

THE STATE OF TB

IN SOUTH AFRICA

CLOSING GOVERNANCE GAPS

TO IMPROVE CARE

**A report by the TB Accountability Consortium
March 2023**



**Accountability
Consortium**

Acknowledgements

The TB Accountability Consortium was set up in 2021 as a collective that brings together all the stakeholders in the National TB response: policymakers, scientists and researchers and civil society bodies. From the inception of the program and maiden edition of the 2022 report, TBAC has set its sights on establishing a platform that reflects on the changing face of health advocacy in the increased visibility of the TB programme. In this brief space of time we have been able to form fulfilling partnerships such as those within the SANAC Civil Society Forum and its TB Task Team, TB Proof as well as the Treatment Action Campaign who have all been instrumental in sharing their inputs.

We would be remiss in not extending gratitude to public health specialists and personnel who have assisted within the collation of data in making this report one that is credible and backed by scientific evidence. In compiling this report we acknowledge Dr Harry Moultrie for the use of his presentation entitled Data advocacy to improve decision-making & accountability, as presented at the TBAC Mid-term Budget TB Workshop in November 2022.

Lastly, we dedicate this to healthworkers, community based organisations and civil society activists. This was a labour of love in compiling an advocacy document that TBAC hopes will begin shifting community engagement.

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Acronyms and abbreviations

| | |
|--------------|--|
| ART | Antiretroviral treatment |
| CHW | Community health workers |
| CSF | Civil society forum |
| DR-TB | Drug-resistant TB |
| DS-TB | Drug-sensitive TB |
| HIV | Human Immunodeficiency Virus |
| LAM | Lipoarabinomannan |
| MEC | Member of the Executive Committee |
| NICD | National Institute for Communicable Diseases |
| NDOH | National Department of Health |
| NHLS | National Health Laboratory Services |
| NSP | National Strategic Plan |
| RHAP | Rural Health Advocacy Project |
| SANAC | South African National AIDS Council |
| SDG | Sustainable Development Goals |
| SOP | Standard Operating Procedures |
| STI | Sexually Transmitted Infections |
| TAC | Treatment Action Campaign |
| TB | Tuberculosis |
| TBAC | TB Accountability Consortium |
| TPT | TB Preventative Therapy |
| TUTT | Targeted universal testing for TB |
| UNHLM | United Nations High Level Meeting |
| USAID | United States Agency for International Development |
| WHO | World Health Organization |

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FOREWORD

A critical focus on governance

TB has a long history found in Egyptian and Greek antiquity. And it was early as the 1600s that writer John Bunyan named it the “Captain of all these men of death”. More than 400 years later, TB remains a significant public health challenge globally.

The most recent global TB statistics released in the World Health Organisation’s 2022 Global Tuberculosis Report shows that between 2020 and 2021, there was a 4.5% increase in the number of people who fell ill from TB, a 3.6% increase in the TB incidence rate and the burden of drug-resistant TB is also estimated to have increased. According to the report, the impact of COVID-19 is still being felt on the global TB response and the progress made in the years up to 2019 has slowed, stalled or reversed, and global TB targets are off track.

South Africa’s TB landscape has had equally devastating outcomes. Our most recent figures show that in 2021, a total of 54 000 people died of TB in South Africa. About 172 000 people were diagnosed with the disease. In total, an estimated 304 000 people in South Africa fell ill with this curable disease.

For the last two decades South Africa’s TB response has been guided by a National Strategic Plan for HIV, TB and STIs which is updated every five years. The new plan is set to be released in weeks to come. In addition to this plan, the National Department of Health has also introduced a TB Recovery Plan, to help the country regain the significant losses the TB programme felt as a result of the crippling COVID-19 pandemic. These setbacks included declines in the number of people being tested and diagnosed for TB, those coming onto treatment and an increase in the number of TB deaths for the first time in more than a decade.

South Africa is not the only country whose TB programme suffered as a result of the COVID-19 response. The WHO’s Global TB Report reflects the challenges for TB programmes across the world and may be reflective on the complicated, and at times, neglected manner in which TB programme interventions are addressed and sustained.

However, as one of the 30 countries with the highest TB burdens, South Africa is at a greater risk. The truth is that the challenges in South Africa’s TB response predate COVID-19 and need to be understood in the context of its overburdened public health system. It is a country which had to reckon with a HIV/AIDS epidemic at the close of the 1990’s and results of which was to the detriment of those accessing other services including TB. The consequences of providing compromised health care services due to shortages of trained healthcare workers and medication stock-outs are all symptoms of an overstretched and under-resourced system – often one that is plagued by corruption.

This has been worsened by massive inequality that permeates South African society leaving in its wake a bevy of socio-economic challenges that leave the most vulnerable cohorts of the society at risk of developing TB. It begs the question: Is there anyone to champion the Constitutional rights and access to health enshrined by the National Health Act?

In the inaugural State of TB in South Africa report in 2022, TBAC looked at what was needed to regain the momentum in the national fight against TB. The consensus was that there is a need to recalibrate and decide what the focus areas are.



The WHO’s Global TB Report reflects the challenges for TB programmes across the world and may be reflective on the complicated, and at times, neglected manner in which TB programme interventions are addressed and sustained.

It is TBAC's hope that this document breathes new hope in these turbulent times and galvanises the civil society voice to focus on re-energising the will of those who have no voice. A country where all people recognise their agency in transforming our world.



This 2nd edition of the State of TB Report takes a more in depth look at the governance of TB programmes in South Africa, focussing on what is needed to bring about coherence in the implementation of TB programmes. The World Health Organisation defines governance as the need to ensure strategic policy frameworks exist and are combined with effective oversight, coalition-building, regulation, attention to system-design and accountability.

In line with this, TBAC will use USAID's Governance in TB report as a benchmark for the evaluation of governance in the context of SA's TB Recovery Plan.

The report has taken two approaches this time round: the first part of the report conducted a governance evaluation of the National TB programme and the National TB Recovery Plan using global governance indicators conceptualised by USAID. The second portion is an evaluation of the progress towards the National TB goals enunciated in the National Strategic Plan and the National TB Recovery Plan. As part of the evaluation, there has been engagement with key stakeholders in the country's TB response to understand some of the challenges that they face in this regard.

What the report shows is that there are gaps in the cycle of governance around the TB response in South Africa. Although the TB response is guided by a well-considered policy framework which often means that the country is at the forefront of new technical solutions, this has not consistently translated into effective implementation of these policies.

One of the overwhelming positives within the TB community is that there has been a concerted effort to make the TB Recovery Plan a priority.

But there are many challenges.

As a start there is a lack of transparency around the National Strategic Plan as well as the new TB Recovery Plan. The lack of transparency makes it very difficult for people to ask questions around the implementation of these plans and to hold those who are responsible for its implementation to account.

Secondly - and equally as challenging is the fact that the data surrounding the National TB strategy is siloed. While there are various data sets that provide parts of the puzzle around the TB cascade, each set works independently and there are no points of alignment.

Although the incoherence in the approach is felt at a national level, the biggest challenge lies at the provincial level which manages the bulk of the TB services. And this can be seen most significantly in both KwaZulu-Natal and Western Cape, which both remain high TB burden provinces where the TB prevalence sits well over the national 615 cases for every 100,000 people.

The disconnect between the national and provincial levels means there is no clarity on how the National TB Recovery Plan is implemented.

While the trickle-down effect is problematic for the TB response, our report also shows that there is also a lack of consistent community involvement in the TB response.

Collectively these issues all compromise the management of the TB response. And the end result is that the policy framework is not met with effective implementation, adequate support and strong oversight so that there is accountability in the TB cascade holistically.

The focus on governance is a critical one.

With this report, TBAC hopes to cast a light on some of the biggest gaps in the implementation of the TB response and how this affects its governance. While the report is intended to give policymakers an idea of how the lack of governance plays out at a regional, provincial and district level, it has a broader purpose: to strengthen the grassroots level community led governance approach. TBAC believes this will give community activists the evidence that they can use to defend their constitutional rights, primarily in this case being access to healthcare, ultimately taking us further on our journey of ending TB in South Africa.

It is TBAC's hope that this document breathes new hope in these turbulent times and galvanises the civil society voice to focus on re-energising the will of those who have no voice. A country where all people recognise their agency in transforming our world.

Yours in solidarity,

SIHLE MAHONGA
TB Accountability Consortium Project Officer

INTRODUCTION

Why focus on TB?

South Africa is listed in the top 30 high burden countries for tuberculosis (TB), which account for 86-90% of the estimated global incidence¹. Individually, it accounts for 3% of TB cases globally². From 2016 to 2018, TB was the leading cause of death in South Africa, ranking above diabetes, strokes, heart disease, HIV and certain cancers³.

The drivers of the TB epidemic in South Africa are multifactorial and range from biomedical and social to health system related factors. In the 1990s, the high TB rates in South Africa were driven by the HIV epidemic, prior to the roll-out of antiretroviral treatment (ART)². Although there was evidence of declines in TB incidence from 2008 following the scale-up of ART, TB/HIV co-infection in South Africa was as high as 59% in the 2019 Global TB report².

Social factors are also major drivers of TB rates in South Africa and include socio-economic status, delayed health-seeking behaviour in people with TB² and ongoing TB stigma which is a barrier to treatment⁴.

Sub-clinical TB may be another driver of the TB epidemic. According to South Africa's First National TB Prevalence Survey, conducted in 2018, over half of the confirmed TB cases in the study were asymptomatic and the majority of those who were asymptomatic were HIV negative². This meant the actual TB prevalence was higher than expected and highlights the need for active case-finding in the setting of TB to reduce community transmission².

Governance in TB programmes has also been identified as a "critical yet neglected aspect" that can strengthen TB programmes at national and subnational levels of government, as well as at community level⁵.

While South Africa had made substantial progress towards controlling its TB epidemic in the 10 years prior to the COVID-19 pandemic⁶, its response to the COVID-19 pandemic has set back the fight against TB by five to seven years⁷.

As a result of COVID-19 related lockdowns, as well as the redirection of health services to the fight against the COVID-19 pandemic⁷, between 2019 and 2020 TB testing decreased by 23% nationally, laboratory diagnosis by 25% and less than half of TB patients were successfully treated in 2020⁶. The decreased number of people getting tested and diagnosed, means that fewer people would have been initiated on treatment, which would have led to ongoing transmission of TB within communities⁷. In addition, between 2019 and 2020 there was an increase in TB deaths for the first time since 2005⁶.

Governance in TB programmes has been identified as a "critical yet neglected aspect" that can strengthen TB programmes at national and subnational levels of government, as well as at community level.



The National TB Recovery Plan

To regain the losses in the TB programme caused by the COVID-19 pandemic, the National Department of Health (NDoH) developed a TB Recovery Plan⁶. This plan has four key objectives:

- 1 Find** people with undiagnosed TB disease in communities
- 2 Strengthen linkage** of people diagnosed with TB to treatment
- 3 Strengthen retention** in TB care
- 4 Strengthen TB prevention** efforts⁶

OBJECTIVES 1 AND 2: DIAGNOSE PEOPLE WITH TB DISEASE AND LINK THEM TO CARE

At the 7th South African TB conference held in Durban in September 2022, Dr Norbert Ndjeka, chief director of TB control and management at the NDOH, highlighted that the most effective way to reduce both TB incidence and death rate is to find undiagnosed people with TB and effectively link them to care⁴. As part of the TB Recovery Plan the NDOH planned to implement a targeted universal testing for TB (TUTT) strategy that would test all people at risk of TB such as those with HIV, close contacts of TB patients and previous TB patients. This targeted testing would be conducted regardless of the presence of TB symptoms⁴. Other strategies included using innovative testing modalities such as urine LAM¹ tests and screening tools such as the TB Health Check mobile application and mobile digital x-rays⁴. At the same conference, Deputy Minister of Health Dr Sibongiseni Dhlomo, noted that the use of SMS platforms to inform patients of their results, would not only improve linkage to care but would also save the patients unnecessary travel costs as they wouldn't need to attend health facilities for their test results⁴.

OBJECTIVE 3: RETAIN PATIENTS IN CARE

To improve retention in care the NDOH planned to make TB treatment shorter for children (with a new four-month regimen) and for people with drug-resistant TB (DR-TB) (with a new six-month regimen)⁴. Other planned interventions included adherence counselling, multi-month dispensing of medication and dispensing of TB medication through the Central Chronic Medicines Dispensing and Distribution (CCMDD) system⁶.

OBJECTIVE 4: TB PREVENTION

To reduce transmission of TB in communities, TB preventative therapy (TPT) eligibility would be expanded to include all household contacts and the drug regimens used would include both 3HP² and 3RH³ therapy⁶.

1 LAM - lipoarabinomannan, a component of the outer cell wall of the TB bacterium that can be excreted in urine⁶
 2 3HP - rifapentine and isoniazid, which are TB medications taken for 3 months to prevent active TB disease in adults and children >2 years of age⁶.
 3 3RH - rifampicin and isoniazid, which are TB medications taken for 3 months to prevent active TB disease in children <15 years of age⁶.



CRITICAL ENABLERS FOR THE NATIONAL TB RECOVERY PLAN

In order to achieve these objectives, the plan outlines a number of activities and critical enablers. Critical enablers include, among others, improved governance of the TB programme and improved TB surveillance (through better data collection, analysis and use)⁶.

The governance enabler includes activities such as using data to monitor the progress of implementation, reporting on this progress to the South African National AIDS Council (SANAC) quarterly and supporting provinces in the implementation of the plan⁶. The TB surveillance enabler includes strengthening the national TB surveillance system and creating a public-facing TB dashboard to display TB testing, notification and death rate data⁶.

As these are critical enablers in the implementation of the TB Recovery Plan, as well as essential to achieving other TB targets (both national and international), this report focusses on governance in TB programmes and the use of data in governance of TB programmes.

SANAC's role in overseeing HIV and TB services in South Africa is to foster collaboration between government, civil society and the private sector to ensure there is effective implementation of policies like the National Strategic Plan (NSP) for HIV, TB and sexually transmitted infections (STIs)¹⁰. Their main objectives include strengthening governance at national, provincial, district and local levels, as well as monitoring progress towards the goals of the NSP¹⁰. It is for these reasons that governance of the TB Recovery Plan included reporting on its progress to SANAC¹⁰.

PROGRESS TOWARDS OTHER TB TARGETS

The National TB Recovery Plan was not only put in place to regain ground in the TB programme post COVID-19, but also to accelerate progress towards achieving key TB targets set prior to the advent of COVID-19. These targets were set in platforms such as South Africa's NSP, the sustainable development goals (SDG), United Nations high-level meeting on TB (UNHLM) and in the End TB targets⁶.

The purpose of this report

The aim of this report is to assess the level to which the TB Recovery Plan has been implemented and to outline the role governance has played in the plan's roll-out to date.

The report was compiled by conducting a desktop review of both peer-reviewed and grey literature and using insights from key informant interviews, which were conducted via emailed questionnaires. All data presented in this report were sourced from the literature review, a TB workshop presentation and online sources of publicly available data. The national and provincial department of health websites were reviewed for the availability of the TB Recovery Plan and latest TB guidelines.

Five provinces were included in this report based on two criteria:

- ◆ **Those with a high TB burden** (KwaZulu-Natal and Western Cape)
- ◆ **Those with high TB burden districts**¹¹ (Eastern Cape, Free State and North West).

THE GOVERNANCE OF TB PROGRAMMES REPORT

Governance plays a critical role in the success of health programmes and is particularly important in the context of the challenges and complexity common to TB programmes. As such, it is necessary to have indicators to assess and monitor the effectiveness of governance to improve accountability, and ultimately service delivery.

An assessment of governance of TB programmes was undertaken in 22 countries by the Stop TB Partnership and USAID, using four themes: transparency, inclusiveness, legal framework and process efficiency and effectiveness¹². This survey assessed governance looking both at the existence of policies and procedures, as well as their implementation, until the end of October 2020¹². South Africa was one of the countries included in this assessment and thus it is possible to review the strengths and weaknesses of governance in the South African TB programme and to compare these to other low- and middle-income countries.

The following infographic shows more detail on how South Africa performed in this survey, as well as the top performing countries in each indicator for comparison. All data in the infographic is derived from the Governance of TB Programmes report¹².

Findings

From these findings it is clear that there are certain aspects of governance in its National TB programme that South Africa is doing well. In terms of the inclusiveness of the National TB Programme and the guiding legal framework, South Africa performed well in this survey, particularly in the policies for social protection of people with TB¹².

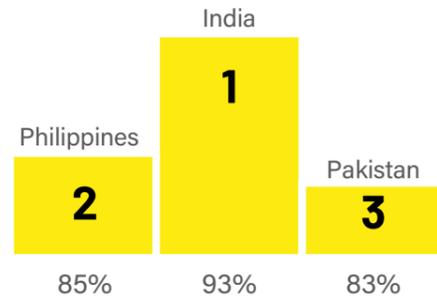
However, there are also a number of areas of governance in which South Africa underperformed. This was most noticeable in the theme of process efficiency and effectiveness, with long approval turnaround times, poor National TB Programme manager empowerment and no available data on the absorption of funds from all sources¹². Even the parameter for which South Africa achieved the benchmark (adoption of international guidelines) was only assessed at national level¹², and thus did not evaluate the dissemination of guidelines to a provincial and district level where implementation would occur. This would be a useful assessment in future surveys.

In the theme of transparency, South Africa underperformed in two of the parameters, one of which was availability of recent notification data on the website¹². This highlights the need for availability of data for monitoring of both the success of TB programmes and the effectiveness of their governance.

GOVERNANCE of TB programmes

TRANSPARENCY

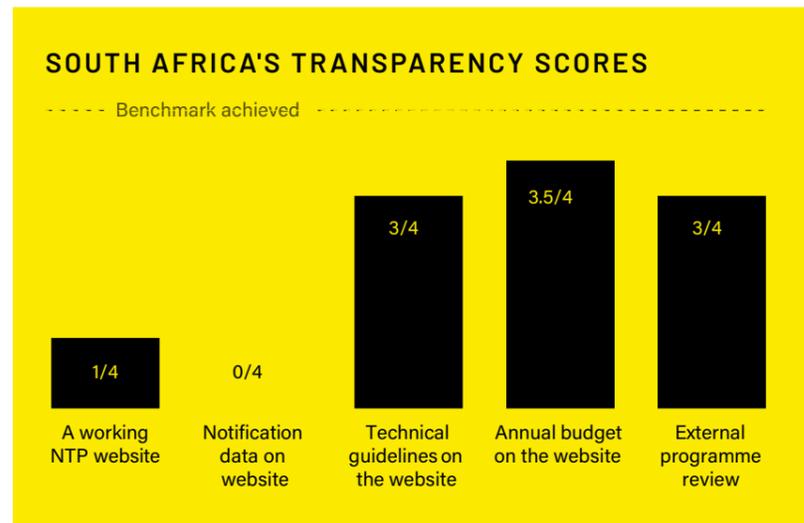
Top performing countries



India achieved **4 out of 5** benchmarks

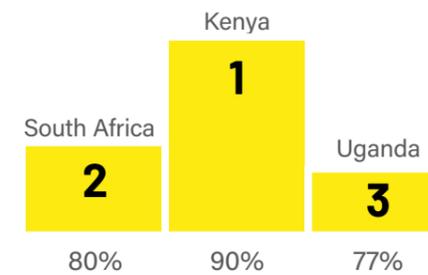
How South Africa fared

South Africa ranked 5th with a score of **53%**



LEGAL FRAMEWORK

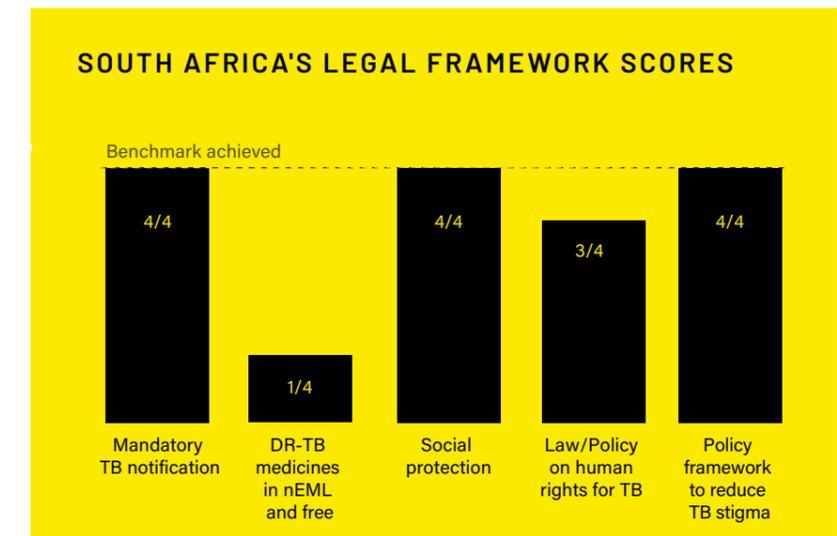
Top performing countries



Kenya achieved **3 out of 5** benchmarks

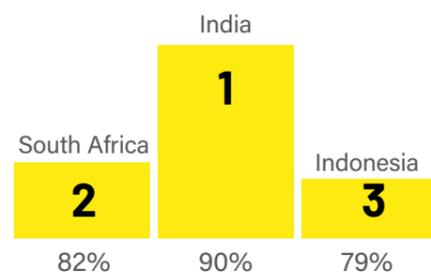
How South Africa fared

South Africa ranked 2nd with a score of **80%**



INCLUSIVENESS

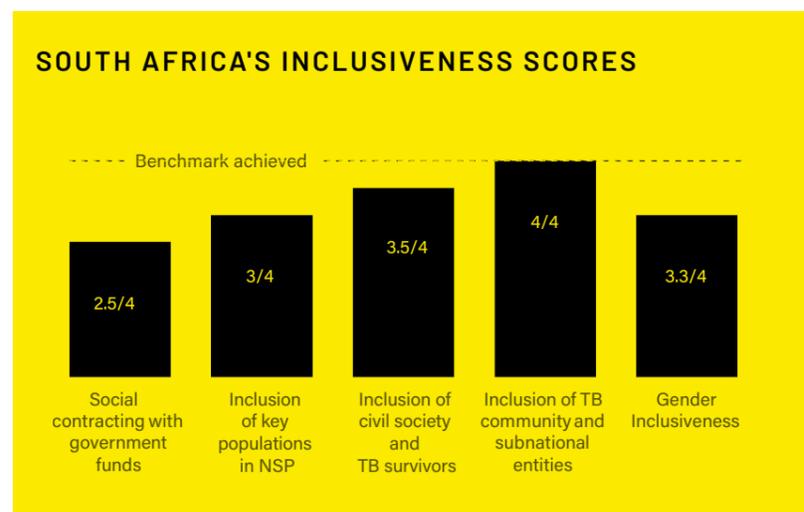
Top performing countries



India achieved **3 out of 5** benchmarks

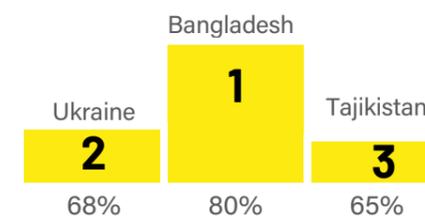
How South Africa fared

South Africa ranked 2nd with a score of **82%**



PROCESS EFFICIENCY AND EFFECTIVENESS

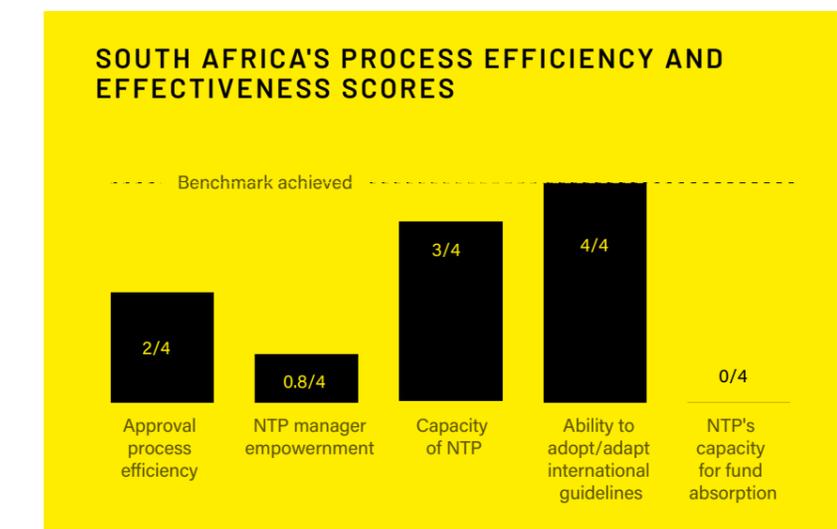
Top performing countries



Bangladesh achieved **1 out of 5** benchmarks

How South Africa fared

South Africa ranked 14th with a score of **49%**



NATIONAL AND PROVINCIAL PROGRESS IN TB OUTCOMES

The TB Recovery Plan was developed to regain ground lost in the TB programme during the COVID-19 pandemic⁶. However, the goals of South Africa's TB programme were not being met even before the COVID-19 pandemic occurred¹³.

Every five years South Africa develops a National Strategic Plan (NSP) for HIV, TB and STIs, the most recent version was for the period 2017 to 2022¹³. The goals set out in this NSP were very similar to those outlined in the TB Recovery Plan, and included:

- 1 Reducing TB incidence** (new infections) through improved TB screening, contact tracing, TB preventative therapy for those at risk and improved linkage to care.
- 2 Implementing the 90-90-90 TB care cascade** through:
 - Improving facility and laboratory diagnosis of TB and introducing new TB testing platforms.
 - Improving TB treatment initiation.
 - Better adherence support, better treatment regimens and efficient monitoring of response to treatment.
 - Addressing treatment supply chain issues.
- 3 Reducing stigma** for people with TB.
- 4 Improving legal protection** of people with TB.
- 5 Improving resource mobilisation** for the NSP goals.
- 6 Improving monitoring and evaluation** of TB outcomes and programme performance, as well as use of this data for decision-making¹⁴.

To evaluate progress towards these goals, publicly available TB data found in the provincial annual financial reports and the National TB Recovery Plan document were used.

The indicators reported for TB programme performance in the provincial annual financial reports were not always standardised across provinces. For example, only KwaZulu-Natal had included TB screening and TB incidence in their reports¹⁵. The lack of standardised reporting, as well as a sparsity of publicly available data, made it difficult to assess progress towards TB targets.

It was found that while laboratory diagnosis of TB was already on the decline between 2018 and 2019 (pre-COVID), an even more marked decline of 25% occurred between 2019 and 2020⁶. This is most likely due to the COVID-19 pandemic and related lockdowns. Similar trends were seen in all provinces and while there was some rebound in 2021, it was not to pre-COVID levels⁶.

At the 7th South African TB Conference in September 2022, Dr Harry Moultrie, a senior medical epidemiologist at the National Institute of Communicable Diseases (NICD), presented data for TB testing using the GeneXpert molecular test. The data showed that while testing numbers were considerably below what was forecast for the period of April 2020 to August 2020, these numbers did rebound to within forecasted levels for the September 2020 to November 2021 period⁴. Moultrie also noted that from December 2021 to the time of his presentation, the TB testing numbers had exceeded the forecasted levels⁴. There were also notable differences in TB testing data between provinces, districts and sub-districts⁴. In his presentation at the TB Accountability Consortium (TBAC) Mid-Term Budget TB workshop in November 2022, Moultrie showed that while KwaZulu-Natal had exceeded their recovery plan target for TB testing, the Western Cape testing numbers were below their target in the first 10 months of 2022¹⁶. Furthermore, while the overall TB testing numbers did increase, the number of positive TB tests did not rebound to predicted levels for 2021 and 2022^{4,16}. This may possibly be attributed to changes in testing strategies (such as TUTT), it being too early to see the rebound or reduced community transmission due to non-pharmaceutical interventions^{4,16}.

Initiation of treatment for TB clients with drug-sensitive TB (DS-TB) was only reported by the Free State¹⁷ and the Eastern Cape, although the indicator for the latter was slightly different as it included all clients over the age of 5 years¹⁸. The Free State had not achieved the 90% target but was gaining ground towards it even in the 2020/21 financial year¹⁷. The Eastern Cape had achieved the target both pre- and during the COVID-19 pandemic¹⁸.

The percentage of people successfully completing treatment for DS-TB in South Africa, has remained below the 90% target during the entire period of the NSP, ranging from 76.8% in 2017 to 78.5% in 2020⁶ (see Figure 1). COVID-19 and the related lockdowns did not appear to have a marked effect on successful TB treatment completion, other than perhaps affecting further progress towards the 90% target. However, loss to follow-up of patients increased between 2017 and 2020 by almost 5%, and the DS-TB death rate also increased between 2017 and 2020⁶ (see Figure 1). This could mean that considerably more patients did not continue receiving TB care or died from TB as a result of the COVID-19 pandemic. However, another possible explanation is that the percentage of patients whose data was 'not evaluated' was lower in the 2018 to 2020 period than it was in 2017⁶ (see Figure 1). The increase in the proportion of patients whose data was evaluated could also account for the increases in loss to follow-up and TB death rate.

FIGURE 1: NATIONAL DS-TB

| | 2017 | 2020 | |
|------------------------------------|-------|-------|---|
| Successful completion of treatment | 76.8% | 78.5% | ✓ |
| Loss to follow-up | 7.8% | 12.4% | ✗ |
| Death rate | 7.5% | 8.3% | ✗ |
| Not evaluated | 7.4% | 0.02% | ✓ |

Provincial reports show that none of the provinces included in this report have been reaching the target of 90% for treatment success^{15,17-20}, with only KwaZulu-Natal achieving above the national average (as seen in Figure 1) in 2020/21 with 81.2%, and remaining at that level for 2021/22¹⁵.

Loss to follow-up for DS-TB patients increased in all provinces for 2020/21 and remained at those high levels into 2021/22^{15,17-20}. This was attributed to effects of the COVID-19 pandemic in three of the five provinces^{15,17,19}. Provinces with a particularly high loss to follow-up rate (above the national average for 2020) included the Western Cape (18.6% in 2020/21 and 17.1% in 2021/22), the Eastern Cape and the Free State¹⁷⁻¹⁹.

Neither the Eastern Cape nor North West provinces reported on the DS-TB death rate^{18,20}, and the only province, of those included, above national average for this indicator in 2020/21 was the Free State with 10.6%¹⁷.

DATA IN GOVERNANCE

The above findings suggest that despite having good policies and plans for improving TB outcomes in South Africa, there remains a gap between policy and implementation. One possible reason for this may be the lack of accessible data.

In an article published in *The Conversation Africa* in January 2022, researchers providing lessons on data handling from COVID-19 note that “some of the most important lessons for public health from the COVID pandemic are about how the government should share data with the public...”²¹. They note that the raw data used to create dashboards and infographics, should be made more easily available for independent analysis by scientists outside government institutions²¹. This helps to increase transparency in decision-making processes and paves the way for community-led governance²¹.

The same is true with aggregated data such as that presented in dashboards. When data is disaggregated it allows for more localised data to be made available to the public, for example differences between provinces or the situation in urban versus rural areas²¹. Thus it would create an environment conducive to more informed policy decisions, as well as evidence-based advocacy²¹.

In keeping with these assertions, Moultrie notes that the flow of data tends to be from local to government levels, which results in top-down decision making¹⁶. He suggests that this flow of data should be bidirectional to increase the district level involvement in data analysis and decision-making¹⁶ (see Figure 2).

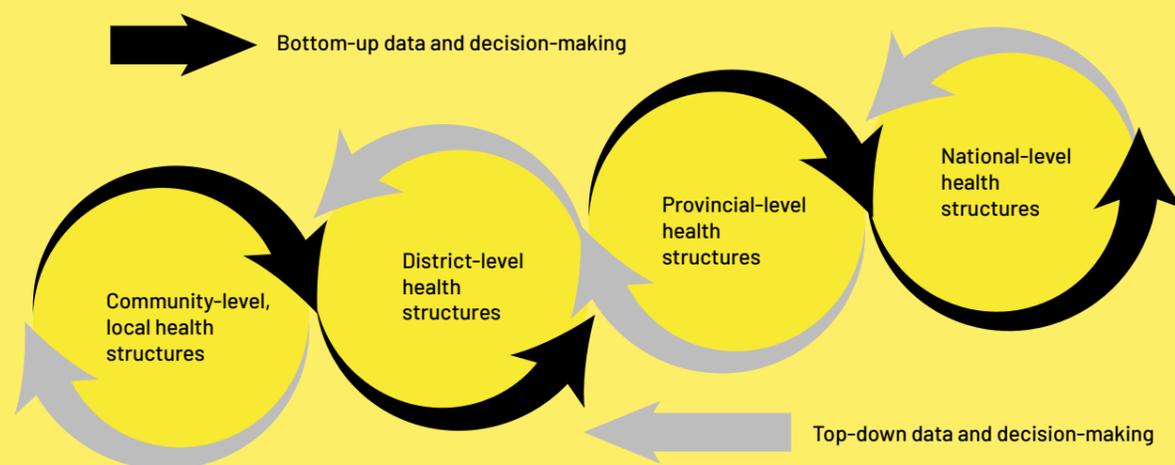


FIGURE 2: BIDIRECTIONAL FLOW OF DATA AND DECISION-MAKING

To improve TB surveillance, a suggestion from Rural Health Advocacy Project (RHAP) Executive Director Russell Rensburg is to link the NICD and TIER.net⁴ data systems. This would allow testing data from the NICD to be compared to treatment data from facility level, and hence improve the assessment of how many people testing positive for TB effectively received treatment²³. This sentiment was echoed by Moultrie, who describes routine TB data as fragmented and proposes linking of data as a solution¹⁶.

A strategy for improved surveillance outlined in the National TB Recovery Plan was to create a public-facing dashboard to display data on TB testing, notification and deaths²³. This would improve transparency in governance of the TB programme⁵ and as a result accountability, provided that the underlying data is also available for independent analysis²¹. In addition, it would also employ useful strategies from the COVID-19 pandemic. As Treatment Action Campaign (TAC) National Organiser Moses Makhomisan says: “TB needs to be approached the same way COVID-19 was approached and this will make it impactful.”²⁴ Smart et al. contend that for data to be meaningful to the public the correct visualisations should be chosen, and they recommend using proportions and percentages as well as absolute numbers²¹. Furthermore in order to create trust through data transparency, the information shared should showcase both positive and negative outcomes²¹.

These data governance strategies will improve the ability to accurately monitor progress towards

⁴ TIER.net is an electronic patient register used to support routine HIV and TB data collection and reporting in government facilities in South Africa²².

PROGRESS TOWARDS OTHER TB RECOVERY PLAN GOALS

TB Recovery Plan guidelines

In July 2022 Health Minister Joe Phaahla confirmed that the TB Recovery Plan was a transitional plan leading up to the 5th edition of the NSP for the period of 2023 to 2028²⁵. The latest version of the NSP (2023 to 2028) is set to officially be released on World TB Day, 24 March 2023²⁶.

Near the end of May 2022, the 6th version of the National TB Recovery Plan had been developed and this was uploaded to South Africa's TB Think Tank website in September 2022⁶. This plan was meant to be rolled out in a phased approach, with the first phase aimed at approval and dissemination of the latest TB guidelines as well as capacity building for healthcare workers on TB management (January to June 2022). The second phase was aimed at implementing activities related to the key objectives of the TB Recovery Plan (June 2022 to March 2023)⁶. While it was expected that provinces would adapt this plan to suit their local context, provincial plans were meant to align with the national objectives.

As of early February 2023, the TB recovery plan was not available on either the NDOH website nor on any of the provincial department of health websites for the provinces included in this report. In addition, the latest TB guidelines and standard operating procedures (SOPs) outlined in the TB Recovery Plan were also unavailable on the NDOH and provincial health department websites. The KwaZulu-Natal, Eastern Cape and North West department of health websites had no TB guidelines available at all. While the Free State had certain outdated guidelines from 2000-2009, and the Western Cape had the 2018 DR-TB clinical guidelines available. This would seem to indicate that this element of the first phase of the TB Recovery Plan is yet to be effectively implemented.

Mabalane Mfundisi, SANAC's Civil Society Forum (CSF) TB Task Team Chairperson, noted that the "NDOH through the National TB Programme not taking the lead to drive the implementation of the plan" created gaps in it effectively being implemented²⁷.

In the *Governance of TB Programmes* report, the availability of TB technical guidelines on the National TB Programme website is an indicator of transparency in governance, and the adoption of international guidelines is an indicator of process efficiency and effectiveness⁵. While South Africa scored well in both of these indicators in the *Governance of TB Programmes* report based on data from 2020⁵, it seems that the release and dissemination of the updated TB guidelines to provincial level may not have occurred. As one of the critical enablers to implementation of the TB Recovery Plan⁶, the lack of available guidelines and SOPs would likely have negatively affected progress towards the plan's key objectives.

This is not only true for the TB Recovery Plan, but for realisation of National TB Programme objectives as well. In fact Makhomisanani noted that one of the ongoing problems in terms of implementing TB programmes in South Africa was the need to "develop and seek approval for introducing integrated guidelines"²⁴.

"NDOH through the National TB Programme not taking the lead to drive the implementation of the plan" created gaps in it effectively being implemented.

MABALANE MFUNDISI, CHAIRPERSON SANAC
CIVIL SOCIETY FORUM (CSF) TB TASK TEAM

Provincial adoption of the TB Recovery Plan

According to the NDOH, implementation of the TB Recovery Plan was meant to be standardized across the provinces, with resources allocated according to their TB burden and population size²⁸.

Mfundisi points out that “whilst certain aspects of implementation may be standardised, the nature of the South African ‘beast’ is that language, geographical location, local dynamics which are politico-socio-economic are mission critical to allow for one TB recovery plan to be successfully implemented through multiple approaches and role players at local levels by government, civil society and private sector role-players”²⁷. Despite the need for adaptation of the plan to local settings, there appeared to be very different approaches to provincial implementation in the two provinces for which details of a TB recovery plan could be found.

The Western Cape announced the launch of its TB response plan in April 2021, which included declaring TB an emergency and approaching the fight against TB using lessons learned from the COVID-19 pandemic²⁹. The plan included many of the elements outlined in the NDOH version which was only made publicly available in September 2022^{6,29}. The first step in the Western Cape plan was to increase awareness of TB and this was supported by the launch of a public-facing provincial TB dashboard in September 2021³⁰. This dashboard displays information on TB tests conducted for both DS-TB and DR-TB, positivity rates of the tests and self-screening statistics from the digital self-screening application³¹. It also contains links to both the desktop and mobile phone versions of the self-screening applications should a visitor to the site wish to perform self-screening³¹. Other steps included enhancing TB prevention through improved screening and TB preventative treatment (TPT), improving TB diagnosis using modalities such as mobile digital chest x-rays and urine LAM testing, and improving linkage to care with SMS notifications of test results to patients²⁹. As can be seen from the TB testing data for the Western Cape presented by Moultrie at the TBAC Mid-Term Budget TB Workshop¹⁶ in November 2022, these initiatives introduced by the Western Cape have not necessarily translated into reaching the targeted TB testing levels as yet.

Of the provinces included in this report, the only other province to publicly outline a version of the TB Recovery Plan, was the Free State in a Spotlight article in January 2022³². The main focus of the Free State’s plan was to encourage TB patients who had stopped taking their medication during the COVID-19 pandemic, to return to clinics and recommence treatment³². Part of the National TB Recovery Plan included increasing the number of TB patients enrolled on the Central Chronic Medicine Dispensing and Distribution (CCMDD) programme⁶, which makes it easier for patients to collect medication, and thus improves their adherence. However the Free State Director of TB stated that TB patients in the province would not be enrolled in the CCMDD programme, but treatment would remain clinic-based³².

In addition, in a response to media questions by the Free State Department of Health, it was mentioned that x-rays would not be used for screening people for TB³². This is despite the fact that performing digital chest x-rays for screening is one of the goals in the National TB Recovery Plan⁶ and the fact that South Africa’s first TB prevalence survey showed that 58% of people who met the survey case definition for TB, had chest x-ray findings suggestive of active TB, but were asymptomatic². The latter highlights the usefulness of chest x-rays as a TB screening tool. The contrast between the Free State’s approach at that time and that outlined in the National plan, underscores the need for disseminating national programme guidelines, policies and SOPs to provincial level for effective governance and standardised implementation, especially where the latter is empirically based.

“Provincial leaders have been part of the plan development”, according to Makhomisani, yet he notes that “there’s not much they communicated to their Provinces”²⁴. Mfundisi further stated that at “National level the plan has been communicated including engagements that have taken place with the Minister of Health and the Deputy President in his role as the SANAC Co-Chairperson. This also includes at provincial levels as all provincial TB Programme Managers and their MECs⁵ at the National Health Council and with individual MECs.”²⁷

Despite this there seems to be a lack of available information on provincial implementation of the TB Recovery Plan which may suggest that either this plan has not been implemented effectively at provincial level or that there is no readily available record of this implementation. In the same line TB Proof⁶ noted, according to their stakeholder consultations regarding the TB Recovery Plan in the second half of 2022, that policy level stakeholders indicated that the provincial implementation plans were not clear.³³ TB Proof is an advocacy organisation that aims to help improve access to high quality TB treatment, address stigma and improve support of people affected by TB³⁴.

5 MEC – Member of the executive council

6 All TB Proof comments in this report are based on stakeholder consultations regarding the TB Recovery Plan conducted in the second half of 2022.

National initiatives for the TB Recovery Plan

Even though the provinces do not appear to have a standardised adoption of the National TB Recovery Plan, certain elements have been implemented in a number of provinces.

One example is that a pilot study for the use of mobile digital chest x-rays as a screening tool was run in six districts, including one in the Western Cape, one in KwaZulu-Natal and one in the Eastern Cape³⁵. This pilot study was co-ordinated by the NDOH and supported by donors such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and USAID, and it found that three in every hundred people x-rayed had active TB between November 2020 and April 2022³⁵. This figure differed slightly between provinces, but most had a considerable percentage of those eventually testing positive (bacteriologically) for TB that were asymptomatic and would not have been detected without the use of the mobile digital chest x-ray³⁵. This intervention also has a great deal of potential to improve the detection of TB cases in rural areas, as the mobile x-ray vans make this service accessible to those who would usually have to travel to regional or central provincial hospitals³⁶. The pilot study results were also to be used in order to determine whether national and provincial departments would submit requests to the National Treasury for funds to scale-up the project³⁵. Thus this study demonstrates progress towards implementation of the TB Recovery Plan through nationally run initiatives.

While the Western Cape is the only provincial health department that has a public-facing TB dashboard, the NICD had already launched a TB Surveillance Dashboard in March 2017³⁷. This dashboard allows the trends in TB incidence to be visualised at national, provincial and district levels as far back as 2011³⁸, which is progress towards making TB data more accessible to the public. According to Moultrie's presentation at the TBAC Mid-Term Budget TB Workshop, an updated public TB dashboard has been developed and is awaiting approval¹⁶. The availability of TB notification data on the National TB Programme website was one of the indicators for measuring transparency in governance in the Governance of TB Programmes report⁵. South Africa did not have available notification data and scored zero for this indicator. While neither the NICD dashboard nor the Western Cape dashboard include TB notification data, they could provide a foundation from which to build and develop more complete public-facing TB dashboards for all provinces and thus improve transparency in the TB programme governance. Two of the factors necessary for successful implementation of TB programmes in South Africa, according to Makhomisanani are improved TB surveillance and improved "data systems to obtain real time access to TB data."²⁴

Other barriers to implementation

Other barriers to implementation of the TB Recovery Plan include that "it is not clear who will champion the plan from the side of the Department of Health" says Makhomisanani²⁴. In addition, Mfundisi states that "Without room for engagement that ensures buy-in, the TB Recovery Plan is unimplementable when the local role players do not embrace but see it as a project of National through Province via the District. With the locals feeling pushed by District-Province-National role players, at local/facility level there is resistance and the required buy-in is not at the level that ensures successful implementation."²⁷ This in turn results in "a great plan but which lacks at implementation level", says Mfundisi²⁷.

**It is not clear who will
champion the plan
from the side of the
Department of Health.**

**MOSES MAKHOMISANI,
TAC NATIONAL ORGANISER**

COMMUNITY-LED GOVERNANCE

What is community-led governance?

“Community governance may be defined as community level management and decision-making that is undertaken by, with, or on behalf of a community, by a group of community stakeholders.”³⁹ This is contrasted with governance undertaken by local government structures, organisations or the public sector³⁹.

Within the context of TB programmes community governance can take various forms. In the Governance of TB Programmes report, the concept of community governance was described under the indicator of inclusiveness. This measures the extent to which community groups such as TB-affected communities, key populations and civil society, are encouraged to participate in national TB responses⁵. South Africa performed reasonably well for this indicator, achieving the benchmark for receiving input from the TB community through their inclusion in the national TB technical working groups, and showing good progress towards the inclusion of TB civil society and TB survivors in the various programme reviews⁵.

RHAP Community Liaison Officer Zimbini Madikiza states: “The people we engaged with are not involved in TB specific governance. But they are knowledgeable about health governance which they refer to as clinic committees and district health councils⁴⁰. She goes on to say that while clinic committees are established to “provide a platform for communities to raise health related issues with them, then they take up those issues. From what we are getting from the people we engage with, there are a number of concerns that are raised which show that the existing clinic committees are not functional and therefore they are not accessible to the communities⁴⁰.”

Community-led governance and the TB Recovery Plan

The role of community-led governance in implementation of the TB Recovery Plan has been limited by a number of factors, one of which is the lack of communication of this plan to local levels. “Communities including service providers (Professional Nurses) have no idea about the recovery plan and their role”, says TAC’s Makhomisan²⁴. This is confirmed by Mfundisi from SANAC, who when describing communication of the TB Recovery Plan says that “when it comes to District level and local/ facility levels, the different role players are at different levels of being briefed with many not properly or adequately briefed²⁷.”

In addition to improving communication of the TB Recovery Plan to district and local levels, other suggestions to improve its implementation include using a more bottom-up governance approach. According to Mfundisi, it is necessary to have “local engagement to ensure ownership and driving of the plan.”²⁷ He goes on to say that “whilst a top-down approach is relevant in that it has created a plan, there is a need for a bottom-up approach that will ensure local understanding and therefore local ownership of implementation²⁷.”

“The role of governance at a community, facility and district level is to make sure that the TB recovery plan is being implemented. Governance at local level is very important because it has a great potential of empowering communities in realising their rights”, says Madikiza⁴⁰.



The people we engaged with are not involved in TB-specific governance. But they are knowledgeable about health governance which they refer to as clinic committees and district health councils.

ZIMBINI MADIKIZA
RHAP COMMUNITY LIAISON OFFICER

Improving community-led governance in TB programmes

To achieve a patient-centred TB programme, a health literate constituency and bidirectional decision-making for community-led governance, a number of factors need to be considered.

Mfundisi recommends that clinic committees and hospital boards be made up of individuals who are “elected/ selected based on their common interest in using their skills for improved health outcomes”. He says that “this approach will ensure that the voices of the patients form the backbone of the governance structures and which in turn will be translated into effective management because governance is fixed and is inclusive”²⁷.

Makhomisani puts forward that “greater involvement of people affected by TB in decision making will assist to understand the deeper challenges that is facing people who are affected by TB”²⁴. He goes on to say that it is necessary to “establish community-centred TB dialogues or engagement meetings that will be specifically speaking to issues of TB”²⁴.

The Ritshidze community-led healthcare monitoring project collects data at 400 primary healthcare facilities in South Africa, to specifically monitor quality of service delivery in the country⁴¹. This data includes medicine supplies, drug stockouts and TB infection prevention and control measures at facility level⁴¹. The data collected is also made publicly available in the form of a dashboard and is used for advocacy to decision-makers, improved accountability in governance and feedback to the facilities⁴¹.

Furthermore, while a new national community-led monitoring working group is being established, there is a lack of clarity regarding the mechanisms for its coordination and accountability, according to TB Proof³³.

Community health workers (CHWs) could also play a vital role in community-led governance. TB Proof, in their engagements with policy level stakeholders in the second half of 2022, found these stakeholders recognised that CHWs can play a key role in strengthening TB services but also acknowledged the various issues regarding the terms of employment and conditions of service of CHWs which need to be addressed. This includes the need for training. According to TB Proof, CHWs require regular training to generate and support community-based demand for quality TB services as well as to support community leaders in calling for accountability³³.

Through these various mechanisms, community-led governance has the potential to improve accountability of decision-makers and thus improve service delivery in TB programmes.



THE
STATE
OF TB
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ZIMBINI MADIKIZA
RHAP COMMUNITY LIAISON OFFICER

RECOMMENDATIONS

Based on the findings of this report, the following are recommendations to improve implementation of TB programmes and achieve the objectives of the NSP for 2023 to 2028. These recommendations address three of the four themes from the Governance of TB programmes report: transparency, inclusiveness and process efficiency and effectiveness⁵, and are intended to be used for the purposes of advocacy in TB programmes and for improved accountability in TB governance.

Plans, policies and SOPs

Expedite development, approval and dissemination of the latest TB guidelines for screening, TB preventative therapy, TB treatment and recording and reporting.

Availability of the latest TB guidelines and SOPs on the NICD, NDOH and provincial department of health websites.

Raising public awareness of the TB services available (based on these guidelines, SOPs and the NSP) through various campaigns both at community level (using CHWs, events and outreach programmes) and on digital platforms.

Data and governance

Link data systems such as the National Health Laboratory Services (NHLS), TIER.net and the District Health Information System (DHIS), so that testing and treatment data can be integrated. This will allow better tracking of linkage to care, retention in care and treatment success rate in TB patients. In addition it will allow for more empirical decision-making in governance.

Make raw, disaggregated data easily available for independent scientific analysis to increase transparency and accountability in TB programme governance, increase evidence-based advocacy and enable community-led governance.

Build on existing platforms and create a national public-facing TB dashboard that displays national and provincial data on TB screening, testing, notification and deaths. Ensure this displays data in a way that is meaningful to the public. This will provide a similar platform to that used for COVID-19 and allow the public to engage with TB data and gauge progress towards achieving TB targets.

Train district and facility level stakeholders in improving the quality of collected data, as well as in data analysis and interpretation to allow for empirically-directed and locally relevant decision-making. This will aid in increasing bidirectional flow of data and decision-making.

Standardise the TB indicators that provinces report on for improved monitoring and evaluation, and align these indicators with specific programme targets (e.g. reporting on TB screening and incidence).

Advocate for specific annual reports on the progress of the TB programme, as currently this data is integrated into the provincial annual finance report. Make this new report available on all provincial department of health websites. This will create greater transparency and accountability in TB programme governance.

Community-led governance

Improve bidirectional communication between national, provincial and district health departments, as well as communities. This will ensure that plans, guidelines and SOPs are communicated to implementers (top-down), but also that district and community stakeholders are given the opportunity to give input on these documents (bottom-up). This will create ownership and opportunities for improved implementation.

Empower communities for self-advocacy by increasing awareness of their health-related rights, existing TB policies and plans, as well as the currently available TB services.

Empower community stakeholders to make use of data from projects such as the Ritshidze community-led healthcare monitoring project to advocate for better service delivery at facility level, and hold governance structures accountable. This could be implemented for improving services such as medicine supplies and minimising stockouts for TB medications, for example.

Empower communities to advocate for more representative and approachable clinic committees.

Obtain **clarity on the new national community-led monitoring working group** and the mechanisms that will be in place for coordination and accountability.

Community Health Workers

Train CHWs on TB guidelines, SOPs, plans and policies.

Clarify the conditions of service of CHWs to ensure the realisation of their full potential in contributing to TB services including screening, treatment success, contact tracing, community education and demand creation for TB services.



LIMITATIONS

- ◆ Literature reviewed for this report included journal articles, reports and grey literature sources obtained through desktop review process.
- ◆ No data analysis was conducted for this report.
- ◆ All data that have been presented in this report were sourced from the literature review, a TB workshop presentation and online sources of publicly available data. As such we did not have control over the methods used for data collection and analysis.
- ◆ The key informant interviews were conducted via emailed questionnaires.
- ◆ The key informant perspectives and answers are presented as given and thus represent the views of the respondents.
- ◆ Only five of the nine South African provinces are included in this report, as such the findings related to provincial elements may not be representative of all the provinces in South Africa.
- ◆ This report has an emphasis on the use of governance strategies as a means to improve TB programme implementation and has not explored other means to do so.

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