of strength and masculinity undermine men's willingness to admit illness (Mwansa-Kambafwile et al. 2013). Limiting use of healthcare services in general (for all illnesses), particularly biomedical healthcare services, is a common way of asserting masculinity (Treves-Kagan et al. 2017; Mahalik, Burns, and Syzdek 2007) most HIV-stigma research focuses on individuals; further the intersection of gender, testing and stigma is yet to be fully explored. We examined the relationship between anticipated stigma at individual and community levels and recent testing using a population-based sample (n = 1126. Jody Boffa (2018) and colleagues further found that, in relation to TB, men are less likely to complete IPT than women, possibly due to notions of masculinity undermining engagement in care.

#### 7.1.2 Women

Women generally access biomedical healthcare to a greater extent than men, largely because they start to engage with the healthcare system through family planning and pregnancy (Treves-Kagan et al. 2017). The same seems to apply for TB. Notions of appropriate femininity, and of being a good mother and wife, seem to positively impact on uptake of IPT (Boffa et al. 2018). At the same time, the need to be a good caregiver and homemaker can act as a barrier to treatment access (Govendar 2017). Despite women being relatively quick to seek care, TB in women may still be under-diagnosed: symptomatic women are markedly less likely than men to be offered sputum testing due to the assumption that TB is more likely to present

in men (Racow 2013; Austin, Dick, and Zwarenstein 2004; Smith et al. 2016). When women are offered a sputum test, they are less likely to receive a positive diagnosis than men. It is unclear whether this lower rate of diagnosis in tested women is because of lower rates of TB, or whether it is also attributable to the poorer quality of the sputum samples received by women due to their being less comfortable coughing (Smith et al. 2016). Gender disparities in sputum submission were found to peak during child-bearing years, decreasing until old age (75 years and older), at which point the differences disappear (Austin, Dick, and Zwarenstein 2004). Pregnancy was also found to lower the sensitivity of TB symptom screening in HIV-infected women, which may also result in under-diagnosis (Hoffmann et al. 2013). Under-diagnosis in women may be a further consequence of women having higher rates of harder-to-diagnose extra-pulmonary tuberculosis, including spinal TB (Godlwana et al. 2008). Available research also points to differences in the experience of having TB between the two genders, with women being more impacted by the disease compared to their male counterparts. In the case of women, this includes higher levels of psychological distress, greater fears of stigmatisation and a gendered expectation to keep quiet if they experience problems or have concerns about a treatment regimen (Courtwright & Turner 2010; Peltzer & Louw 2013; Boffa et al. 2018). This is especially true in the case of TB and HIV co-infection (Peltzer et al. 2012; Theron et al. 2015).

#### 7.1.3 Transgender women/sexual minorities

There is very little research on TB in gender and sexual minorities in South Africa, but findings on general access to healthcare for gender minorities indicate that transgender and gender non-conforming individuals continue to be humiliated and judged for their gender identity in society, as well as in healthcare facilities (Müller 2017). This is despite the fact that the South African constitution has one of the strongest provisions in the world in terms of the right to healthcare (Müller 2016). It is the only African country to offer constitutional protection against discrimination based on sex, gender and sexual orientation (South African Litigation Centre 2016, 38). Notably, Section 8 of the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 ('the Equality Act') prohibits unfair discrimination based on gender. This extends to healthcare as well. The country has further adopted laws and policies on Gender Affirming Care (GAC), which aim to prevent discrimination and advocate for equal treatment of people regardless of their gender identity. Poor healthcare service for gender minorities is reinforced by a lack of routine education about working with gender minorities (Müller 2013), and healthcare providers have indicated that they do not have the knowledge and resources at their disposal to better respond to the health needs of gender minorities (Graves 2013).

**IN WOMEN,  
THE NEED TO BE A GOOD  
CAREGIVER  
AND HOMEMAKER CAN  
ACT AS A BARRIER  
TO TREATMENT ACCESS**

(GOVENDAR 2017)

<sup>41</sup> For more on mine workers and TB see the section on mine workers below.



## 7.2 Selected key populations and TB

### 7.2.1 Farm dwellers

Farm dwellers in South Africa are particularly vulnerable to TB infection due to concerning levels of exposure to silica quartz through regular farming activities such as soil preparation (Basu et al. 2009). Exposure to silica dust can lead to silicosis, predisposing individuals to TB, yet protective clothing to minimise dust inhalation does not seem to be a common practice in South Africa (Swanepoel & Rees 2011) physicians, and nurses. The literature documents numerous barriers to care for farm workers and dwellers. The temporary nature of employment for many workers who provide seasonal labour can make access to TB treatment and care particularly difficult (Clarke et al. 2003), especially for migrant foreigners (Kruger et al. 2015). Distance from treatment facilities and reliance on employer transport are further noted as key barriers to treatment access for farm dwellers (Clarke, Dick & Bogg 2006; Maswanganyi et al. 2014). Long distances from the clinic and difficulties with transport also mean that farm dwellers arrive at clinics late and are therefore turned away by clinic staff (see also Maswanganyi et al. 2014). In terms of facilitators to care access, lay healthcare workers who visit farms have been shown to facilitate improved treatment outcomes, while substantially reducing costs to the public budget (Clarke, Dick, & Bogg 2006).

### 7.2.2 Healthcare workers

The heightened risk of infection faced by HCWs (see section 5) has been directly linked to occupational exposure (Adams et al. 2015). Unacceptable levels of occupational exposure have been linked to an absence, or poor implementation, of TB infection control programmes (van der Westhuizen & Dramowski 2017) a lack of training about protective measures (Malotle et al. 2017), and poor sensitivity of the tool that assesses infection control in facilities, i.e. the CDC Audit Tool (Claassens et al. 2013). The high TB burden experienced by HCWs has also been linked to the fact that routine TB screening among HCWs is not mandatory (Grobler et al. 2016; Tudor et al. 2014) and is generally incorrectly administered (M. Claas-

sens et al. 2014b; Tudor et al. 2014). Conversely, training on infection control is related to a reduced risk of infection (Ayuk 2013). Though CHWs have indicated that they feel vulnerable to infection (TB Proof 2018), HCWs may also fail to take measures to protect themselves due to false perceptions about their own invulnerability (Nathavitharana et al. 2017; Von Delft et al. 2015). Healthcare workers in general may also be dissuaded from self-protection by the lack of self-protection culture in the healthcare system. For medical students, the lack of institutional safety culture and senior staff shaming junior staff for taking precautionary measures undermines self-protection efforts (Nathavitharana et al. 2017; Ehrlich 2018). HCWs are not immune to suffering TB-related stigma and discrimination in the workplace. HCWs fear that their status will not be kept confidential (Kranzer et al. 2010; Ehrlich 2018) and that an HIV-positive status will either be revealed or assumed (Nathavitharana et al. 2017; Von Delft et al. 2015). Some HCWs are also afraid of losing their jobs when a positive TB status is disclosed (Von Delft et al. 2015). Ehrlich (2018) and colleagues illustrate that there is insufficient policy and programming protection for HCWs who contract TB. Stigma and lack of confidentiality have been shown to result in delays in terms of diagnosing new infections and non-disclosure of infection (Von Delft et al. 2015; Ehrlich 2018; Padayatchi et al. 2010; van der Westhuizen & Dramowski 2017). The literature further indicates that medical students who contract TB experience high social and financial costs due to a TB diagnosis, including missed academic time, depression, as well as the cost of treatment (van der Westhuizen & Dramowski 2017). Drug-resistant TB requires that HCWs take time off work (Jarand et al. 2010) and TB infection has generally been linked to HCWs leaving their TB-related jobs - placing additional pressure on a sector that is already strained by limited human resources (Padayatchi et al. 2010). Overall, the literature on HCWs in South Africa is more substantial than many other TB key populations, despite the fact that HCWs contribute a relatively small proportion of the overall TB burden (Chimoyi 2018). This seems partly because HCWs are mobilising among themselves to ensure better working conditions and responses to TB infection

and disease (the organisation TB Proof has been particularly influential in this regard). Part of this mobilisation is through the publication of articles related to TB in healthcare workers (Von Delft et al. 2015; van der Westhuizen and Dramowski 2017). Studies, however, have tended to focus on HCWs in healthcare facilities, rather than community health workers, who tend to work outside facilities. We, in contrast, focused our qualitative work on community health workers..

### 7.2.3 People who use substances

The TB burden is higher than average in people who use drugs and alcohol (see Section 5). Drug use is associated with delayed treatment seeking (Versfeld 2017) and poor treatment adherence. Naidoo et al. (2013) the burden of disease caused by TB remains a global health challenge. The co-infection between TB and HIV adds to this disease burden. TB is completely curable through the intake of a strict anti-TB drug treatment regimen which requires an extremely high and consistent level of adherence. The aim of this study was to investigate factors associated with adherence to anti-TB and HIV treatment drugs. METHODS: A cross-sectional survey method was used. Three study districts (14 primary health care facilities in each found that people who scored 'medium risk' on the Alcohol Use Disorder Identification Test had an almost twofold chance of non-adherence to treatment. People with a 'high risk' score had a greater than twofold chance of non-adherence compared to non-drinkers. In MDR patients, recent alcohol use has been found to double the risk of treatment interruption or cessation (Kendall et al. 2013) South Africa. RESULTS: Fifty percent of patients were cured or completed treatment, 27% interrupted treatment, 14% died, 4% failed treatment, and 5% transferred out. Recent alcohol use was common (63% of patients). Noted barriers to treatment access and completion include experiences of stigma and discrimination within the healthcare system, difficulties recognising illness due to the similarities of the symptoms of TB and substance use withdrawal, and policies and practices that emphasise abstinence, rather than a harm reduction approach with people who use substances and have TB (Versfeld 2017 2018).

### 7.2.4 Contacts of TB index patients

While the high burden of TB in TB index patient contacts (see Section 5) indicates that effective contact tracing and linkage to care could notably reduce the TB epidemic in South Africa, TB index patient contact tracing is recorded to be happening poorly and ineffectively. This is even when contacts are well documented (Black, Amien, and Shea 2018) although in South Africa (SA). The attrition rate of children at each step of contact tracing - from identification to preventive therapy completion - is high (Black, Amien, & Shea 2018) although in South Africa (SA and Osman et al. (2014) showed that completion rates of preventive therapy in children in 14 primary healthcare centres in Cape Town was (at 14%) very low.

**HIV**  
IS A KEY RISK FOR  
**TB**  
INFECTION  
& DISEASE  
IN CHILDREN  
(LEE FAIRLIE ET AL. 2011)



The literature sets out numerous barriers to successful contact tracing and linkage to care for TB index patient contacts. Chetty-Makkan et al (2018) find that contact tracing is undermined by overlapping responsibilities between HCWs, a lack of clear lines of communication and poor supervision. Inadequate monitoring and evaluation systems, as well as logistical challenges such as human resource constraints, heavy workloads and lack of transport are all further barriers (Chetty-Makkan et al. 2018)we explored enablers and barriers to the delivery of HHCT activities. METHODS: In-depth interviews were conducted with directors, managers and TB co-ordinators from TB and primary health care directorates at sub-district, district and provincial levels within Ekurhuleni (Gauteng. Du Preez et al. (2011)reported missed opportunities for implementing chemoprophylaxis in over 70% of eligible children with culture-confirmed TB disease, with the TB index patient being the parent in nearly half of these cases.

Barriers to clinic attendance for TB index contacts include the difficulty of getting time off regular daily activities, the anxiety of not being able to produce sputum, lack of transport, travel commitments, long queues, the anticipation of waiting and the lack of service at facilities (DeSanto et al. 2018)digitally recorded, transcribed and translated. A codebook was created to establish themes and record their frequencies within interviews. Inductive thematic analysis was carried out. RESULTS: Twelve people with TB and five HHCs were interviewed. Participants were aged 19 to 60 years and most (n=12/17, 70%. Shapiro et al. (2012) found that most contacts with culture-confirmed tuberculosis were asymptomatic, undermining the sense of needing to seek healthcare. Skinner and colleagues found that it is difficult for parents to understand why an apparently healthy child needs preventive medication (2013).

Poor understanding of TB in TB index patient contacts seems to further impact negatively on contact tracing. A study in which home visits were made to TB contacts of newly diagnosed pulmonary TB patients in the Mangaung district found that only half (52.9%) of the symptomatic household contacts of TB index patients referred for follow-up clinic appointments attended. 59.9% (N=259) these contacts thought TB was hereditary (Little et al. 2018). Another study in the same dis-

trict showed that 65% of participants thought it could be cured by herbs (Kigozi et al. 2018).

### 7.3 Additional key populations

#### 7.3.1 Children under five

Young children are also at high risk of developing severe and disseminated forms of disease (Marais et al. 2004; du Preez, Schaaf, et al. 2018). Du Preez (2011) et al found that nearly 25.3% of the approximately 400 children seen annually with TB at a Cape Town hospital had TB meningitis and/or miliary TB. HIV-infected infants have much higher risk of culture-confirmed and disseminated TB (Hesseling et al. 2009).TB diagnosis in children is particularly challenging. The paucibacillary nature of childhood TB disease makes it difficult to confirm the diagnosis bacteriologically and there is a lack of available sensitive diagnostics (Zar, Connell, and Nicol 2010). These difficulties result in diagnosis often only occurring at hospital level ( K du Preez, Schaaf,et al. 2018; K du Preez, du Plessis, et al. 2018), with long diagnostic delays particularly noted for TB meningitis (Solomons et al. 2016). Challenges with recording and reporting of child TB cases has also been documented in both DS-TB (du Preez, Schaaf, et al. 2018) and MDR-TB (Rose et al. 2013). A number of studies note poor implementation of contact tracing and delivery of preventive therapy in children exposed to TB index patients (Van Wyk et al. 2011;Black, Amien, and Shea 2018; Osman et al. 2014; du Preez et al. 2011). We deal with this further above in the section on contacts of TB index patients.

#### 7.3.2 The elderly

TB prevalence of TB risk among the elderly (aged 65 years and older) is increased by frailty, co-morbidities, and high-risk social behaviour such as smoking and substance use as well as poor quality of life (Karstaedt and Bolhaar 2014; B. Clark, Kahn, and Tollman 2013). Beyond this, data was not found about TB vulnerability and care access in the elderly in South Africa.

#### 7.3.3 Migrants and asylum seekers

There is limited research on TB in migrant populations in South Africa, while the general challenges faced by migrants and asylum seekers are documented to include poor treatment from HCWs, difficulties communicating due to language barriers, and denial of treatment due to a lack of documentation or foreign national status (Vearey and Nunez 2010).

Care providers are also documented as finding the mobility of migrant patients and the lack of a fixed address challenging for care provision. This is particularly the case where patients need further treatment and follow-up (Vearey and Nunez 2010). Refugees and asylum seekers - even if they have documentation - may be subject to refusal of care, premature termination of care, excessive healthcare charges, verbal harassment, and maltreatment due to their foreign status or identity (United Nations Department of Peacekeeping Operations 2009).

Migrants with HIV and TB tend not to access healthcare while travelling. This means that treatment is only started when they reach their final destination (Ponthieu, A and Incerti 2016). Delayed diagnosis, interruptions in treatment, poor quality of treatment and the high frequency with which diagnosed individuals are lost to follow-up in migrant populations all contribute to challenges with MDR-TB prevention and management (Lange et al. 2017).

Limitations to TB care and treatment include possible difficulty getting time off work to seek health services off-site and fear of losing employment should an individual be diagnosed with either HIV or TB (Ponthieu, A and Incerti 2016). Poor treatment outcomes may also be due to the financial costs of TB diagnosis and treatment. If retrenched as a result of illness, healthcare costs and care become the responsibility of the individual and their family (S. J. Clark et al. 2007; Bocquier et al. 2009). Migrant workers, especially mineworkers, fuel the spread of tuberculosis when they return home or move to a new location while sick (Lange et al. 2017; S. J. Clark et al. 2007).

Though there is very little information available on TB in asylum seekers in South Africa there is clear evidence that asylum seekers detained at the Lindela Repatriation Centre have been documented to face human rights abuses related to lack of TB prevention, testing and treatment (Drew Aiken 2018). While there have been numerous legal challenges to these conditions, it seems that there have been no advances in setting up details about minimum standards in immigration centres in South Africa (Drew Aiken 2018).



MIGRANTS & ASYLUM SEEKERS



### 7.3.4 Mineworkers

Miners face numerous barriers to diagnosis and treatment. In 2015, only 56% of gold mines in South Africa had TB and HIV testing and treatment facilities (Motsoaledi 2011). Small-scale and illegal mining operations most likely do not provide healthcare services for their employees, who therefore rely on public services that may be difficult to access (Dharmadhikari et al. 2013), particularly for foreign nationals.

Mine workers at larger mines are likely to have access to occupational health services while they are working, but continuity of care, adherence, support and access to diagnostic facilities are not always available once they return home (Stuckler et al. 2011; Basu et al. 2009). Furthermore, miners sometimes avoid seeking diagnosis or treatment because of fear of stigma from family members and HCWs (L. V. Adams et al. 2017).

Mineworkers often return or are sent home after acquiring TB, where social networks and support systems may be stronger, to convalesce and possibly to die (S. J. Clark et al. 2007; Macdonald and Mutendi 2017). People returning to labour-sending communities tend to have poor treatment outcomes (Roberts 2009) and carry their infections with them. The TB burden among miners is fuelling a broader epidemic of more than 760 000 cases per year in South Africa and throughout the Southern African region (Dharmadhikari et al. 2013). Moreover, miners returning home sick places additional strain on the families and communities they come from who have to carry the burden and costs of care, as well as the risks of infection (Dharmadhikari et al. 2013) without the income that the miner would have sent home as remittances (Roberts 2009). Women in rural labour-sending communities lose their primary breadwinner and have the combined burden of having to look after the sick, care for children and look for a job - causing not only physical distress, but also emotional distress in many of these women and their families (Charles 2015). The TB epidemic in peri-mining and labour-sending communities is often exacerbated by misinformation, TB stigma and healthcare mistrust (L. V. Adams et al. 2017). Additional barriers to care in these communities include lack of access to mine occupational health services and having to travel long distances to access care (L. V. Adams et al. 2017; Roberts 2009).

Compensation for occupational diseases such as silicosis and TB remains difficult for miners' families to obtain. This compensation typically includes only work shifts lost due to hospitalisation, and requires evidence of second-degree tuberculosis or permanent lung damage from a medical doctor (Ehrlich et al. 2017; Basu et al. 2009). Families typically report no compensation or delayed compensation, which contributes to poverty after the loss of the household breadwinner (Ehrlich et al. 2017). This also means that the families of disabled miners and ex-miners bear the direct costs of care (Lebina et al. 2016).

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### 7.3.5 People with diabetes

Diabetes patients in South Africa have been shown to have a 2.4 fold higher odds of TB (Oni et al. 2017). This association is significant, regardless of HIV status, though in the high HIV burden setting, HIV-TB-diabetes co-morbidity is common (Oni et al. 2017). There is limited research on how diabetes-HIV co-morbidity impacts on TB diagnosis and treatment, adherence and health outcomes (Oni et al. 2015) the prevalence of multiple morbidities (MM). Prior to the implementation of nurse-initiated and managed antiretroviral treatment (NIMART), which enables nurses to start patients on ARVs instead of the patient needing to be referred to a doctor, the competing requirements of a fragmented healthcare system necessitated patients with TB-HIV-diabetes multi-morbidities to attend a variety of different healthcare facilities, undermining their health-seeking behaviour (Govindasamy et al. 2013) tuberculosis (TB). Often co-morbidity and healthcare requires that referrals be made to an appropriate facility for treatment (Govindasamy et al. 2013) tuberculosis (TB). Lack of treatment-seeking behaviour in HIV-positive individuals was found to be due to the loss of a referral letter (18.8%), insufficient time to visit a clinic (15.6%) or relocation in 12.5% of cases (Govindasamy et al. 2013) tuberculosis (TB). Similarly, the majority of people with TB symptoms and diabetics who failed to link to care reported having insufficient time to attend a clinic (70.5% of people with TB symptoms reported this, and 50.0% of diabetics). Another common barrier was individuals having limited financial resources for transport to healthcare facilities, particularly if an individual had multiple diagnoses (Govindasamy et al. 2013) tuberculosis (TB). It is unclear how this has changed since the implementation of NIMART.

### 7.3.6 People who smoke

Smoking does not seem to impact on symptom reporting (Sattar et al. 2014), though there are indications that it complicates TB diagnosis in HIV-positive patients as interferon-gamma release assays are less likely to show tuberculosis (Oni et al. 2012). Nationally, there is limited information available on the effects of smoking while undergoing TB treatment. However, one study found that current smoking delays 2-month sputum conversion, which increases the risk of relapse and prolongs the period of infectiousness (Visser et al. 2012).

## REGULAR SHORTAGES OF TB & ARV DRUGS,

CAUSE PATIENTS TO INTERRUPT TREATMENT AND EXPERIENCE DELAYS IN TREATMENT INITIATION  
(HEALTH SYSTEMS TRUST, 2017)



Studies have found a high motivation to quit smoking in people with TB (Shangase, Tsoka-Gwegweni, and Egbe 2017) and with TB/HIV co-infection (L. Louwagie and Ayo-Yusuf 2013). Integrating smoking cessation efforts with TB treatment has been shown to be feasible. There is no literature on the ways in which healthcare providers respond to smoking in tuberculosis patients, or whether efforts are made to explain the benefits of cutting down or quitting. Yet it has been noted that smoking cessation should be encouraged in all TB patients and appropriate support provided through counselling. Motivational interviewing has been recognised as one of the most effective approaches to encourage long-term abstinence from smoking in TB patients (G. Louwagie, Okuyemi, and Ayo-Yusuf 2014). At the same time, a study in Soweto, Gauteng, found that 6% of people reported smoking at the time of tuberculosis onset - as opposed to 26% having stopped two months prior to TB diagnosis (Lam et al. 2013).

### 7.3.7 People with silicosis

Silica-dust-associated TB is of particular concern because it is often recurrent and disease often appears after an extended latency period of up to 20 years (Rees & Murray 2006). Silicosis may develop only after people are no longer exposed to silica dust, or have retired from working in the environment where they were exposed (Lebina et al. 2016). This delay hinders diagnosis and treatment access, as the infected individuals are likely to have retired from the working environment and are no longer able to access the healthcare resources that may come with working on the mines. This results in difficulties with silicosis and TB diagnosis, as well as poor TB treatment rates (Lebina et al. 2016).

### 7.3.8 Pregnant women

The challenges of diagnosing TB during pregnancy are related to low sensitivity in symptom screening (Hoffmann et al. 2013; Odayar et al. 2018). Under-detection of TB in pregnant women is therefore likely (Bekker et al. 2016). Linkage to treatment for TB, as well as drug treatment of TB-infected pregnant women is a challenging task due to difficulties in diagnosis, delays in diagnosis and high rates of HIV co-infection (Sugarman et al. 2014; Bekker et al. 2016). Only a little over half (41/74 or 55%) of pregnant women were found to have favourable treatment outcomes in a Cape Town-based study (Bekker et al. 2016). Unfavourable TB treatment outcomes were documented in 45% (33/74) of women and 65% (49/75) of newborn babies were born prematurely, 59% with low birth weight (Bekker et al. 2016). In-utero TB transmission is rare, but possible (Bekker et al. 2016). In a Durban study of 107 pregnant women with TB, 15% of the cohort's neonates showed evidence of TB bacilli within their first 3 weeks of life (Pillay et al. 2004). Infection after birth is more common (Bekker et al. 2016). Two studies show that 15% of mothers with active tuberculosis transmit the infection to their newborn babies within the first 3 weeks of life through inhalation and breastfeeding (Pillay et al. 2001; Mathad & Gupta 2012).

### 7.3.9 Prisoners/Inmates

The National Guidelines related to the management of tuberculosis in correctional facilities stipulate that TB symptom screening must be conducted on all inmates on arrival and (at least) bi-annually, as well as on departure. Symptomatic inmates must provide sputum samples for further investigation (Republic of South Africa Department of Health, 2013). Systematic screening in prisons has been shown to be effective, yielding 3,5% new diagnoses in previously undiagnosed inmates (Telisinghe et al. 2014).

Once infected with TB, the inmate is expected to be provided with free treatment within 48 hours of diagnosis (Republic of South Africa Department of Health 2013). However, Green's (2015) case study of an incarcerated individual in Cape Town found that commencement of TB treatment could take up to four days due to the results not being processed quickly enough and sent back to the correctional facility.

The reported TB cure rates of diagnosed inmates improved from 83% (1 034/1 250) for the 2016/17 financial year to 87% (636/728) for the 2017/2018 financial year (Republic of South Africa Department of Correctional Services, 2018). However, there is a lack of information on the continuation of treatment upon release from prison.

### 7.3.10 Urban Poor/Informal settlements

People living in informal settlements often have limited access to healthcare facilities due to long distances from healthcare facilities. As a result, individuals often need to travel in order to access these services. Studies have found that these individuals sometimes have to walk up to 30 minutes in order to access public clinics when in need of healthcare assistance (Housing Development Agency 2013). An informal settlement status report done in Cape Town investigated the primary source of medical help, the means of transportation used to get to health facilities and the time taken to travel to health facilities. The study found that 77% of individuals access public clinics as their primary source of medical help, 67% of these individuals primarily walk to health facilities to access care and 45% of individuals are within 30 minutes of the nearest facility using their usual mode of transportation (Housing Development Agency 2013).

In the 2017 Household Survey, 71.2% of the total population recorded making use of public sector health services when they fall ill (Stats SA 2017). Approximately 13 718 individuals make use of one public clinic, which exceeds the WHO guidelines of 10 000 individuals per clinic (Matsos MP SB 2011). Within the public health sector, there is one medical doctor assisting a total of 2 457 treatment-seeking individuals (Health Systems Trust 2017). These findings show that there are insufficient human resources and clinic facilities for service delivery compared to the high demand of services in the public health sector. Public healthcare facilities have also been found to experience regular shortages of TB and ARV drugs, causing patients to interrupt treatment and experience delays in treatment initiation (Health Systems Trust 2017).

WITHIN THE PUBLIC HEALTH  
SECTOR, THERE IS

**ONE**  
**MEDICAL DOCTOR**  
**ASSISTING A TOTAL OF**  
**2 457**

TREATMENT-SEEKING INDIVIDUALS

(HEALTH SYSTEMS TRUST 2017)



## 8. Qualitative research findings

This section provides the findings of the qualitative research. It starts with overarching findings, which emerged across the different populations we included. We then move on to the gender-related findings, followed by the findings relating to the selected key populations.

### 8.1 General findings

This research followed the areas of focus as set out in the protocol, focusing on particular populations.

We did not seek to investigate all the causes of vulnerability to TB infection and disease, or the barriers and facilitators to TB treatment, but rather focused on these factors as far as they directly relate to gender and the selected key populations. Despite this, some findings emerged consistently across the different areas of research.

We highlight three key general findings: TB knowledge is limited in people affected by TB; TB-related stigma is pervasive; and TB counselling and support processes are too concentrated at the beginning of the treatment period. We highlight these general findings here because they are relevant to the state of the TB epidemic and response in South Africa, and because they provide a basis for understanding the findings that follow. While we do not reiterate these in relation to each population included in the qualitative research, these findings should be assumed to apply.<sup>1</sup>

Firstly, TB knowledge is limited in people affected by TB. While many people know that TB is airborne, numerous other understandings circulated (and sometimes dominated) during the course of our research. TB was, for example, described as resulting from eating or drinking cold things, contact with water (for example, when doing laundry), working in cold places, inhaling dust or fumes, being unhygienic, heavy smoking, alcohol use, and HIV converting to TB:

“ In fact, I don't know whether it was the mines where I was working [that made me contract TB] or it's the cold. They say cold also causes it...” (Focus group discussion, men, Western Cape).

“ My [male partner] worked in the fridges at Pick n' Pay, so that's how he got it [TB]. I got it first though...” (Focus group discussion, women, Western Cape).

<sup>1</sup> There are, of course, numerous other ways in which the general population is made vulnerable to TB and many barriers to treatment access, which affect all people. Our inattention to these in this study is not to say they are not important, but rather because a broader focus was outside of the scope of the qualitative work in this study.

“ ...maybe you eat a lot of cold things. And we work – a lot of the times we are busy with water...” (Focus group discussion, women, Western Cape).

“ If you take a taxi to work, the taxi driver won't allow you to open the windows. During the time in the taxi, there's the smell of petrol...” (Focus group discussion, men, Western Cape).

“ The issue might be that [men] work on construction sites, or he paints, so all of those things enter his system – all that dust.” (Focus group discussion, women, Cape Town).

While some of these activities (such a smoking) may predispose people towards TB infection, the distinction between cause and predisposition did not seem clear to the participants. There was very little understanding of what MDR or XDR-TB are, how these are contracted or develop, and how these relate to drug-sensitive TB. For example, one MDR-TB patient told us he did not know about TB because he did not have TB, he had MDR. We were also repeatedly asked to explain what MDR-TB was during focus group discussions.

Secondly, TB-related stigma is pervasive. TB-related stigma affected everyone. While the extent to which stigma impacted on individuals varied, there were no TB-affected individuals that clearly said that TB was not a stigmatising disease. TB-related stigma was related to:

- HIV-related stigma and the assumption (whether true or not) that TB-affected individuals are necessarily HIV positive:

“ The issue is that, once you have TB, they say that you...it isn't just TB – once you have TB you have AIDS, [but] perhaps a person really doesn't have AIDS, they simply have TB.” (Focus group discussion, men, Western Cape).

“ I wasn't nice for me. Because I lost a lot of weight and then people said I was sick – they made fun of me saying that I have AIDS.” (Focus group discussion, women, Western Cape).

- The misunderstanding that TB is indicative of poor personal hygiene:

“ With some people, the thought that arises with TB is that TB is dirty, in other words [the person affected by TB] is dirty.” (Focus group discussion, farm dwellers, Western Cape).

**INTERVIEWER:** What do they say about people with TB? What would other healthcare workers say? What is the stigma actually?

**PARTICIPANT:** You stay in a dirty place.

**PARTICIPANT:** We don't take care of ourselves.

### 3 KEY FINDINGS

# 1

**TB knowledge is limited in people affected by TB;**

# 2

**TB-related stigma is pervasive;**

# 3

**TB counselling and support processes are too concentrated at the beginning of the treatment period.**

### KEY GENERAL FINDINGS



## TB-RELATED STIGMA IS PERVASIVE

## TB-RELATED STIGMA AFFECTED EVERYONE

**PARTICIPANT:** We don't eat healthy.

**PARTICIPANT:** So there is a lot of blame that comes with it...*(Focus group discussion, healthcare workers, Eastern Cape).*

- Fears of infection and the unknown:

“ People are discriminating. It's like when you've got TB you've got this big thing that people don't understand...”  
*(Focus group discussion, people who use substances, Western Cape)*

The effects of stigma described included gossiping, scolding, shaming and social shunning:

**PARTICIPANT 1:** Some people are going to tease you.

**PARTICIPANT 2:** Some will scold you.

**PARTICIPANT 3:** Sometimes one feels so ashamed.  
*(Focus group discussion, farm dwellers, Western Cape).*

“ There are those people that when they find out you have this kind of disease, they don't want to come close to you. Because they are scared. You lose your friends, too.”

**INTERVIEWER:** What changed in your life after you knew that you had TB?

**PARTICIPANT:** What changed was that I didn't have friends after I got sick – there weren't any friends and I was just a person alone...They just stopped coming... When they heard I was sick, they weren't there.  
*(TB-affected individual, illness narrative, Western Cape).*

Stigma, the links between TB and HIV, and lack of community knowledge about TB were described as making disclosure of TB status difficult:

**PARTICIPANT 1:** You can tell your friends and family about that but not everyone...[because] they don't know what TB is like.

**PARTICIPANT 2:** Or [people will say] he will infect us, you have to stay away from him. That's the problem. So, it's not easy to have everyone know. You can tell your friends and family about that, but not everyone.  
*(Focus group discussion, men, Khayelitsha).*

“ I [only] told my mother...[others] are going to gossip.”  
*(Focus group discussion, farm dwellers, Western Cape).*

“ Let's say the patient is HIV positive and not ready yet to disclose [their] HIV status to the family and if later the same patient is diagnosed with TB, sometimes they are

reluctant to tell their families that they have TB with the fear that the HIV status might be disclosed. This is common to patients who don't have good relationship with their families and it leads to poor support from the family side.”  
*(Key informant interview, Médecins sans Frontières (MSF), Western Cape).*

Finally, TB counselling and support processes are too concentrated at the beginning of the treatment period and are overly focused on adherence to treatment, without providing support for potential psychosocial or structural barriers to taking treatment.

Participants consistently said that counselling was an event that happened at the beginning of treatment, which largely consisted of being told to take treatment as prescribed:

“ They told me if I take the treatment correctly, then TB can be cured. I shouldn't mix it with certain things – maybe I drink and not finish taking my treatment.”  
*(Illness treatment narrative, female, Western Cape).*

**INTERVIEWER:** “Was there no one that sat you down and explained about TB?”

**INTERVIEWEE:** “No. No. You just take your treatment only, and they tell you that you take treatment at these certain times only.”  
*(Illness narrative interview, male, Cape Town).*

Counselling was not described as dealing with the complexity of TB treatment, medication taking and cure and the fact that the path from diagnosis to cure is often a complex one. In no cases were ongoing support processes reported. Healthcare providers emphasised this insufficient counselling - suggesting that patients do not understand their disease, are rushed through the system and are not adequately supported or included in their own treatment decisions:

“ Patients don't understand. They just take the pills and go home. They don't know the importance of taking the pills or going back to the clinic. They don't know why they are doing that, they are doing this to take the pain away from their body.”  
*(Key informant interview, MSF, Western Cape).*

“ [Patients] have just been shoved through a system of ‘Just drink your tablets! Why don't you just drink your...tablets?!’”  
*(Focus group discussion, healthcare provider, Western Cape).*

“ Support from families and intensive counselling throughout the treatment journey from health workers is very crucial to a TB patient because treatment alone is not enough. TB

## GOSSIPING SCOLDING SHAMING SOCIAL SHUNNING

THE EFFECTS OF STIGMA





patients need social, physical and emotional support from family and friends through their long treatment journey which a packet of pills cannot provide.” (Key informant interview, MSF, Western Cape).

- “ We are not involving the patient as much in their treatment journey as we could. HIV care is more patient centred – patients can take control of their disease, but in TB we still have a sort of passive approach.” (Key informant interview, Clinical TB researcher, Western Cape).

## 8.2 Gender

In Section 4 we raised the fact that there are notable differences in TB morbidity and mortality between men and women in South Africa. In our qualitative research we noted clear gendered differences in where men, women and transwomen identified their TB risk; in how they responded to the experience of illness; the ease with which they accessed services; and in the extent to which they felt clinics were providing the services they needed in an appropriate manner. Below we explore each of these areas as they emerged for men, women and transwomen in our qualitative research.

### 8.2.1 Men

#### 8.2.1.1 Reported vulnerabilities

TB-affected participants in the study consistently reported that men’s risk of TB infection came from outside the household. This included work and related activities, such as transport to and from work:

- “ If you take a taxi to work, the taxi driver won’t allow you to open the windows. During the time in the taxi there’s the smell of petrol...” (Focus group discussion, men, Western Cape).
- “ The issue might be that [men] work on construction sites, or he paints, so all of those things enter his system – all that dust.” (Focus group discussion, women, Cape Town).

Participants also described men’s risk of contracting TB as rooted in social behaviour. Smoking, drinking and getting cold after exercise or during work were all described as putting men at risk of infection. These explanations seemed to imply that smoking and drinking happened in crowded and unclean spaces, therefore infection was considered to be more likely. These behaviours and of themselves, were also seen as putting people at risk of becoming sick:

- “ So, I would say they [men] are at risk in the sense that when they are at the place where they drink or maybe a place where they have fun at, maybe the place is not clean, or the

environment [is not clean] because some people spit wherever and others are sick. So, it’s easy then to catch a disease and then now even when a person sees that alcohol is not good for them, their weight decreases, it goes down, he still continues to drink.” (Focus group discussion, healthcare providers, Western Cape).

Cultural practices, particularly the exposure to smoke (from fires) in enclosed spaces during traditional initiation ceremonies, was also reported to be a risk to TB infection in one focus group:

- “ In our culture, [sometimes] you must stay in a place where there is smoke, that causes the TB, like in an initiation school.” (Focus group discussion, men, Western Cape).

Initiation ceremonies as periods of heightened risk to TB infection are not mentioned elsewhere in the literature, thus more research is required to ascertain how generalisable this assertion is.

While the places where men might contract TB were mostly correctly identified, the reasons they might contract TB in these places were often incorrect, such as TB transmission resulting from exposure to dust:

- “ When you’re sweeping, you [should] throw water on the floor first because of the dust.” (Focus group discussion, men, Cape Town).

#### 8.2.1.2 Diagnosis and treatment: Access and quality

Men affected by TB tend to experience challenges accessing healthcare due to cultural norms that discourage healthcare access unless illness is severe. The majority of men reported that accessing care was challenging, and that they would first make efforts to heal themselves or wait and see if they got better:

- “ I hate clinics. But the time I went there, I was not myself. I was very weak. I tried to treat myself but after, I went to the clinic.” (Focus group discussion, men, Western Cape).

Reluctance to access care tended to be explained through the social expectations associated with men and presentations of masculinity. Seeking biomedical care when not desperately ill (and being seen doing so) was described as a weakness. As the members of a male focus group in Cape Town asserted:

- “ We believe that when you’re sick and you go to [the] clinic, people will look at you like you’ll die, or [you] are weak. When you’re a man, you’re proud. You can heal yourself

There are notable differences in TB morbidity and mortality between men and women in South Africa.



without going to the clinic. If you got stabbed, you can heal yourself without going to the clinic. Even if it's painful." (*Focus group discussion, men, Western Cape*).

When asked whether it would be better to have more men's clinics instead, one man explained that:

“ Yeah, the other men can know what you are going for. It's a shame with [the] ladies. It would be better if there was a men's only or a women's only clinic or a backdoor.” (*Focus group discussion, men, Western Cape*).

A further reported barrier to care access for men was the requirement to provide for their families (one of the key identified roles of men in society):

“ When men are sick, they want to heal themselves because they are expected to be strong because society has socialised them to be providers, to be the head of the families. So, if you're the head of the family, you need to hold it up for everyone. So, you can't be the one who's sick, you can't be sick.” (*Key informant interview, gender researcher*).

This was related to the fear that a positive diagnosis would result in loss of employment. Loss of employment was further described as a real possibility for men working in insecure contract environments (also see the section on farm dwellers below).

We further found that clinics are not seen or experienced to be male-friendly spaces. In line with their reluctance to access public healthcare settings, trying alternative methods of healing or attempting to self-heal (such as by rubbing their chests with 'Vicks', using medicinal herbs or visiting a traditional healer) were more frequently described as the first option for men (and markedly less so for women). This was further confirmed in a key informant interview:

“ When [men] felt unwell or felt a cold that wouldn't go away, they would do more cleansing in terms of vomiting or enema with water or herbs, or they seek help through a healer because [the healers] didn't have those same expectation where they sit and wait in a space that was a women's space.” (*Key informant interview, gender researcher*).

Men's reluctance to attend treatment may be supported by healthcare providers, who were reported to discourage check-ups for men. A key informant interviewee explained that:

“ He would ask to get a check-up every time a mobile clinic came through just to check up on how things were. He was told by the staff of the mobile clinic, “What are you doing

here, you're fine. Go away. This is for people who really need help, like pregnant women, and older people.” (*Key informant interview, gender researcher*).

The reluctance to encourage men to attend healthcare facilities more often or to access medical services regularly may be because healthcare providers - the majority of whom are female - are fearful of potential violence. This was highlighted to us at one healthcare facility:

“ We can appreciate men coming to the clinic, but when four or five men come, Yoh! And you know men are associated with robbery.” (*Focus group discussion, healthcare providers, Eastern Cape*).

## 8.2.2 Women

### 8.2.2.1 Reported vulnerabilities

The women in our study identified their main source of risk as emanating from their roles as caregivers for family members at home. Two key risks were identified in relation to this. The first, and most common, was the risk of living with, or caring for, a man who was TB infected but not on treatment:

“ I'm saying a woman, she is able to be infected quickly because a man refuses to go to the clinic to go find out how is his situation. For example, you are able to reprimand a man and he becomes stubborn and says, ‘You can see I'm still healthy.’” (*Focus group discussion, women, Western Cape*).

“ Yet a woman [has] the risk at the time when the man was sick... [men] are able to persevere, or they are able to suppress something, whilst it has not [actually] been suppressed. They make it seem like it doesn't matter, yet they are causing danger at home.” (*Focus group discussion, healthcare workers, Western Cape*).

“ I was looking after someone who had TB and there wasn't anyone else to stay with him, and [as the other participant said] that a man will refuse to go to the clinic, so I was doing everything for him as he was already bedridden.” (*Focus group discussion, healthcare workers, Eastern Cape*).

Another pervasive (and incorrect) understanding was that TB infection was a result of too much contact with water, for example when doing laundry and cleaning the house:

“ ...And we work – a lot of the times we are busy with water...” (*Focus group discussion, women, Western Cape*).





“ There are people who are constantly doing their laundry, and you see that they are always busy with water doing the laundry, they don't want any dirty clothes in their houses.”  
(Focus group discussion, women, Western Cape).

“ [I got TB because] I used water a lot – doing the laundry.”  
(Focus group discussion, women, Western Cape).

### 8.2.2.2 Diagnosis and treatment: Access and quality

TB-affected participants often said that they access care as needed, that they needed to be in care to protect their families and that being on treatment did not reflect negatively on them in the work setting. Many of the women also reported that they accessed biomedical care relatively early after noticing that they were unwell. It was rare for a woman to report that she took longer than two weeks to access care, and in instances where this was the case, it was usually related to other factors such as substance use. Women did not consistently report any gender-related barriers to care access and completion, beyond the occasional mention of treatment making aspects of childcare difficult:

“ [The treatment] used to result in my hands swelling up – they'd swell up and be painful and I wouldn't be able to hold anything. I had a baby at that time – I couldn't even breast-feed it – my eldest child would have to take my breast out. It would be difficult to even move in a chair because my feet would be sore.” (Focus group discussion, women, Western Cape).

When women were asked to reflect on why they accessed care quicker than men did, this was sometimes framed as a consequence of women's inability to manage suffering. However, female participants also indicated that they sought care because they needed to be healthy for their children:

“Those are my two children, so I must come!” (Focus group discussion, women, Western Cape).

## 8.3 Transgender women

### 8.3.1 Reported vulnerabilities

Transgender women identified numerous risk factors for infection and disease. Participants explained that in the context of pervasive stigma, it was emotionally safer to be living on the streets with other supportive transgender women, which often resulted in transgender women congregating and living together. Living together also allowed the women to move through the streets as a collective, finding physical safety in numbers. While the women suggested that street living was associated with the aforementioned benefits, they also acknowledged that the conditions they lived in were often dirty, crowded and cold.

Participants suggested that ostracism from mainstream society and difficulty finding employment as a transgender person meant that many relied on sex work as a means of survival. This, in turn, provided the conditions required for making the body vulnerable to infection - including working late at night and wearing minimal clothing (even in cold conditions) because this was required to attract clients. Sex work was directly linked to incarceration, HIV and increased chances of contracting TB:

“ Because of the sex work [you get HIV], when you have HIV, it's very quick to get TB...your immune system in very weak. Because you're not on top of your ARVs like you're supposed to be.” (Focus group discussion, transgender women, Cape Town).

**INTERVIEWER:** “What do you think makes you vulnerable to TB?”

**PARTICIPANT:** “I would say prison. Most of us transgenders are sex workers and they get locked up for illegal sex work.” (Focus group discussion, transgender women, Cape Town).

Participants indicated that the burden of HIV was linked to experiences of physical violence, sexual abuse and sex work. Drug use – also reported as common by the group – may also have contributed to HIV positivity, though the researchers did not ask the extent to which the drugs were injected or smoked. The latter is more common in South Africa (Dada et al. 2018).

Participants further reported that their continued exposure to other group members who were not on treatment was placing them at risk of contracting TB. The group further indicated that there was a general avoidance of the healthcare system by transgender women. Due to experiences (and expectations) of stigmatising responses by the healthcare system, this meant that they were exposed to TB infection through peers who had TB and were not accessing care. We expand on this below.

### 8.3.2 Diagnosis and treatment: Access and quality

Transgender women faced notable barriers to care access at multiple levels. Simply moving about in public opened them up to abuse from the public. As one woman described:

“ I [get] up in the morning, and now I'm thinking of getting to the hospital, and all the stressful things you're going to get along the road. As I'm walking now, and I have to pass the parade and there's a lot of rude people along the road. But I ignore them, I just walk past them...But now there is this [clinic] staff that's talking... among each other chatting, gos-





## TB patients need social, physical and emotional support from family and friends.



### KEY INFORMANT

siping. See there's a "moffie"<sup>2</sup>. He acts like a girl but he's not a girl. And then I have to come back. But I come back the same way. Then it's passing these people again. Mocking me, but as I walk." (*Treatment access narrative, transgender woman, Western Cape*).

The combination of homelessness, joblessness and sex work was described by the participants as setting up very difficult conditions for treatment completion:

“ Without a job, treatment is really hard. And being trans, it's not easy to get jobs.” (*Focus group discussion, transgender women, Western Cape*).

“ Being on the streets, you won't take your treatment as it's supposed to be taken. Today you're going to feel like not standing up, I don't feel like going [indistinct] and treatment is not going to go on the same, because on top of that, you do sex work at midnight. So, in the morning you're going to be a little bit tired and by the time you must be at the clinic, you won't be at the clinic.” (*Focus group discussion, transgender women, Western Cape*).

Treatment interruption was also reportedly exacerbated by drug use. During one focus group, a participant indicated that she had replaced her TB medication with heroin (which she was already using) because the TB medication made her feel worse. Conversely, the heroin made her feel better. Replacing TB treatment with drugs or alternating the treatment with drug use is not uncommon. (See section 8.6 below.)

The women also described additional factors influencing their experiences of TB, including fears about disclosing their TB status to those close to them. This, they explained, was because relationships often felt tenuous for transwomen. Being accepted and loved as a transgender woman made some feel “lucky”. The women explained to us that partners already had to accept so much about them that was unconventional, therefore disclosing their TB status was an additional difficulty that they would prefer not to endure. This was explained in a discussion about one woman (who had TB and was not on medication) in this particular group of participants:

“ I can't tell her to take the chance [of disclosing that she has TB] because I don't want her to lose him. Because she loves him very much and he loves her also. He stuck with her through all her sickness. She was almost dead already, he was still with her.” (*Focus group discussion, transgender women, Western Cape*).

<sup>2</sup> Derogatory term for homosexual.

Their discomfort at healthcare facilities was not only because of the responses they received from the staff, but also because of the scrutiny suffered from other people accessing treatment. The general lack of acceptance of gender identity was described by participants as discouraging clinic attendance because waiting while being scrutinised by other clinic attendees was uncomfortable and proved difficult to manage:

“ I went to the clinic, but the clinic was full. I was shy to go to where the TB room is and where the TB sister is because everyone is watching you. And I'm a trans, if you come in the clinic everyone's head turn around ... so I turned around and went out again...I thought to myself, I'm going to die [because] of not wanting to go to the clinic...” (*Illness narrative, transgender woman, Western Cape*).

Healthcare providers were also described as more often than not guilty of singling out transwomen and blaming them for their illness:

“ Since you're transgender, you are the people spreading TB. You're the people spreading disease, you brought this disease here. You must take better care of yourself because you move around with transgender people that is why you bring diseases into our community.” (*Focus group discussion, transgender women, Western Cape*).

The poor treatment described in the group included a lack of service provision, an insistence on using the biological pronoun rather than the chosen identity pronoun, scolding, gossiping, lecturing and moralising:

“ When they see you are trans, they turn nasty towards you. They put other people in front of you.” (*Focus group discussion, transgender women, Western Cape*).

“ I was treated at [a] day hospital when I had TB. They weren't nice to me, even [though they knew] that I was a nurse. I'm sure it was because I was trans. Because you come in by this door then [the nurse] goes there and you can see they are gossiping about you.” (*Focus group discussion, transgender women, Western Cape*).

“ They see [you] are trans but they still say he, sir...” (*Focus group discussion, transgender women, Western Cape*).

“ When I go, on my folder my name is [a male name] and I go for my meds, they call me [the male name] when they see me, they say look how [he] looks, he looks weird!” (*Focus group discussion, transgender women, Western Cape*).

# TRANSGENDER WOMEN AND OTHER SEXUAL AND GENDER MINORITIES EXPERIENCE POOR TREATMENT IN HEALTHCARE FACILITIES.



Healthcare workers themselves acknowledged the difficulties faced by transgender people (both men and women) within the healthcare system:

- “ You must remember subconsciously your value system is your value system...[you need to] consciously make yourself aware of the fact that [you] need to treat this person as a human being although as a Christian that goes against my beliefs.” (Focus group discussion, healthcare providers, Eastern Cape).
- “ We laugh at them, I mean they walk into the clinic centre and you find the patients they laugh at them so it’s basically that they are still ridiculed and sometimes we’re part of that without realising that, we as caregivers.” (Focus group discussion, healthcare providers, Eastern Cape).

Poor treatment in healthcare facilities is not limited to transgender women only, but also extends to other sexual and gender minorities. In our limited facility observations, we noted two instances of stigmatising treatment. In one facility, one woman, who described herself as queer, was repeatedly referred to as “he” despite asking to be referred to as “she”. In another facility, the staff (healthcare providers and a cleaner) repeatedly tried to touch the breasts and genitals of a patient to confirm she was female. The patient kept trying to be polite about how they were violating her rights. She explained that if they kept trying to touch her, she would report them to the clinic management and get them arrested. While in the prior example the healthcare provider apologised to the patient, in the latter example the providers continued to treat the situation as a joke despite the patient’s protestations.

#### 8.4 Key populations

The participants in our qualitative research – farm dwellers, healthcare workers, people who use substances, and contacts of TB index patients – identified numerous ways in which people in these populations are vulnerable to TB infection, face additional barriers to care access, and, critically, find the quality of the care they receive compromised by their affiliation to, or membership of, a key population. We outline this for each selected key population below.

#### 8.5 Farm dwellers

##### 8.5.1 Reported vulnerabilities

A number of reasons for vulnerability to TB were reported to us in the qualitative research discussions. These included poor working and living conditions, exposure to pesticides and the related development of lung conditions, as well as exposure to other infected farm dwellers (especially migrants). We elaborate on each of these below.

Farm dwellers reported that working in wet, cold conditions put them at risk of contracting TB:

- “ For example, you work in the rain. Then I tell [the boss] the work that we do in the rain is not right. You need to prune [trees] and it is raining, then the rain goes down your sleeves. Then you are sent home to put dry clothes on. Then you come back in the rain again.” (Focus group discussion, farm dwellers, Western Cape).

Poorly maintained, crowded living conditions on farms (either in separate houses or in farm hostels) were described to us by some farm dwellers (though not all) and key informants:

- “ They are living in one RDP house, where there are five, six, seven or eight people in the house.” (Focus group discussion, healthcare providers, Western Cape).
- “ We live like little sardines, we live in a heap, in a bundle [of people] in the house.” (Focus group discussion, farm dwellers, Western Cape).

In one focus group, participants reported that they had contracted TB from people who lived in the same house with themselves who were not on treatment at the time. They further said that they knew many people on the farm they lived on who had TB, but were not taking their medication. This same group reported that sleeping with open windows was not possible due to the presence of insects and small animals entering their rooms while they were sleeping.

Migrant workers who temporarily stay on farms during peak work periods were also thought to be carriers of TB (see the section on migrant workers and asylum seekers below):

- “ I did see there was a man [on the farm] with TB. We used to drink together. But that man moved on again to another farm...I didn’t know that man had TB, he ran away, and I found out later he had TB. Now other people probably also have it.” (Illness narrative interview, farm dweller, Western Cape).

Another risk mentioned by key informants, was exposure to pesticides and the development of related lung conditions:

- “ It doesn’t matter if you are a worker or live on a farm whatever you exposed to pesticides.” (Key informant interview, farm dweller, Western Cape).

Farm dwellers themselves did not make the link between pesticide exposure and TB, but when asked about working with chemicals, one focus group concurred that the exposure left them feeling unwell:

“  
We live like  
little sardines,  
we live in a heap,  
in a bundle of  
people in this  
house.”

FOCUS GROUP DISCUSSION



“ Access to care may be particularly restricted when operating hours of health facilities clash with working hours. ”

“ After spraying those poisons on the trees, your body doesn't feel right.” (*Focus group discussion, farm dwellers, Eastern Cape*).

Poor diet, smoking and drinking were all reported by farm dwellers as possible reasons for vulnerability to TB. It has previously been shown that farm dwellers face elevated TB risk due to poverty and chronic malnutrition, as well as lack of education about TB (Clarke et al. 2003). Poor living conditions also affect people working on farms who live in peri-urban communities and are transported to work on a daily basis:

“ If you were to go into many of these towns, into the informal settlements around 8pm, there will be a massive truck dropping off [farm workers] in overcrowded trucks.” (*Key informant interview, Women on Farms, Western Cape*).

While some people were clear that TB was airborne and therefore could be contracted anywhere where there was someone who was infectious, there was generally very poor knowledge about TB and TB infection control among farm dwellers. We were asked what the “big TB” (MDR) is; whether overflowing, stinking drains could spread TB bacteria; and whether HIV could turn into TB. When asked what TB is, one TB-infected participant explained:

“ It is not something we really understand. It is just, it is a disease that we really wish we didn't have. But if you have it you have to accept it and do your best to get rid of it.” (*Focus group discussion, farm dwellers, Western Cape*).

A lack of understanding about what TB is and how it is spread decreases an individual's capacity to protect themselves against the disease.

### 8.5.2 Diagnosis, care and treatment: Access and quality

Descriptions of access to care varied greatly and seemed to be dependent on the farm owner. Healthcare workers explained that farm owners and managers were involved in the TB diagnosis and care process. Supportive farm owners or managers were described as facilitating access through transporting farm dwellers to and from clinics or through providing DOTS support themselves:

“ On the farms, the foreman can give the tablets...” (*Treatment provider interview, Western Cape*).

“ When the sputum is positive, then the clinic phones the farm owner or foreman and asks them to please bring the patient in.” (*Treatment provider interview, Western Cape*).

Conversely, unsupportive farm owners or managers were described as undermining treatment seeking in numerous ways. They were described as simply not acknowledging that farm dwellers were sick:

“ [When] you tell the boss you don't feel well and he tells you that you must stop your drinking [alcohol].” (*Focus group discussion, farm dwellers, Western Cape*).

We were also told that skilled farm dwellers are not allowed sufficient time off work to heal because the farm owners or managers required their skills on the farm:

“ And then that worker is pressured by the employer to get back to the farm because it is harvest season and he needs this one man.” (*Key informant interview, healthcare provider to farm dwellers, Western Cape*).

The temporary nature of employment for many workers who provide seasonal labour can make access to TB treatment and care particularly difficult (Clarke et al. 2003), especially for migrant foreigners (Kruger et al. 2015):

“ Contract or casual workers lose their jobs because they have to attend the clinic for a disease that they contract completely out of their hands. And they get fired because they need to go to the clinic every day.” (*Key informant interview, healthcare provider to farm dwellers, Western Cape*).

“ I got a job on a dairy farm...I first went to the clinic and they said I've got pneumonia. I didn't understand what pneumonia is, but there are some tablets that they gave me, and they said I must come for the next week...If I missed that day, I was going to be out of the job.” (*Focus group discussion, people who use substances, Eastern Cape*).

Distance from treatment facilities and reliance on employer transport were noted as key barriers to treatment access for farm dwellers in the literature (Clarke, Dick & Bogg 2006; Maswanganyi et al. 2014). This was also evident in our own research. Transport, when not provided by the employer, is expensive and time-consuming (which means time off work). For the people living on the farm but not working there (such as family members of farm dwellers), access to farm transport may be denied - making healthcare access particularly difficult.

**POOR DIET,  
SMOKING AND  
DRINKING  
WERE ALL REPORTED BY  
FARM DWELLERS AS  
POSSIBLE REASONS FOR  
VULNERABILITY TO TB.**



## CASE STUDY

An elderly woman who lived with family members on a farm did not have access to the farm transport. She described her treatment access, which was a daily round trip for DOTS every day. At best, her daily routine to access treatment started at 5:30 in the morning and ended at 4:00 in the afternoon, if she was able to catch a taxi for part of the trip. When she could not catch a taxi, she would walk the whole way. She did this for a few weeks until, as she described it, “My legs gave way” and she stopped taking her medication. (Illness narrative, farm dwellers, Western Cape).

Long distances from the clinic and difficulties with transport also mean that farm dwellers arrive at clinics late and are therefore turned away by clinic staff (see also Maswanganyi et al. 2014):

“ When they arrive, they... especially if they live far distance away from the clinic, they’ve walked early in the morning to get there, there’s not necessarily transport for them. And elderly women living on a farm, you don’t have a job on that farm, or you’ve never had a job, you don’t have any transport you must walk those eight kilometres to the clinic then you’ll get turned away because you don’t have an appointment.” (Key informant interview, healthcare provider to farm dwellers, Western Cape).

“ The TB Sr says that usually when people arrive late it is because they live far away and she names some places. I ask how far these places are and she says a 15 – 20 minute drive, but it is difficult to get transport, because there isn’t transport from there.” (Fieldnotes, 13 November 2018, Healthcare facility, Eastern Cape).

DR-TB also poses a problem to rural clinics and farm dwellers. The distance from the clinic can mean that starting treatment requires hospitalisation and treatment may be delayed until space becomes available. One MDR-TB-affected participant explained that she had to wait weeks for a hospital bed to become available and in the meantime, was blamed for the infection risk she posed to those in her community during this period. Moreover, clinic staff do not necessarily have the capacity to deal with more complex TB cases, resulting in these not being dealt with in a timely manner:

“ There are clinics where you have maybe one sister and maybe one clerk... the clerk manages the result [when they come in] and file it. And they are not [trained] to pick up

or manage the results and serious things that need to be flagged. It [is only when] the patient returns and [the sister looks at the results that] they find out the patient is actually a pre-XDR or MDR patient.” (Key informant interview, healthcare provider, Western Cape).

Our participants further raised the issue that the defined areas that clinics are meant to serve do not necessarily align with transport routes. People may find it easier to access more distant clinics if these clinics are located along transport routes. Furthermore, the number of people that need to be served may be higher than accounted for due to the fluctuations that happen seasonally with migrant workers and the increasingly permanent informal settlements of farm dwellers:

“ In a lot of farmworker towns, the informal settlements are shifting and changing because of the seasonal nature of the work.” (Key informant interview, Women on Farms, Western Cape).

“ There is entirely an informal settlement [in that area], [which has] been formed out of seasonal workers, who are now living there permanently, and working in high season. They have a small, small brick building [that must now serve many people]. It has no outside or indoor waiting space. People will wait in plastic chairs out in a long line, rain or shine.” (Key informant interview, Women on Farms, Western Cape).

However, we also found that most of the people we spoke to (considering the small geographical areas we explored) had access to mobile clinics. Our participants were all able to access these during work hours due to supportive farm managers. Clarke and colleagues note that access to care may be particularly restricted when there are only mobile clinics rather than fixed ones, and when the operating hours of health facilities clash with work hours (Clarke, Dick, & Bogg 2006). The ease of mobile care access we found is likely partly due to selection bias within the study – farm managers and owners who agreed to have their workers participate in our research were those with good relationships to non-profit organisations or projects in the area. We did, however, note a concern from workers on one farm: they felt that there was no way of reporting the poor service provided by mobile clinics:

“ Who do I tell if I am unhappy with what is happening on the mobile clinic?... They are giving injection outside with no privacy.” (Focus group discussion, farm dwellers, Eastern Cape).

A number of key facilitators to treatment access and completion were also raised during our discussions. This included active engagement with farm owners and managers in TB management and care, as has successfully been done by the USAID TB South Africa Project operating in the Sarah Baartman District in the Eastern Cape and the West Coast District in the

Loss of employment and income were real consequences of TB infection for people on farms.



People will wait in plastic chairs out in a long line, rain or shine.

Western Cape Province. Our participants also said that mobile clinics were reaching some people as frequently as once a week to provide medication and treatment support:

“ They come here to the farm, then we just come down from the house to them.” *(Focus group discussion, farm dwellers, Western Cape).*

For farm dwellers who have certain difficulties accessing services, we noted that treatment providers consistently described being flexible around the amount of medication given at one time. This was based on the needs of each individual patient and was primarily done to facilitate treatment:

“ The mobile [clinic] is going out every six weeks to the farms...but in the winter they can't reach the patients, so they give the patients maybe more tablets...” *(Key informant interview, healthcare provider, Western Cape).*

“ The TB sister says that she assesses each client on a case by case basis and decides if they can take the treatment at home or should come into the clinic. Unlike most clinics, her standard practice is “to make it easy for them” and to give treatment for long periods *(a month at a time from the beginning) for people to take from home. She says people might disapprove, but one can look at the files, her results show that she gets better adherence this way.*” *(Fieldnotes, 13 November 2018, Healthcare facility, Eastern Cape).*

Loss of employment and income were real consequences of TB infection for people on farms. Farm managers and owners were known to fire contract workers based on missing work due to clinic attendance, or over a TB diagnosis:

“ Not a lot are having a problem, but we heard that other [farm managers or owners] they are having a problem, they are stigmatising the patients because they normally ask, ‘which treatment are you on?’ The other [worker] was fired.” *(Key informant interview, Women on Farms, Western Cape).*

Employers also reportedly booked farm dwellers off work without pay. This forced workers to go back to work while they were still feeling sick:

“ I told the doctor I can work while sick [with TB]. Otherwise the boss doesn't pay me and what are my children going to eat?” *(Focus group discussion, farm dwellers, Western Cape).*

“ There is no clinic around and they are afraid to talk [to the farm owner]...and there is no way they can get money [if they are not working], which means they must force themselves to work to get food on the table.” *(Focus group discussion, healthcare workers, Western Cape).*

## 8.6 Healthcare workers

### 8.6.1 Reported vulnerabilities

In our research, we largely spoke to CHWs who are at the frontlines of screening and testing patients in their homes, providing treatment support at home and recalling patients who have interrupted or ceased treatment. CHWs are of particular concern because they are classified as volunteers who receive stipends for their work, and their basic employment rights are not always respected. While some indicated that they thought they had contracted TB elsewhere (for instance from a partner), others indicated that they thought they had contracted TB at work:

“ I saw myself losing weight. I was working actually in a TB environment. I would wake up in the morning and go to work and work with people who had TB...that's how I got TB, it's by working with people who have TB. I was working there.” *(Focus group discussion, Healthcare workers affected by TB, Western Cape).*

“ I'm not sure just because I have never lived with someone who has TB, but I work with people who have TB, so I don't have proof to say where I got it. But I would say then I work with people who have TB...” *(Focus group discussion, Healthcare workers affected by TB, Western Cape).*

Participants in our research identified a number of ways they thought healthcare workers (including themselves) are vulnerable to TB infection. A key vulnerability that emerged was the difficulty of protecting oneself when doing screening and providing home-based care. In a context where many people are not well informed about TB, community health workers (CHWs) become the primary sources of TB information. HCWs explained to us that it is difficult to take precautions before sufficient TB education has been done, and education is often conducted in crowded, risky conditions:

“ [Patients will ask you] what are you going to do here?” [They will say], “No I don't want you!...I don't want you, I don't want to be visited. Why am I sent someone? I was never told that someone is going to come?” *(Focus group discussion, Healthcare workers affected by TB, Western Cape).*

“ When we are doing door-to-door, sometimes the windows in a house are closed. It's easy for you to catch it.” *(Focus group discussion, Healthcare workers affected by TB, Eastern Cape).*

“ So it's people in a small house and then when you enter and there's someone who's got TB – and what I noticed they have only a door, no windows. If they get a house with win-

Mobile clinics are reaching some people as frequently as once a week to provide medication and treatment support.





HCWs REPORTED THAT

**TB**  
**EDUCATION**  
 IS OFTEN CONDUCTED IN  
**CROWDED,**  
**RISKY**  
**CONDITIONS.**



**I told the doctor  
 I can work while  
 sick [with TB].  
 Otherwise the  
 boss doesn't pay  
 me and what are  
 my children going  
 to eat?**



dows, they close the windows, putting bricks or something. They only open the door." (Focus group discussion, Healthcare workers affected by TB, Eastern Cape).

It is also difficult to wear a respirator before patients have been diagnosed with TB. This makes self-protection difficult for HCWs screening for TB. Healthcare workers described this in the focus groups:

“ Patients, they don't like us to wear a respirator when they're doing screening. It's easy when someone is already diagnosed because the sister or you as the healthcare worker, you teach them about spreading the infection. You tell him or her about the importance – what he or she must do to protect the infection.” (Focus group discussion, Healthcare workers affected by TB, Eastern Cape).

**PARTICIPANT 1:** [When I arrive at a house with a respirator the residents] are going to argue now. They might even chase me away.

**PARTICIPANT 2:** I would even chase you out. Why are you first going to put a respirator? [Were you told] you must come like this?

**PARTICIPANT 3:** It is like I'm disgusted by you, but I say I came to help you.

**PARTICIPANT 4:** Unlike hand gloves [which are accepted as normal protective practice]. (Focus group discussion, Healthcare workers affected by TB, Western Cape).

NGO workers who get respirators from their NGOs rather than at the clinic may experience delays in acquiring respirators:

“ Some of us don't work with the gloves on, respirators or aprons. [The NGO we work for] supplies ours...Then we don't get at the clinic because we don't work at the clinic...” (Focus group discussion, Healthcare workers affected by TB, Eastern Cape).

N-95 respirators are not necessarily sized and fitted. The healthcare workers we asked were not aware that there were different sized N-95 respirators. This lack of knowledge was confirmed by a key informant:

“ Many [CHWs] receive little to no training on TB infection control. [They do not know that they have] to wear a respirator, how to wear a respirator, [how to] access a respirator that is tested, knowing which patients are potentially infectious, which patients can spread disease and which ones don't. I think there is a big knowledge gap from various different tiers.” (Key informant interview, TB Proof).

Community health workers who often see patients at home reported that they were not always informed about the status of the patient they were recalling, even in instances where these patients had MDR-TB. In such instances, extra care was thought to be warranted:

“ ...Even with MDR you are able to be told to go recall someone without being informed that this person [has] MDR [TB] maybe, maybe it's [someone with MDR who has stopped treatment]. You know, a person that is MDR when they infect, they infect you as MDR, you also become MDR.” (Focus group discussion, Healthcare workers affected by TB, Eastern Cape).

A key informant in our study explained that HCWs may, however, also place themselves at risk through failing to protect themselves because that requires a full recognition of the dangers their work entails:

“ ...acknowledging that you can get TB and that you are at risk is such a scary concept because it has implications for your career and the way that you practice. I think many people comfort themselves by saying “Oh only if you are weak you will get TB, only if you have certain risk factors”. Or they'll say “I've worked in this place for 30 years and I don't have TB yet, so I'll never get TB.” (Key informant interview, TB Proof).

### 8.6.2 Diagnosis and treatment: Access and quality

HCWs often experience TB-related stigma within the healthcare system (Von Delft et al. 2015; Jarand et al. 2010). Our research confirmed this, although for the most part our participants identified this as coming from community members rather than other healthcare workers:

**INTERVIEWER:** What do they say about people with TB? What would other healthcare workers say? ....what is the stigma actually?

**PARTICIPANT 1:** You stay in a dirty place.

**PARTICIPANT 2:** We don't take care of ourselves

**PARTICIPANT 1:** We don't eat healthy

**PARTICIPANT 3:** So there is a lot of blame that comes with it... (Focus group discussion, Healthcare workers affected by TB, Eastern Cape).

Our participants indicated that the fact that they could simply test at work could be seen as a facilitator to care access, because it meant that they could test while working. However, they also indicated that it may not be possible to keep their TB status confidential if the tests and treatments are



done in the TB section of the clinic, because other staff members working in this ward will have access to their records:

“ When I do my tests, we are two in that clinic...We know each other. Everybody is inquisitive to know what is happening to my partner. The results come and we sort them by ourselves. Even if you want to hide it, you can't. Because every day you update the register, today it's you, tomorrow it's somebody else. So you come and you see[that] “Oh, [so-and-so] is positive”” (Focus group discussion, Healthcare workers affected by TB, Eastern Cape).

Consequently, some healthcare workers indicated that they sought care through the private healthcare system by paying for it themselves:

“ Then I explained to him [the private doctor] why I didn't want to go to the clinic. The people there are going to ask a whole lot of questions, and I am not yet over the biggest one. [I have not yet dealt with the fact that I am HIV positive]. I knew the procedure at the clinic. I was scared they were going to ask me to do an HIV test.” (Illness narrative, healthcare worker, Western Cape).

Most HCWs in our study described their management as being very supportive during their period of diagnosis and treatment:

“ I'm just saying they were supportive. At times they would tell me and say to me, 'If you feel that you are not okay...don't come to work.' But [having TB] didn't knock me out or make me fall.” (Focus group discussion, healthcare workers, Cape Town).

This positive assessment may well be due to selection bias because we accessed healthcare workers through the non-profit organisations they worked for. Therefore, we only accessed those who had open communication with their employers about their (past) TB infections. Two key informants indicated that stigmatising, unsupportive responses from healthcare managers were not uncommon:

“ I met many medical students who are doing their training who were already getting occupational TB, but were so stigmatised that they were too scared to share their stories [because they were worried that] people would ask them, you know, “What is wrong with you? Why didn't you protect yourself?” (Key informant interview, TB Proof).

One of our key informants linked us to another healthcare worker who contracted MDR-TB at work - a particularly illustrative case study of what can happen when management is not supportive of occupational TB.

#### CASE STUDY:

The healthcare worker started working as a DOTS supporter in 2009 in a healthcare facility. When she started at work, and every year subsequently, the TB test was negative, then in 2014 she tested positive with MDR-TB. When she went to the operational safety officer of the facility, she was told that anyone can have TB, that, “it is an airborne disease that you can get on a taxi or in the mall” and that she could not prove she got it from work. She approached the sub-district, who gave the same response and told her to go back and deal with it in the facility. She has received no support or compensation for the fact that she had contracted TB while working as a community healthcare worker.” (Key informant interview, healthcare worker).

Our participants discussed the difficulties associated with infection, as well as their fear of re-contracting TB. However, they also spoke about the positive impact that the infection had on their work because they became more empathetic towards their patients because of contracting TB themselves:

“ You see me, since I've had [that] experience, I have taken TB treatment. I feel that it becomes easier [to provide support]...I encourage them and then I tell them that I had them as I am speaking from experience.” (Focus group discussion, Healthcare workers affected by TB, Western Cape).

Our participants reported varying testing frequencies, from every three months to annually. This testing was exclusively for active rather than latent TB.

## 8.7 People who Use Substances

### 8.7.1 Reported vulnerabilities

Participants in our study noted numerous reasons why they thought substance use was related to TB infection and disease. One frequently mentioned risk factor was the sharing of cigarettes, alcohol (from the same glass) and drugs. For the most part, this risk was thought to be contained in the sputum passed from one person to another through shared substance use, rather than through the spaces inhabited while substances were being consumed:

Some healthcare workers indicated that they sought care through the private healthcare system by paying for it themselves.



- “ We share too much, maybe of the [heroin]. Or cigarettes, we share too many cigarettes.” (Focus group discussion, people who use substances, Eastern Cape).

This (mis)understanding of how TB is spread was also common among HCWs:

- “ It’s possible that what brings them together [the substance] will go around starting from this mouth it goes to this mouth then the next mouth, you will find that its infectious.” (Focus group discussion, healthcare workers, Cape Town).
- “ When we drink together, we drink out of one glass. I don’t know whether she’s got TB. So I take the glass, I drink the wine and I give it to her. So it infects one person to another.” (Focus group discussion, healthcare workers, Western Cape).
- “ When they smoke, they don’t finish a cigarette alone. They must share that small cigarette, which means cross infection. If I’ve got MDR, all of that seven can get it.” (Focus group discussion, healthcare workers, Western Cape).

Substance use was also thought to result in behaviours and circumstances that render people vulnerable, including not drinking water and not eating:

- “ Sometimes when you drink alcohol, you don’t eat. You just drink and drink, and then you smoke.” (Focus group discussion, people who use substances, Western Cape).
- “ Especially the next day, when you’re done drinking and the next day...you sleep the whole day. And you don’t feel like eating...” (Focus group discussion, people who use substances, Western Cape).

Other factors that were thought to make people susceptible to TB included living on the streets, living in crowded spaces (particularly for heroin users) and a general avoidance of the healthcare system by infected friends and peers. The latter was commonly reported by people who use drugs.

### 8.7.2 Diagnosis, care and treatment: Access and quality

Our research sought to provide insights into the reasons why people who use substances are not accessing the healthcare system as required for TB diagnosis and treatment – a topic barely explored by the literature. Participants, especially those who used heroin, reported delayed treatment access because they did not initially recognise the symptoms as being indicative of an illness. Rather, they assumed that the symptoms were the result of drug use or withdrawal (also see Versfeld 2017):

- “ I think the symptoms and the turkey [withdrawal] are very similar...well, it happened to me, and I put it [getting tested] off, put it off put it off, and eventually I went for tests...” (Focus group discussion, people who use substances, Eastern Cape).

- “ In my case, I got sick. I could see that I lost weight. But I thought I’m losing this weight due to drugs and smoking buttons. But I also had a terrible cough and at the same time, I was smoking a cigarette and even when I am taking a pipe, I was coughing. Still not knowing.” (Focus group discussion, transgender women, Western Cape).

For people who use heroin, the reported reason for not seeking medical care once illness had been recognised was poor treatment within the healthcare system:

- “ Once people know that you use heroin then they don’t care about you because you don’t care about yourself. It’s been told to me many times.” (Focus group discussion, people who use substances, Eastern Cape).
- “ I battled to get the [TB] results. I battled to get anything out of [the facility staff], I really battled...People treat me like I’m not even there.” (Focus group discussion, people who use substances, Eastern Cape).
- “ ...after 48 hours in the waiting room, we go home without being helped.” (Focus group discussion, people who use substances, Eastern Cape).

A further key barrier was the fear of withdrawal while waiting for medical help, and the need to have enough resources to purchase enough supplies to last as long as the waiting period at the clinic:

**PARTICIPANT 1:** “I also took a long time to go to the clinic...I just didn’t make enough money to. I always believed I must have like two bags before I can go to the clinic, because you are going to sit there for hours... That is a big problem.”

**PARTICIPANT 2:** “It’s about having enough heroin. I have quite a few of our friends [who] have *died* with trying to get enough to go to the doctor.” (Focus group discussion, people who use substances, Eastern Cape).

For people who use heroin and live on the streets, the barriers seem prohibitive. In a focus group of seven people who use heroin, six had been diagnosed with TB (the other had been advised that she needed to start IPT soon). One participant had started treatment in prison, and then stopped after being released. Another participant had taken one dose of their medication, while the other four participants had not started their treatment at



**She has received no support or compensation for the fact that she had contracted TB while working as a community healthcare worker.**



KEY INFORMANT INTERVIEW



Once people know that you use heroin then they don't care about you because you don't care about yourself.

#### FOCUS GROUP DISCUSSION

all. Instead of visiting the clinic and taking their TB medication, people who use heroin reported self-medicating with heroin:

“ So when we don't get help from the clinic, you'll end up using heroin as medication, because it helps you sleep better. And those pains you feel and all those things, it reduces all of them...We don't say it's right, we have to get a better medication that can cure for TB than using heroin, but now the treatment you get there of the clinic, the nurses are fighting with you there and they are shouting [at] you, like embarrassing you like in front of, many, many people.” (Focus group discussion, people who use substances, Eastern Cape).

Avoidance of the healthcare system makes it particularly difficult to link contacts of TB index patients:

“ The TB sister talks about how TB is spreading in families. I ask her about this, she says it is when one family member has TB, but is refusing to come in. I ask why they would be refusing, she says that a lot of it is because of drug use.” (Field notes, Eastern Cape).

“ To penetrate [the networks of people who use drugs for contact tracing] is exceptionally difficult for a number of reasons. First of all, they're highly criminalised so they're suspicious of anybody who comes there, who's got an official role or who's part of the bureaucracy or the system that's kept them down for so long and criminalises them.” (Key informant interview, SANPUD).

While complete avoidance of the healthcare system was not reported by people who use alcohol, they also reported avoiding the clinic when noticeably intoxicated, which led to scolding from the clinic staff:

“ Maybe you drank alcohol yesterday so you come the next day. The staff shout at you, 'Why didn't you come on your date?'” (Focus group discussion, people who use substances, Western Cape).

A key informant interviewee pointed out that healthcare providers are not sufficiently trained in how to manage people who are intoxicated or withdrawing:

“ I think walking into a waiting room high if the staff of that clinic don't know that all you need is a glass of water and a chair is a problem. But you do. We get people who come in here who are sweaty and agitated, they're either high or withdrawing, and you have to be able to contain them. If you can't contain them, they walk out.” (Key informant interview, Anova Health Institute Health, Western Cape).

At the same time, some healthcare providers were described by participants as supportive and encouraging:

“ There [are] those [healthcare providers] that are alright, they strengthen you, they encourage you that, please man, go to the clinic. They sit with you and chat with you so that you don't feel bad in between all those other people...” (Illness narrative, people who use substances, Cape Town).

We further noted that patients, as well as some staff members (but not all) providing TB treatment were unaware of the fact that people who were on TB medication did not need to abstain from alcohol and/or drug use completely while on TB treatment. One healthcare provider said that people died because they “just don't want to listen to the rules that they were given at the clinic” about abstaining from substance use. Another said:

“ We advise them not to drink because it doesn't go hand-in-hand. It doesn't work with alcohol. We advise them to stop for those six months, just for them to complete the treatment. For the drugs it's difficult...” (Focus group discussion, Healthcare provider, Western Cape).

This advice may encourage people to stop substance use. Indeed, a few participants reported that they had stopped using alcohol while sick with TB, and then completely stopped after their treatment was complete. However, it may also cause people to alternate between substance use and TB medication when they do not want to or are unable to abstain from substance use (Versfeld 2017). This was confirmed by a healthcare worker:

“ They [TB patients] normally say, 'During weekends, we usually don't take treatment' because they have got that idea that if they can't take that treatment with liquor...there is that perception.” (Healthcare provider interview, Eastern Cape).

This method of alternating TB treatment and alcohol was mentioned by a number of participants. One participant explained that this was because of the undesirable effects of mixing alcohol and TB treatment:

“ It was a problem because sometimes when I drink, there was this, during the week, I drank and then I ate the pills and then I drank and then they make me very, very dizzy. And that's why I stop and I use [alcohol] only over the weekends. Because I cannot drink and also drink my pills as well.” (Focus group discussion, people who use substances, Western Cape).

Another barrier that is common for the treatment of complex TB cases (and that was reported to be particularly important for people who use drugs) is that the referral system requires a fixed address, an identity doc-

**AVOIDANCE OF THE HEALTHCARE SYSTEM MAKES IT DIFFICULT TO LINK CONTACTS OF TB-INDEX PATIENTS.**



Healthcare providers are not sufficiently trained in how to manage people who are intoxicated or withdrawing.

ument and a contact number, which many people who use drugs and live on the streets do not have:

- “ If you have no papers you can't get into a tertiary hospital. So if somebody is an immigrant and they're on the street they're using drugs, they don't have a permanent residency or even if they do have refugee papers - they cannot be referred to a tertiary hospital.” (Key informant interview, Anova Health Institute Health, Western Cape).
- “ It used to be I would phone a registrar and they would say yes this sounds serious, bring the patient in. Now you fax a letter and they contact the person directly. We're systematically excluding who doesn't have a fixed address or cell-phone.” (Key informant interview, Anova Health Institute Health, Western Cape).

### 8.8 Contacts of TB index patients

Our research was limited in that we did not speak to the contacts of TB index patients themselves about their experience of linkage to care. However, our findings nevertheless raised indications of barriers to care linkage for contact patients. Above we highlighted that stigma and TB-related shame is pervasive, which makes disclosure (essential for contact tracing) difficult:

- “ It was very difficult for me to tell my people that they must go and test for TB. Because it is an infectious disease. I was ashamed that I was sick because I didn't know how I got sick. I felt that if I had infected them they would blame me. I brought the sickness to them.” (Focus group discussion, farm dwellers, Western Cape).
- “ The health care workers from the clinic encourage the index cases to disclose their TB status to their families in order for the close contacts to come to the clinic for TB screening. The index case might fear to disclose their TB status to the friends and family as stigma is still an issue in our communities.” (Key informant interview, MSF, Western Cape).

Stigma undermines HCWs' efforts to find TB-affected people in their homes - a requirement for active contact tracing. HCWs repeatedly told us that they would go seek patients only to find that they were not home, hiding, or had provided an incorrect address because they did not want to be seen being visited by a HCW because this would mark them as sick:

- “ Sometimes the other people don't open the doors because maybe they're ashamed [to be seen visited by a social worker in the] community. They have visitor so why [is the

visitor] visiting?” (Focus group discussion, people who use substances, Western Cape).

- “ Sometimes it is a challenge for health workers to do home visits as patients fear or refuse to be visited due to stigma related issues in the community.” (Key informant interview, MSF, Western Cape).

Other times, finding the homes of TB-affected patients is difficult because they have moved, or simply because of the haphazard nature of informal housing:

- “ There are so many new shacks coming up. My client will tell me [they are] going to give you this address because [their] mother lives there and there is a number on the shack, but [that they] actually live on the back of whoever or by in-laws, but there isn't a number.” (Focus group discussion, health-care workers, Western Cape).

As mentioned above, we often found that understandings of TB aetiology were poor and often erroneous, even in TB-affected people. Though many of our participants indicated that their household members had been tested for TB, they often did not understand why it was important for close contacts to get tested, what the purposes of preventive therapy was, and how it differed from treatment. Key informant interviewees suggested that a lack of knowledge is disempowering, and understanding TB is a key requirement for index patients to be able to link their contacts:

- “ I think the concept of prevention is often difficult for patients to understand and we could do more to improve the way we engage and educate TB patients, their families (and even communities), on the importance of screening of contacts and availability of preventive therapy.” (Key informant interview, Clinical TB researcher, Western Cape).
- “ If this index case that we are diagnosing here has a clear [way] of understanding the TB disease...[they] can go willing to the relative and [disclose and tell them] “Go back to the clinics so that you can screens yourselves”. I think that can work better then. But the education is [not enough] and the patients don't understand why [they should link their contacts].” (Key informant interview, MSF, Western Cape).

A number of healthcare providers suggested that contacts of TB index patients are often in “denial” about the fact that they are at risk of TB infection and that this denial makes it difficult to bring them into care:

- “ The Sister says that they ask all patients for their contacts, and the patient will tell them [who these contacts are], but often [the contacts] don't want to come in. I ask why, and

If you have no papers you cannot get into a tertiary hospital

KEY INFORMANT INTERVIEW



**Stigma undermines HCW's efforts to find TB-affected people in their homes.**



**KEY INFORMANT INTERVIEWEE**

she says there's this thing with people of denial. She says we don't want to face things that don't affect us directly." (Fieldnotes, 13 November 2018, Eastern Cape).

Healthcare providers also emphasised that a focus on curing patients through taking medication is not matched with an emphasis on public knowledge and prevention:

- “ Historically it's just been curing, curing, curing...so the patients also only see it that way, they don't really see the prevention side of it.” (Key informant interview, Gender and TB researcher).
- “ Most people in communities don't believe in prevention. Only when they notice that their health is deteriorating, and have symptoms, it is then they start seeking medical attention.” (Key informant interview, MSF, Western Cape).

The lack of understanding about prevention seems to be particularly pressing in relation to child contacts. The TB-affected participants with young children almost all indicated that they had been asked about child contacts and had brought the children they were in close contact with to the healthcare facility for testing and – where necessary – treatment. However, we found that there was limited understanding of exactly what preventive therapy was, why it should be taken or how long it should be taken for:

- “ When they found out I have TB, the people at the clinic said I must bring all three of my children so that they can get the vaccine for six months, so that the TB doesn't get in.” (Patient illness narrative, female, Western Cape).

**PARTICIPANT:** [My child] took [the medication] every day like I did.

**INTERVIEWER:** So you took it together?

**PARTICIPANT:** Yeah, just for a few weeks [then my child stopped]. The thing I don't understand is [about how] they can't test a child for TB...so they just gave him treatment. (Patient illness narrative, male, Western Cape).

Key informant interviewees explained that this was linked to the fact that it is difficult for parents to understand why an apparently healthy child needs preventive medication also see Skinner et al., 2013):

- “ It's one thing if a child is sick to get parents to buy into six months of medication, but parents struggle to understand the need for treatment if their child is running around healthy and happy and the risk is not real [to them].” (Key informant interview, Clinical TB researcher, Western Cape).

Furthermore, TB contact tracing in children under five was thought to be partly dependent on whether the index patient was the parent or not:

- “ Often the TB patient would be the parent, making it a little bit easier for the nurses to follow up on the contacts...It is much more difficult to follow up and engage with parents/caregivers of child contacts if they are not the TB patient. It's one thing if you have a parent in this case who understands the risk...But now you have to go through the entire process of education again with somebody who is not a TB patient.” (Key informant interview, Clinical TB researcher, Western Cape).

Key informants emphasised the historical lack of record-keeping relating to contacts of TB index patients, and that this possibly provided the incorrect impression that contact tracing was not a priority:

- “ I think we need to emphasise documentation of all close contacts an index patient has in the household so that we can be able to see if all close contacts [have] come for TB screening.” (Key informant interview, MSF, Western Cape).
- “ We may have created the impression that contact management and preventive therapy was of lesser importance [than other aspects of TB management], because this was not [historically] included in the routine TB program indicators.” (Key informant interview, Clinical TB researcher, Western Cape).

At the same time, healthcare providers may simply not have the time and resources to dedicate to effective TB index patient contact tracing:

- “ Given the often limited available resources and time, one can understand that in busy clinics healthcare workers may prioritise TB patient care above contact tracing. That is why it is critically important to support health care workers with automated and electronic resources to maximise efficiency and improve their ability to identify and facilitate recall of lost-to-follow-up patients as well as contacts.” (Key Informant Interview, Clinical TB researcher, Western Cape)

## 9. Discussion: Literature, findings and the legal and policy environment

In this section, we draw together reflections on the existing literature and our qualitative findings. We note the key themes that have emerged in this assessment and what these illustrate about the legal and policy environment as it currently stands. We start with a section on the overarching findings. These are crosscutting themes that emerged in our research,



**Most people in communities don't believe in prevention.**



**KEY INFORMANT INTERVIEW**



Parents struggle to understand the need for treatment if their child is running around healthy and happy

KEY INFORMANT INTERVIEW

despite the fact that we did not seek them out. They are particularly important, because they provide some key areas of concern, and a basic context for understanding the findings particular to the populations included in our qualitative research. We follow this with reflections on the impact of gender on TB vulnerability and care access and quality. Here we note that gender has a far greater impact than seems to be recognised in policy and practice. We finish with examining TB vulnerability and care access for each of the researched key populations. Cross cutting themes that emerged from our research are discussed below and analysed in terms of the existing legal and policy framework. Cross cutting themes that emerged from our research are discussed below and analysed in terms of the existing legal and policy framework.

### 9.1 Overarching findings

We list five overarching findings from this research: TB knowledge is generally limited in people affected by TB; TB-related stigma and discrimination is pervasive; counselling processes as they stand are inadequate; gender has an important impact on vulnerability to TB infection and access to care; and human rights contraventions are occurring frequently in TB care provision in the public healthcare sector, especially for members of key populations, and there is limited access to justice for violations. We discuss the first three of these findings here. We deal with the final two overarching finding in the sections that follow.

Despite the high burden of TB in the population, TB knowledge is generally limited in people affected by TB. Misunderstandings about what TB is and how it is spread are common. While most people understood that TB infection came through the air, this did not preclude other explanations for TB aetiology, such as the understanding that TB illness comes from working with water, exposure to the cold, or alcohol consumption. Poor knowledge of TB aetiology and spread among people affected by TB suggests an inadequate understanding of the disease in the general public. We note that there has not been the same kind of public information campaign about TB as there has been about HIV.

This lack of knowledge is pertinent because, as set out in Section 6, the Constitution provides all persons with the right to access health care services, and this includes the right to health information. The NSP also makes clear provision for information and social behaviour communication around TB. It appears, however, that messages are not reaching TB-affected people and their contacts. This is possibly an implementation and resource issue, rather than a failing of the legal and policy framework.

We further found that TB-related stigma is pervasive. This echoes findings of the South African Human Rights Baseline Assessment. Stigma and discrimination undermine the TB response by causing people affected by TB to hide their illness, avoid treatment, and fail to link their close contacts to

screening and treatment where required. It further contributes to the negative impacts TB infection has on individuals, which include income and employment loss, social isolation, psychological distress.

As set out above, South African law and policy protects the equality rights of all people and provides for non-discriminatory access to healthcare, while not specifically on the grounds of TB. In addition, all persons also have the right to legal redress for rights violations. The NSP furthermore provides for intensified efforts to reduce healthcare-related stigma and discrimination in the context of TB, including sensitisation training for HCWs, strengthening monitoring and complaints mechanisms, and improved access to justice. However, responses to TB-related discrimination are still fairly new. There is a need for further understanding of TB-related stigma and discrimination and successful responses, and for expansion of existing programmes, as was evidenced in the South African Human Rights Baseline Assessment as well as to seek ways to strengthen access to justice for human rights violations.

A third theme that emerged in all the research populations, was the inadequacy of current counselling processes. At present, TB counselling tends to be cursory, in practice provided at the beginning of the treatment period, and almost exclusively focused on taking medication. The currently enacted standard of care does not seem to include more nuanced, patient-centred counselling sessions that deal with the social determinants of health and the structural, social, cultural and physical barriers to taking medication and supporting patients in overcoming these. Nor does it seem to ensure that patients sufficiently understand what TB is and what the options are for prevention. We suggest, then, that as practices stand, the simplicity of the messaging is not in line with the complexity of the disease. Even in our short, focused research period, it was evident that the social complexities of the disease (for example through social isolation and stigmatising responses) play an important role in the experience of illness and the likelihood of attaining cure.

As set out above, the NSP and TB Management Guidelines (2014) do provide for counselling at various intervals during the treatment period, including for TB index patient contacts. They also provide for training of health workers, including counselling training for CHWs. However, the TB Management Guidelines do not provide for sufficient ongoing counselling and education processes. In addition, it appears that in practice facilities do often not have sufficient capacity and resources to implement holistic counselling and support.

### 9.1 Gendered dynamics of the TB epidemic

The TB burden in South Africa is distinctly gendered. Infection and disease rates differ by gender, as do experiences of illness and treatment. Men have higher morbidity and mortality rates than women and are more





reluctant to enter into biomedical care. Our findings confirmed the literature in this regard. Women generally did not report many barriers to treatment access, whereas men reported struggling to access treatment. Powerful notions of masculinity undermine willingness to reveal illness (see also Treves-Kagan et al. 2017; Mahalik, Burns, and Syzdek 2007), clinics are viewed as female spaces (see also Mahalik, Burns, and Syzdek 2007; Govendar 2017) health-seeking is a feminine practice (Gibbs, Jewkes, and Sikweyiya 2017; Gittings 2016). It is also sometimes justifiably feared that a TB diagnosis will result in loss of earnings or employment, undermining men's capacities to provide for their families (Govendar 2017). As a result, men are more likely to delay care access and access traditional healers. To some extent, men's avoidance of the healthcare system might suit healthcare providers, some of whom reported discomfort with clinics filled with men due to concerns about their own personal safety.

The Constitution and labour law provide all employees with the right to fair labour practices and to be protected from, and compensated for, occupational injury and disease, as detailed in Section 6. However, we heard no mention among our participants about their rights to a safe working environment and to compensation for men who contracted TB at work. This suggests that there is a need to increase awareness of their rights and support access to compensation.

Our work expanded on currently available information by emphasising the extent to which men and women identify their infection risks differently: whereas the majority of men identified the risk as coming from outside the home space, often at work, most women believed that their greatest TB infection risk came from the men they lived with (or cared for) who had TB that was not controlled or treated.

Our findings further expanded on currently available research in its focus on transgender women, highlighting extensive vulnerabilities to infection. Exclusion from families, communities of origin and the workplace drive transgender women towards living on the streets, sex work, drug use and HIV infec-

tion, creating conditions of extreme vulnerability to TB. Furthermore, transgender women suffer extreme stigma and discrimination within the healthcare system, resulting in avoidance of care and treatment in the public healthcare system. Stigmatising and discriminatory responses to transgender women has been noted in relation to healthcare generally (Müller 2017), but there has been no published literature on this in relation to TB specifically. There are no available statistics from the burden of TB in transgender women, but this context of vulnerability and exclusion from quality care indicates that TB rates are likely to be high.

Poor treatment in healthcare facilities is not limited to transgender women only, but also extends to other sexual and gender minorities. In our limited facility observations, we noted two instances of stigmatising and discriminatory treatment, including incorrect pronoun use and physical abuse in the form of touching genitalia in lesbian women. As we explore further in the key populations discussion below, it is common for people who are considered 'different' and who do not (or cannot) fit into the expectations of care providers, to suffer exclusion and rights abuses in the healthcare system.

Constitutional, anti-discrimination and health law protects the rights of all persons to equality and non-discrimination, including within the healthcare setting and specifically in terms of sexual orientation and gender. However, it appears that this legal framework is inadequate to protect people from discrimination on the basis of sexual orientation and gender identity within health care facilities. Laws criminalising sex work are reported to contribute towards and exacerbate stigma and discrimination, including from healthcare workers, impacting on (largely) women, including transgender women involved in sex work, and creating barriers to their access to services.

In addition, legal commitments towards promoting gender equality, including a clear commitment within the NSP to recognise and respond to the gender dynamics in the national response to TB, have not resulted in adequate, gender-transformative health responses. Given the clearly gendered dynamics of

TB infection and treatment access, it is notable that there is an inattention to the impact of gender in TB infection and treatment in policy, programming and data use. The National TB Treatment Guidelines (Republic of South Africa 2014) do not specifically refer to gender, other than providing guidance on the diagnosis and treatment of pregnant and breastfeeding women. The policy guidelines for the treatment of drug-resistant TB only refer specifically to females when warning to provide contraception to women of childbearing age, due to the damage that treatment can cause to the foetus (Republic of South Africa 2011). The Policy Framework on Decentralised and Deinstitutionalised Management of Drug-resistant TB for South Africa (2011) and the Management of Tuberculosis, Human Immunodeficiency Virus and Sexually-transmitted Infections in Correctional Facilities (2013) similarly only refer to gender differences in relation to pregnancy, childbearing and breastfeeding. At a national level, gender-disaggregated data is not available, though this is gathered at a facility level. This means that healthcare providers are not necessarily planning and shaping their services to the populations they are serving.

## 9.2 Selected key populations

### 9.2.1 Farm dwellers

There is limited knowledge about TB in farm dwellers around the country, and even less information is available about those who work on farms but do not live on farms - a trend that is increasingly common in the country. The data that is available is almost exclusively from the Western Cape and KwaZulu-Natal, with virtually no data from the other seven provinces in the country. Qualitative data about the experience of TB in farm dwellers and the gendered dynamics of the disease among this population is lacking. Our qualitative data, which examined this, though limited, contributes to an under-studied area of research.

Of all the populations we worked with for the assessment, farm dwellers in our research appeared to have the poorest understanding of what TB is, though they face numerous vulnerabilities to TB infection and disease. The literature notes that exposure to silica dust in the soil predisposes farm workers to silicosis and TB (Basu et al. 2009), yet protective clothing is not standard issue for farm workers (Swanepoel & Rees 2011). We found that reported vulnerabilities included crowded living conditions; a substantial migrant population; and exposure to other people who are not on treatment; and exposure to pesticides.

We noted that population also faces notable barriers to access to care, including long distances to healthcare facilities and reliance on employer transport (see also Clarke, Dick & Bogg 2006; Maswanganyi et al. 2014); high costs of transport; uncompromising healthcare staff; clinic catchment areas that do not align with transport flows or the population served; fear of loss of income and employment; and healthcare facilities that are not

**THE TB BURDEN IN SOUTH AFRICA IS DISTINCTLY GENDERED. INFECTION AND DISEASE RATES DIFFER BY GENDER, AS DO EXPERIENCES OF ILLNESS AND TREATMENT**





equipped to manage more complex cases of TB. Furthermore, the literature notes that the temporary nature of employment for many workers who provide seasonal labour can make access to TB treatment and care particularly difficult (Clarke et al. 2003), especially for migrant foreigners (Kruger et al. 2015).

The combination of lack of knowledge and poor access to care - particularly for those without access to mobile facilities - is a concern. A further concern is the extent to which access to care is dependent on the support (or lack thereof) of farm owners and managers. Supportive employers are important for facilitating access to care, and engagement of farm owners and managers in processes to support the people living and working on their farms has been shown to be an effective way of improving TB prevention and management in the Eastern Cape (Lebona 2018). However, in being a supportive part of TB diagnosis and treatment, patient confidentiality may be compromised - especially when farm owners are used to supply treatment.

The difficulties that farm dwellers face when accessing care seem to be resulting in healthcare providers being more willing to take liberties with standing policies on how to provide treatment, including providing treatment for extended periods of time and not observing the policy of treatment being observed for the first two weeks. We found that this was done where healthcare providers felt that standing policies did not serve the needs of their patients.

Overall, our research indicates that farm dwellers merit more research in relation to their vulnerability to TB and access to care. Our research did not delve into the particular conditions faced by people who work, but do not live, on farms. Nor did we delve into the conditions of migrant farm workers, who likely face numerous additional barriers to care access. These areas warrant further study.

All employees, including farm workers who are employees, are entitled to equality and non-discrimination within the workplace, fair labour practices, occupational health and safety, and compensation for occupational injuries and diseases. However, despite the particular vulnerabilities of farm dwellers to TB,

the research could not find specific agriculture-related policies or guidelines relating to safe working conditions in the context of TB, access to care and compensation for occupationally acquired TB, as has been provided for in the mining sector. It appears that farm workers' labour rights are unprotected in practice, and often also in law - since they may not be employees, but contract workers. In addition, health guidelines do not sufficiently provide for sensitivity to their specific needs and the barriers they face in accessing healthcare.

### 9.2.2 Healthcare workers

Despite workplace laws protecting the rights to a safe working environment, healthcare workers remain at high risk of contracting TB within the workplace (Adams et al. 2015). This is - as others have shown - related to inadequate implementation and enforcement of infection control procedures within the workplace (van der Westhuizen & Dramowski 2017), insufficient training (Malotle et al. 2017), and lack of routine screening (Grobler et al. 2016; Tudor et al. 2014), which is effectively implemented (M. Claassens et al. 2014b; Tudor et al. 2014).

Our work has further shown that CHWs face significant difficulties protecting themselves when working in the homes of patients. We noted that some people who have worked as CHWs lacked basic understanding of TB infection and all the measures that can and should be taken for the purposes of infection control, as has also been noted by TB Proof (2018). We further noted that the lack of knowledge about TB in the general public makes it difficult for CHWs to take adequate protective measures, such as habitually using an N-95 respirator, while working in places where they might be at risk. Wearing a mask is especially difficult before TB diagnosis, meaning that vulnerability is highest while people are most infectious. Furthermore, care workers are not always aware of whether or not the patient they are recalling has MDR-TB, and, therefore, whether they should take extra protective precautions. The recently introduced 2018 Policy Framework and Strategy for WBPHCOT may lead to improved training and supervision of

community health workers, including in terms of occupational health and safety.

Our qualitative work further confirms the literature (Von Delft et al. 2015; Padayatchi et al. 2010; van der Westhuizen and Dramowski 2017; TB Proof 2018) in highlighting the fact that HCWs are not immune to TB-related stigma. This is despite broad protection in law for equality and non-discrimination, as well as specific provision within the NSP for addressing TB-related stigma and discrimination including at work. This extends from self-stigma, to stigma and discrimination in the workplace and in the general community. However, our findings were mixed. A number of our participants indicated that they had no problem sharing their TB status with their colleagues because they did not feel it was stigmatising. Others indicated that they shared their status selectively (for example, only with other colleagues in the TB ward, who they felt would understand and possibly not judge them).

Mixed experiences of TB infection and disease extend to the ways in which facility management responded to occupationally acquired TB. The literature (Ehrlich 2018) points to HCWs struggling to access compensation for occupationally acquired TB, particularly for those who work outside of official employment laws (e.g. interns, community health workers). These mixed findings indicate the extent to which systems of support and compensation for occupationally acquired TB for HCWs continue to lack uniformity, and, therefore, the extent to which responses to HCWs who contract occupational TB are dependent on facility management. CHWs who are 'volunteers' are not protected by labour regulations, including those relating to occupational health and safety and compensation, that apply to employees.

In a context where there is a lack of comprehensive policies about occupationally acquired TB, responses to occupationally acquired TB seem to be variable and dependent on management. COIDA also fails to provide for compensation for extra-pulmonary occupational disease nor does it protect healthcare workers who are not employees (e.g. medical interns and community health workers). In addition, it appears that systems and support for claiming compensation in terms of COIDA are inconsistently applied at the hands of facility management, so that healthcare workers struggle to claim compensation in some facilities. The management of occupational disease claims in general by the Compensation Fund has been dysfunctional, with long delays in resolution of claims and payment of health care providers, and other administrative barriers such as failure to respond to inquiries, duplicate requests for documents and opaque decisions (Ehrlich 2012). The lack of clear, well-enforced guidelines about protections and compensation for HCWs is especially problematic, given the important role they play in the national TB response.



IN OUR RESEARCH  
**FARM DWELLERS**  
APPEARED TO HAVE THE  
**POOREST UNDERSTANDING OF WHAT TB IS**



### 9.2.3 People who use substances

The South African literature establishes the fact of the overlap between substance use and TB well

(Mertens et al. 2010; K Peltzer et al. 2013; K Peltzer, Davids, and Njuho 2011; Kendall et al. 2013; Versfeld 2017), but bar a few exceptions (Versfeld 2017, 2018), there is very little information on how and why this happens, and what the consequences of this are. Our qualitative research sought to provide insights into the reasons why people who use substances are not accessing the healthcare system for TB diagnosis and treatment – a topic barely explored by the literature. Our findings indicate that many people who use substances had a very poor understanding of TB disease and infection. It further emerged that healthcare workers themselves did not necessarily understand the risks of substance use as they relate to TB and treatment thereof. TB bacilli need to be aspirated for infection. It is therefore the shared air that puts people at risk, rather than shared utensils or substances. This means that risks are incorrectly assessed consequent of substance use per se, rather than located in the context and location of that use.

Our findings further show that people who use substances face barriers directly related to their substance use. Intoxication can disrupt clinic attendance, the symptoms of TB may be confused with the symptoms of drug use or withdrawal and, especially for people who use heroin, fear of withdrawal makes the long wait required at clinics an impossible task. People who use substances may also face substantial barriers at the level of service provision. Stigma, scolding and discrimination from healthcare providers is an established expectation (see also Myers, Fakier, and Louw 2009). This disrupts the desire to attend healthcare facilities and undermines trust that the necessary services will be provided. Furthermore, messaging that abstinence from substances is required for TB treatment may assist people to slow or stop substance use, but it may also result in erratic medication use which puts them at risk of developing drug-resistant tuberculosis. The HCWs we spoke to consistently spoke about people who use drugs as their most difficult patients.

Difficulty managing people who use substances may, as a key informant pointed out, be partly because HCWs are not equipped to effectively manage people who use substances. HCWs are generally ill-informed about the medical consequences of substance use while on TB medication. They are consequently often providing incorrect information to people who use substances, such as the incorrect fact that complete abstinence is a requirement for TB cure. This contributes towards poor treatment adherence and outcomes.

Reluctance to work with people who use drugs also, however, points to the level of stigma and discrimination which exists in the general community towards people who use substances and the general sluggish uptake of harm reduction in South Africa (Scheibe et al. 2017; Versfeld 2017). The common disregard for the human rights of people who use drugs in particular, makes it easy for HCWs to treat them as if they are not worthy of care.

Stigma, exclusion and discrimination is, then, pervasive, despite broad protection in law for equality and non-discrimination for health care, as well as specific provision within the NSP for addressing TB-related stigma and discrimination and for the implementation of a harm reduction response. A key issue here is that law that criminalises drug use is used as a justification for a moralistic, rather than human-rights based approach to providing care for people who use drugs. Ongoing stigma and discrimination suggest that existing stigma and discrimination reduction efforts are inadequately implemented and enforced and requires further expansion and a prioritisation of the needs of people who use substances. Access to justice for rights violations, including in healthcare, require strengthening in terms of the rights of all persons to access legal remedies.

Furthermore, harm reduction is a key approach in the forthcoming NDMP, but this is not yet signed into policy and is presently not integrated into the TB management system. The previous NDMP (currently still the standing policy document) uses a local definition of harm reduction, which is not in keeping with international harm reduction principles.

### 9.2.4 Contacts of TB index patients

Effective TB index patient contact tracing, if followed with effective preventive and therapeutic treatment, has the potential to bring many of the missing TB cases into the system. The literature indicates that contact tracing is undermined by inadequate monitoring and evaluation systems, as well as logistical challenges such as human resource constraints, heavy workloads and lack of transport (Chetty-Makkan et al. 2018). While TB-affected participants largely reported bringing their children in for testing and treatment, the literature indicates that there are, in fact, many missed opportunities for effective preventive processes with children (du Preez et al. 2011). We were not able to get a sense of the extent to which they linked their extended network of contacts, including adults. Nor were we able to get a sense of whether their children completed preventive therapy if it was required.

The literature indicates that barrier to linkage to care for contacts of TB index patients include lack of symptoms (Shapiro et al. 2012), lack of knowledge about TB (Kigozi et al. 2018), the difficulty of getting time off regular daily activities, the anxiety of not being able to produce sputum, lack of transport, travel commitments, long queues, the anticipation of waiting and the lack of service at facilities (DeSanto et al. 2018). We ascertained a number of other reasons why linking contacts to the healthcare system might be difficult. Many of these reasons relate to the overarching findings discussed in the beginning of this section, TB-related stigma is pervasive, counselling and support throughout the illness period is insufficient, knowledge about TB infection and spread is minimal and TB messaging is simplistic and overly cure-focused. This context, we suggest, makes it difficult for TB patients to disclose their TB status to those around them - a key requirement for linking TB contacts to the healthcare system.

A further problem seems to be that the healthcare system has not been set up in a way that emphasises TB index patient contact tracing. Effective tracing and linkage to care for TB index patients is provided for in TB policy and treatment guidelines, although there is some confusion between various health guidance documents as to who should be regarded as a contact patient and whether or not these are necessarily household members. A broad definition of 'household' which includes people living in additional structures on the same property may be required to adequately include people at risk (Van Wyk et al. 2012). However, the greater challenge appears to be not the policy framework, but rather the lack of training, capacity and resources for implementation. Healthcare facilities lack capacity, monitoring and evaluation systems are set up to emphasise other aspects of TB care, and healthcare staff are insufficiently trained in managing the medical aspects of prevention through the use of Isoniazid Preventive Therapy for people with HIV or children under five. Moreover, though the NSP provides for a systematic contact tracing process, the cur-



FINDINGS INDICATED THAT

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## TB-INDEX CONTACT TRACING IS UNDERMINED BY INADEQUATE MONITORING & EVALUATION SYSTEMS, AS WELL AS LOGISTICAL CHALLENGES

rent TB Guidelines currently lack clarity about who a contact is, and how contact tracing should be implemented.

The Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions 2017 require the notification of TB, including MDR-TB. In some respects, the Regulations may strengthen monitoring of TB incidence and prevalence, supporting improved contact tracing in South Africa. However, the Regulations also provide for mandatory examinations and confinement in exceptional circumstances. The fear of punitive measures may further discourage disclosures necessary for contact tracing; as a result these Regulations and the way in which they are implemented require careful monitoring in their application.

However, it may be that the need for active contact tracing and for additional healthcare worker capacity to trace contacts of TB index patients would be reduced if there was a better understanding of TB in the community as a whole (including a better understanding of prevention) and less stigma attached to TB infection. This could possibly ease the burden of disclosure on the index patient and support their capacity to link their contacts to care. We suggest that understanding the difficulties of contact tracing needs to be understood in the context of broader areas of the TB response where improvement is needed.

### 10. Recommendations

#### 10.1 Overarching recommendations

- 1. Implement a national TB education campaign as provided for by the NSP.** A national education campaign that focuses on ensuring that the general population has a better understanding of what TB is, how it is spread, as well as how it can be prevented should be implemented. This should include comprehensive education about prevention strategies, information about children's vulnerability to TB infection, information about the gendered dynamics of TB infection, and information on health rights.
- 2. Develop a comprehensive and coordinated national stigma and discrimination reduction plan.** This should include further efforts to understand TB-related stigma at a community and facility level and to coordinate and fully implement, monitor and evaluate the scale up and expansion of existing strategy and policy commitments and programmatic responses.
- 3. Improve counselling and support processes for TB-affected people in policy and in practice.** Building on the provisions in the NSP, review TB Treatment Guidelines to provide for continuous counselling and support processes through the illness period for people affected by TB that, among other things, fully integrate rights-based issues.

#### 4. Build recognition in policy makers and healthcare providers that gender impacts on vulnerability to TB infection and on care access, to review and improve gender-sensitive and transformative policies, plans and programmes.

- 4.1 Support the use of the gender-disaggregated data gathered by healthcare facilities to review and strengthen gender-transformative TB policies, planning and programming.
- 4.2 Ensure implementation of gender-transformative policies and programmes, through provision of training and resources.

#### 5. Ensure that all measures to prevent and address TB-related stigma and discrimination, especially for vulnerable and key populations, as outlined in the NSP, are implemented.

- 5.1 Ensure that HCWs receive sound, continuous training on a human rights-based approach to service provision.
- 5.2 Strengthen awareness of and access to complaints and accountability mechanisms to facilitate reporting of violations and to ensure consequences for healthcare providers who contravene human rights in the process of care provision.

#### 10.2 Gender recommendations

##### 10.2.1 Men

- 1. Recognise men's particular risks of TB infection in TB policy and programming.**
  - 1.1 Consider law and policy review to encourage all risky work environments to develop TB-specific prevention and care protocols and processes. These can build on the example provided by the mining industry.
- 2. Review policy and guidelines and develop programmes to recognise and work with notions of masculinity and cultural norms that discourage treatment seeking in TB programming and planning.**

2.1 Seek to actively include traditional healers and cultural leaders in the TB response.

- 3. Implement a drive to create male-friendly TB diagnosis and treatment facilities, times and locations.** Experience and insights gathered from services for men who have sex with men could be used to create safe spaces for men in general.
- 4. Ensure that healthcare providers are sensitised to the difficulties men face accessing care and trained on their responsibility to provide equitable care to all people.**

4.1 Ensure that staffing and security provisions in clinics are adequate, and that facility staff are trained in managing gender dynamics and de-escalating potential conflicts, while still upholding the right to treatment access.

##### 10.2.2 Women

- 1. Review policy and guidelines and develop programmes that seek to fulfil the right of access to information, including health information, to minimise women's risks at home and as care providers to men.**

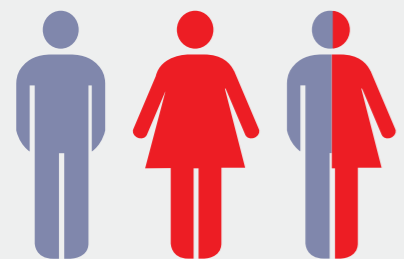
1.1 Provide additional counselling and support to women to enable them to disclose to healthcare workers when they have a partner or cohabitating person who is potentially putting them at risk of TB infection.

1.2 Provide TB education and support processes that target couples, families and cohabitating units. This should include training on communication about managing TB in intimate relationships.

- 2. Ensure that there is adequate psychosocial support for women affected by TB who are care providers.**

##### 10.2.3 Transgender women

- 1. Ensure that transgender women, and transgender people more broadly, are included in the Integrated Bio-Behavioural Surveillance (IBBS) and population size estimation activities for key and vulnerable populations, as**



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provided for by the NSP.

2. **Ensure that there is adequate policy and programmatic focus on TB prevention for transgender people in addition to the law reform recommendations for decriminalisation of sex work made by the NSP.**
3. **Integrate the needs of transgender people into a comprehensive plan to tackle TB-related stigma and discrimination.**
  - 3.1 Implement further efforts to understand transgender-related stigma at a community and facility level.
  - 3.2 Coordinate and fully implement the scale up and expansion of existing policy commitments and programmatic responses, including “know your rights” campaigns, peer navigation systems and various measures to strengthen access to justice.
4. **Scale up human rights and gender sensitivity training and education processes for all HCWs.**
  - 4.1 Ensure the involvement of gender minorities in design and implementation of gender-transformative programming as provided for by the NSP.

### 10.3 Selected key populations recommendations

#### 10.3.1 Farm dwellers

1. **Consider law and policy review to encourage TB-specific prevention and care protocols and processes for farm workers and dwellers.** This should include reasonable accommodation within the working environment to access healthcare.
2. **Engage with farm owners and managers to educate them about TB, to improve cooperation with healthcare services and ethical, rights-based care access and provision.** Engage further with farm workers to educate them about their rights and access to legal redress.
3. **Improve the capacity of rural service provision.**
  - 3.1 Extend the reach of mobile clinic facilities to rural areas where possible.
  - 3.2 Ensure that all facilities are matched to the size of the population they serve.
4. **Improve HCWs’ ability to provide effective, human rights focused care.**
  - 4.1 Sensitise HCWs to the difficulties faced by farm dwellers in terms of accessing care to ensure that those who arrive at the clinics late in the day are still provided with assistance.

- 4.2 Allow for sufficient flexibility in treatment protocols so that they can be adapted to the capacities and needs of individual patients.
- 4.3 Empower HCWs to make patient-centred decisions about how and when treatment should be provided.

#### 10.3.2 Healthcare workers

1. **Improve infection control implementation, accountability and support for TB infected HCWs in all healthcare facilities.**
  - 1.1 Implement a process of tracking occupational TB and providing infection control support to facilities with high rates of HCW infection.
  - 1.2 Implement an assessment of latent TB in HCWs and develop a policy on the provision of preventive therapy for HCWs with latent TB.
2. **Improve CHWs’ capacity to protect themselves.**
  - 2.1 Provide education on HCW vulnerability to TB infection, training on what a respirator is and how it should be worn.
  - 2.2 Improve training and support for community health workers to ensure they are equipped to manage home-based situations where potentially infectious people are reluctant to take preventive measures.
  - 2.3 Advocate for government-funded full-time employment (directly or through civil society organisations) for CHWs, with fair pay and opportunities for career development.
3. **Finalise the Draft Policy on Occupational Health for HCWs in respect of HIV and Tuberculosis to strengthen protection for occupationally acquired TB.**
  - 3.1 Ensure adequate budget allocations for strengthening occupational health services at a facility level.
4. **Ensure that HCWs are educated on the policies that protect them and know how to act**

on policy recommendations.

- 4.1 Ensure that the government amends the Compensation for Occupational Injuries and Diseases Act 130 of 1993 to include criteria on extra-pulmonary TB for HCWs.

#### 10.3.3 People who use substances

1. **Actively seek to minimise and remove the barriers to care that are entrenched in current policies and treatment guidelines experienced by people who use substances.**
  - 1.1 Support calls to decriminalise the use of drugs.
  - 1.2 Amend procedures to provide for referrals and hospital admission for people who do not have a fixed address or identity document.
  - 1.3 Amend policy to provide for the routine availability of opioid substitution therapy during and after inpatient TB care.
2. **Strengthen the implementation of human rights-based training and sensitisation for healthcare providers, as provided for by the NSP, to provide non-judgemental, non-stigmatising and inclusive services to people who use substances.**
  - 2.1 Include people who use substances in designing and implementing training.
  - 2.2 Set up peer navigation systems and harm reduction champions in healthcare facilities.
3. **Seek to create a more inclusive response for people who use substances.**
  - 3.1 Integrate TB prevention, diagnosis and treatment into programmes that provide services for people who use substances, to reduce waiting times and overcome reluctance to access the healthcare system.
  - 3.2 Implement peer navigation processes, in which trained and knowledgeable peers provide support to people who use substances accessing healthcare services.



**4. Ensure that HCWs are educated on how to respond supportively to people who use drugs.**

4.1 Ensure health care providers are equipped to provide evidence-based messaging about TB and substance use to TB-affected people and their contacts in order to facilitate treatment completion.

4.2 Ensure healthcare providers are equipped to manage and support people who are intoxicated or withdrawing.

**5. Align TB programming with harm reduction principles as outlined in the forthcoming National Drug Master Plan.**

**10.3.4 Contacts of TB index patients**

**1. Implement an assessment of the capacity, education and resource requirements of effective TB index patient contact tracing to ensure that any policies and processes are possible and adequately supported.**

1.1 Develop and implement a comprehensive plan and guidelines that clearly define and guide TB index-patient contact tracing implementation, as provided for in the NSP.

**2. Implement a national TB education campaign as provided for by the NSP.** Inter alia this should include information on the risks faced by contacts of TB index patients, why linkage to screening and testing is important, and how preventive therapy functions. This should include a focus on children's vulnerability and engaging with parents/caregivers.

2.1 Improve counselling and support processes for people diagnosed with TB, including support processes for addressing stigma and discrimination including self-stigma, diagnosis and linkage to care for TB index patients' contacts.

2.2 Strengthen efforts to understand and address the impact of stigma and discrimina-

tion on TB index patient contact tracing, within the comprehensive national stigma and discrimination reduction plan.

**3. Include contact tracing indicators and targets in DOH monitoring and evaluation processes.**

3.1 Work towards integrating existing electronic data sources to minimise administrative burden on staff and enable efficient clinical management of identified contacts.

3.2 Evaluate impact of 2017 Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions on contact tracing, and on the health rights of patients in general.

## 11. Conclusion

South Africa has, for the most part, a progressive legal and policy framework that protects the equality and health rights of all persons. The NSP makes substantial provisions for the implementation of a human rights-based approach to TB that leaves no one behind. Health policies and guidelines have, to a large extent, echoed these provisions. Non-profit organisations and research bodies are seeking innovative ways to respond the challenges of providing inclusive and effective care. Tuberculosis diagnosis and treatment is provided by a wide network of public health facilities, supported by CHWs.

Reducing the national burden of TB is however, still proving challenging. Drivers of TB such as high rates of poverty, high HIV prevalence and increasing rates of drug-resistant TB are challenging effective management of the epidemic. There is, moreover, room for improvement in the TB response. This lies less in strategy, and more in implementation. There is a clear need to strengthen implementation of strategic plans and commitments, including for monitoring and evaluation processes and accountability frameworks. There is, furthermore, room for improvement in terms of strengthening protection of the rights of key populations and gender minorities to ensure that all populations are provided with high quality services. This includes supporting men to access prevention and care, reducing the multiple barriers to care faced by gender minorities and key populations, not least the high levels of stigma they may face from healthcare providers who are supposed to serve them. It may also include the decriminalisation of sex work and drug use and updating health and labour guidelines and protocols to fully reflect rights-based commitments to TB.



**HUMAN  
RIGHTS  
BASED  
APPROACH TO  
TB**





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